LIVED EXPERIENCES OF WOMEN AGEING WITH LOCOMOTOR DISABILITIES ACQUIRED EARLY IN LIFE: A STUDY IN THE KAMRUP METROPOLITAN DISTRICT OF ASSAM

Thesis submitted to Jawaharlal Nehru University in partial fulfillment of the requirements for the award of the Degree of

DOCTOR OF PHILOSOPHY

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DECLARATION

I declare that the thesis entitled "**LIVED EXPERIENCES OF WOMEN AGEING WITH LOCOMOTOR DISABILITIES ACQUIRED EARLY IN LIFE: A STUDY IN THE KAMRUP METROPOLITAN DISTRICT OF ASSAM**" is being submitted by me in partial fulfilment of the requirements of the award of the degree of **DOCTOR of PHILOSOPHY** of Jawaharlal Nehru University. This thesis has not been submitted for the award of any other degree of this university or any other university and is my original work.

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Glossary

Kinship Terminologies used by the Research Participants

Ma	: Mother
Deuta / Pita / Papa	: Father
Baideu/ Ba	: Older Sister
Bhonti	: Younger Sister
Dada/ Kaka	: Older Brother
Bhaiti	: Younger Brother
Aita	: Grandmother
Burhi Aita	: Great Grandmother
Koka	: Grandfather
Bordeuta	: Father’s Older Brother
Borma	: Father’s Older Brother’s Wife
Khura	: Father’s Younger Brother
Khuri	: Father’s Younger Brother’s Wife
Pehi	: Father’s Sister
Peha/ Pehadeu	: Father’s Sister’s Husband
Mahi	: Mother’s Sister
Moha	: Mother’s Sister’s Husband
Mama	: Mother’s Brother
Mami	: Mother’s Brother’s Wife
Bhindeu	: Elder Sister’s Husband
Bou	: Elder Brother’s Wife
Bhotija Suwali Daughter	: Older Brother’s
Buari	: Daughter-in-law
Juwai	: Son-in-law

Nonod	: Husband’s Younger Sister
Jaa	: Husband’s Older Brother’s Wife

Other frequently used words in the text

Dangor	: Big/ Elder
Xoru	: Young/ Small
Maju	: Middle
Bhaal	: Good/ Non-Disabled
Beya	: Bad
Lengeri	: One who limps
Bhori	: Legs
Kopaal	: Fate
Bhagyo	: Destiny
Xonxaar	: Conjugal life

Introduction

In January 2009, at the age of 64, my father suffered from a mild stroke that paralyzed the left side of his body permanently. This was perhaps the most dramatic crisis in our family, as overnight a fully functioning individual had to depend on others for his daily living activities, which most of us, as able-bodied people, take for granted in our everyday lives. His disability changed the dynamics of my parents' relationship with each other. After this incident, my mother who was a homemaker all along and whose primary responsibility was to look after the home and her daughters, had to take on additionally responsibilities as my father's primary caregiver as well as doing other important activities outside of the home, like paying bills, buying groceries, visiting different offices, etc. which were things she never had to bother about for over 30 years since she got married. This drastic change was not easy for either of them, especially because all of us siblings had left home by that time. My parents fought frequently during that period for minor issues. My father, for instance, was irritated with the minutest of things like if he was asked twice about what he wanted to have for lunch or dinner, if my mother was late in going somewhere because she was carrying on her household responsibilities and so on. My mother, on the other hand, got irritated when my father tried to help her with the household responsibilities as he did earlier, but often ended up increasing her workload. For instance, since my father had diabetes, rice was often cooked in a saucepan and not in a pressure cooker. Due to this, one had to strain the starch from the saucepan after the rice is cooked. If my mother was busy elsewhere, he often came to strain the starch with his one functional hand but ended up spilling it completely. These disputes had become a usual part of their life, but never once did my mother leave him alone. For those three years, till his death in January 2012, my mother made sure that either she or someone else is with him at all times. He, in fact, hardly went out of the home during that period, either to avoid the stares and fake concerns of people or because the infrastructural barriers restricted his mobility completely.

Apart from my father, there have been several other persons with locomotor disabilities in my family. My mother often talked about the difficulties of growing up in a household where both her parents had developed their impairments over the life course. My *Aita* (maternal grandmother) was married at the age of 12 years, as per the customs of that period. She gave birth to three children in the following years, and by the age of 20, she was unable to leave her bed due to some kind of chronic pain. She attributed her pain to the mischiefs she had committed as a child when she did not listen to her elders and climbed trees and the rooftops just like her seven brothers. According to my mother, *Aita* used to fall down while jumping from the trees or the rooftops, and she had probably severely injured herself during that period. This caused the chronic pain that she suffered from her adulthood up until her death at the age of 51 years in 1986. Her condition did not have a name; it was only referred to as *gaar bix* (body pain). According to my mother, because medical knowledge was not so advanced during that period, her condition could not even be diagnosed, let alone be cured.

My *Koka* (maternal grandfather) was probably in his mid-30s when he married *Aita*. He worked at the State Bank of India and had to move around every few years. At the age of 41, he suffered from a stroke that paralyzed one side of his body. My mother and her two brothers were very young during that period. Seeing the plight of the family with two disabled parents, *Aita*'s father considered it wise to bring the entire family to Guwahati where all of them received love and care from *Aita*'s middle-aged parents. Even though the social customs in an upper caste middle class Assamese family were quite rigid during that period, no one raised any objection when my disabled *Aita* returned back to her natal home with her disabled husband and three young children. Probably their disabled status relaxed the social norms for them. My mother and her siblings never faced any deprivations in their new home because *Aita's* family was considerably well-off to feed so many extra people. They received significant support from their grandparents, maternal uncles and aunts. *Koka* passed away at the age of 51 years when my mother was about 13 years old. In spite of this, none of the siblings faced any kind of hindrances in their education. All three of them are graduates, and both my uncles worked in respectable places. My mother 'chose' not to work after the birth of my elder sister. However, my mother often told me about the comments she had to hear about my *Aita's* physical condition from distant family members. One of her aunts often wondered how a disabled woman like her mother could be married to a *dhuniya manuh* (beautiful able-bodied man) like my *Koka*. This often irked my mother. It is interesting that no one commented about my *Koka*'s impairment. My mother also told me that there were problems during her marriage when my father's family wanted to ensure that *Aita'*s disability is not hereditary and would not be passed on to the next generation. It is again interesting that no one commented anything about *Koka's* impairment.

In spite of her impairment, Aita was a learned woman and had played a significant role in the lives of her children and her siblings. It is probably due to this reason, that she never faced any kind of neglect from anyone. This is in complete contrast to the experiences of my *Mahi-Aita* (*Aita*'s younger sister, my grandaunt) who was born with congenital heart disease and a mild form of mental disability (again her condition did not have a name). After her birth, a doctor told her parents that she will not survive for many years. She, however, lived till her 70s and passed away in the early 2000s. Probably due to this reason, she was the favorite child in the family. Since her impairment was congenital, *Mahi-Aita* remained unmarried, unlike *Aita* who had acquired her impairment after her marriage. My mother told me that her grandmother was very concerned about *Mahi-Aita*'s future and often prayed to God that either they should die around the same time or *Mahi-Aita* must die before her. This was because she was unsure if anyone would take care of her disabled daughter after she had passed on. She, however, did not have similar concerns about my *Aita*, perhaps because she was married to a man who had a government job, and had three children of her own, who could be entrusted with the responsibility of taking care of her.

During *Mahi-Aita's* old age, I had noticed that her brothers and nephews often made fun of her and teased her about leaving her alone. They enjoyed seeing her angry reaction to such teasing. In the last years of her life, when she became very frail, I noticed that no one wanted to take her responsibility. During that period, no one had space for her in their homes due to which she had to move frequently from the home of one brother to another, one nephew to another until one of her brothers made the arrangement for her to live alone in a small room with a paid caregiver. I also noticed that every time someone in the family passed away, someone who was considered more worthy of living, in the funerals everyone would gather together and wonder about how and why *Mahi-Aita* is alive for so long, troubling everyone. In retrospect, I remember that when she had passed away, no one shed a tear for her. Everyone, in fact, was relieved that she would not bother anybody anymore. This again was in sharp contrast to how people responded to my *Aita*'s death, even though she also required considerable support in activities of daily living. The stories of these two women made me understand the differences that exist among women with disabilities depending on the nature of their impairments, age of onset of the impairment, whether they suffer from any other physical condition, marital status and whether or not they have children.

Through the experiences of all these family members, I became interested in the field of disability studies. In the course of my reading on this subject, I realised that the population of persons with disabilities is huge, in fact, they are considered to be the world's largest minority group, and yet not much is known about the experience of disablement in the context of majority world settings. This is strange given that we are all 'temporarily able-bodied' (Ghai, 2002), and may become disabled at any point of our lives, especially if we live long enough (Wendell, 1989), which is not impossible in today's world given the advancement in medical technology (Addlakha, 2010). Due to this reason, even though persons with disabilities are treated as the 'other' in the ability-centric society, they are not the 'standard other'. There is, therefore, a need to break the silence and unease that surrounds the concept of disability and to initiate conversations around it so that the experience of living with a disability can be brought to focus.

Keeping all these factors into consideration I wanted to study in more depth the lived experiences of other persons with disabilities who may not have had the same privileges that my father or my *Aita* had by virtue of their class position and social capital. During my Masters, at the insistence of one of my Professors, I had conducted a small study on two university-going women with disabilities in Delhi. As I reviewed the literature on disability in the Indian context, I became aware of the disadvantages that women with disabilities experience due to the intersection of a number of factors. However, in several studies it was found that the life experiences of the women were homogenized, and they were depicted to be living under deplorable conditions. From the experiences of my *Aita* and *Mahi-Aita,* I was aware that this wasn't the case. Due to this reason, I continued my research on women with disabilities for my M. Phil dissertation but focused my attention particularly on women with locomotor disabilities. Titled *"Women with Locomotor Disabilities: A Study on the Experience and Complexities of Disablement"* (2014), the broad objective of the research was to understand the lived experiences of women by focusing on their health impairment, psychosocial health, the social environment and access to healthcare and other services. The study participants were contacted with the help of five organizations working in the disability sector in Delhi-NCR. Twelve women in the age group of 21-50 years with different locomotor disabilities[1] were interviewed in-depth in order to understand their lived experiences with regard to living a life with disabilities. The analytical framework of intersectionality paradigm was used for the study in order to understand the different complexities in the lives of these women. The study provided different insights into understanding the intricacies of their lives. Firstly, it was found that impairment is not a purely biological category but is influenced by a myriad of factors including the social location of the person, the type of locomotor disability, age of onset of the impairment, time gap between the age of onset and the current age of the women and support received from the family members. Secondly, the study found that the women experience physical distress which is directly connected to the severity of their impairments, physical overexertion and usage of mobility aids like crutches and prosthetics. Thirdly, it was also seen that the women experience different kinds of mental distress like depression, anger and frustration which are related to their impairments, the social context in which these women live and their interaction with non-disabled persons. It was also found that the women and their close kin members had developed their own mechanisms to deal with their stress. Fourthly, the participants in the study had faced numerous barriers while accessing health care at the time of onset of their disabilities. These barriers include the lack of knowledge of a person's health and the healthcare system by the members of the family which impede their health-seeking behavior, lack of healthcare facilities that houses the appropriate care at close proximity, financial constraints and social network of the family members that hinder timely access to care. Another significant finding in the study was that the vast majority of the participants in the study had faced different difficulties during childbirth. These difficulties ranged from fear of institutional deliveries due to its frequent association with Cesarean Section, inability to arrange for adequate transportation to reach a health facility on time, delayed labor and having repeated miscarriages.

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[1] The study included participants having infective [poliomyelitis (n=5); bone tuberculosis (n=1)] and traumatic causes [road traffic accidents (n=2); fall from height (n=1); tractor run over (n=1); electrocution (n=1)] of locomotor disability. The study also included one participant who was not aware about the cause of her disability.

One of the limitations of this study is that the health issues of these women did not emerge very prominently. The reason for this could be that the women were comparatively younger and, therefore, had not developed secondary conditions or chronic illnesses that are reported in the literature on the health of persons with disabilities.

The current study aims at building on some of these insights in order to have a better understanding of the lived experiences of women ageing with locomotor disabilities acquired early in life (below 20 years) in the Kamrup Metropolitan District of Assam through the life course perspective. Since the study is on women with disabilities, therefore, impairment or health is an important component of this research. However, instead of following the medicalized definitions of health,[2] this research uses the social model of health[3] in order to understand the broader context in which disabilities are created and sustained and how it impacts the life course of the women. In addition to the external factors, the study also attempts to understand the women's subjective understanding[4] about their health in general, and their impairments in particular, in order to deeply understand their life course. The study also elaborates on the different health issues that the women have faced across different phases of their lives. Secondly, this study attempts to understand the role that social support plays in the lives of women with locomotor disabilities across different phases of their lives. At the time of the data collection, it was found that the family and disability organizations are the two institutions from which the women receive the maximum

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[2] The medical model describes health from a scientific perspective that draws on mechanical, individualistic and reductionist understanding. In this model health is viewed in terms of disease, pathology, diagnosis and treatment, where the corporeal body is viewed as distinct from social or psychological processes. Within this model, health is located in the body of the individual, while the causes of ill-health are regarded as biological in origin, requiring intervention from doctors (Warwick-Booth, Cross & Lowcock, 2012).

[3] According to the social model, health is determined by a gamut of factors such as the social, political, economic, psychological, cultural and environmental. Within this model the causes of ill health are considered to be factors that are outside of an individual's body (Warwick-Booth, Cross & Lowcock, 2012).

[4] Lay perspectives about health try to understand how 'ordinary' people understand, experience and perceive their health. It has been highlighted that it is important to listen to people's subjective understanding of health because people themselves know better about their own health. Such perspectives on health are heterogeneous and differ across individuals, communities and cultures as well as on the basis of age, levels of education, social class and gender (Warwick-Booth, Cross & Lowcock, 2012).

support, due to which both these aspects have been elaborated in great detail. Thirdly, the study focuses on the psycho-emotional dimensions of living with a disability to understand in what way social prejudice of the society towards persons with disabilities has impacted the lives of the women in the current study. Finally, the study elaborates on the intersection of various factors in the specific context of the lives of the study participants.

The study has concentrated on studying the experiences of women with disabilities in Assam because very little is known about the lives of persons with disabilities in the state. The district of Kamrup Metropolitan has been purposefully chosen because of the presence of a number of disability organizations that made it easier to recruit the participants for this study. From the review of literature, I came across the medical and the social models of disability and these understandings changed my perception about the lives of persons with disabilities. However, over time I realized that the social model is not adequate to understand the lived experiences of persons with disabilities in the Indian setting. This is when I read more on disability in the context of the majority world countries[5], and came across the conceptualization of disability by majority world theorists, which I felt resonated with the experiences of my study participants from Assam.

In the course of the last one decade, several studies have been conducted on women's experiences of disabilities in India, as we will see in Chapter 1. In spite of this, disability as an experience is a largely unexplored area in the context of Assam. Due to this reason, it was considered best to concentrate on the lived experiences of only women with one type of disability, and who had acquired their impairments at a

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[5] The term 'majority world' is used to refer to the countries where the vast majority of the world's population reside but have access to only a small portion of the world's resources and power. The term, 'minority world', on the other hand, is used to refer to the richest countries of the world where less than half of the world's population reside, but possess a large proportion of global resources (Stone, 1999). In the recent years, several disability scholars have shown their preference to use these terms over the value-laden terms such as 'developed' and 'developing countries'. This is because these terms break away from the geographical notions of wealth and power as there are pockets where great deprivation exists in the countries of the Global North. Likewise, there are pockets of incredible wealth in the countries of the Global South (Ibid). Such an understanding is significant in disability studies because impairment and poverty are intricately connected in the majority world due to which persons with disabilities are more likely to be the 'poorest of the poor' in these countries (Ibid).

particular age. I understand that the experiences of persons who do not fit these criteria would be considerably different, which also require urgent attention, but unfortunately their experiences have not been elaborated in this study. Future studies should explore on this issue.

Chapterization

Chapter 1is a review of the existing conceptual and empirical literature on disability. The chapter is divided into four sections: Section I elaborates on the sociological perspectives on disability and the birth of the disability movement and disability studies in the United Kingdom, followed by a discussion on the different models of disability as developed by disability scholars as well as the role played by the United Nations. Section II elaborates on the critique of disability studies as presented by majority world theorists. Section III elaborates on disability in the specific context of India. Section IV elaborates on some of the themes that are specific in the context of this study.

Chapter 2 lays out the conceptualization, research questions, objectives and research design of the study. This is followed by a note on the process I have followed for data collection and selection of research participants; my experience in the field; a note on data analysis and ethical issues considered for the research.

In Chapter 3, I have elaborates on the context in which the study has been conducted in order to have a deeper understanding of the lives of women ageing with locomotor disabilities. The chapter provides a socio-political history of Assam from the pre-colonial times up until the present period times in order to understand the reasons behind the poverty and backwardness of the state vis-à-vis the rest of the country. The chapter also elaborates on the position of women of the society of Brahmaputra Valley, in order to deepen our understanding about the status of women with disabilities in such a society.

In Chapter 4, I have elaborated on how the women and their family members, particularly their mothers, perceive the occurrence of their impairments in the specific contexts of their lives. The chapter provides long narratives to elaborate on the time period just before and after the occurrence of their impairments. This understanding is important in order to critique the widely held understanding prevalent in disability studies that usually point out the barriers present in the environment. The theoretical approaches of *social suffering* and *structural violence* are used in order to better understand the life situations of the women and their family members.

In Chapter 5, I have elaborated on the support that the study participants have received from their family members across different phases of their life course. The aim of this chapter is to show that in contexts where social security benefits are inadequate, persons with disabilities have to depend on their family members for their care. This care and support from the family sometimes continues throughout their lives due to the nature of their impairments, barriers present in the environment and other social barriers like lack of education and scarcity of well-paying jobs. Due to these reason, western notions such as individualization of disability are inadequate to explain the life situations of the women in this context. The chapter uses the concept of *'disabled household'* to elaborate the findings.

Chapter 6 provides a critique of the absence of theorization of impairment in disability studies literature. The chapter elaborates on Grech's (2009) argument that in countries of the majority world, impairment is a pivotal concern that cannot be negated, even for political reasons. The chapter shows the problems faced by persons with disabilities in Assam due to the absence of proper medical knowledge about their disabilities as well as the absence of adequate healthcare facilities in the state.

Chapter 7 elaborates on the 'psycho-emotional dimensions' [as elaborated by Thomas (2004a; 2004b) and Reeve (2006)] of living with visible physical impairments in the society of Assam. The chapter uses the life course perspective and draws on feminist and disability studies literature to elaborate on the triumphs and tribulations in the lives of the women.

Chapter 8 elaborates on the support that the research participants have received from the respective disability organizations from which they were recruited. Studying this is important because apart from the family, it is the disability organizations that have provided the women with the required resources to face the world bravely. The chapter uses the framework of *social capital* to analyze the support that the disability organizations have provided to the women, that has brought about definitive changes in the lives of the women. The chapter argues that in the absence of any kind of support from the government, the women and their family members tend to depend on the disability organizations for support. But unfortunately these organizations are usually not in a position to provide support to the myriad needs of the women and fall short of their expectations, which is sometimes resented by the women. Although existing studies have shown that the state must provide the support required by the women, this study also shows that in a situation of conflict where various communities are trying to put forth their demands, disability issues perhaps receive the least priority.

Chapter 9 provides a summary of the main findings of the study and concludes it by arguing the importance of understanding the lived experiences of women ageing with locomotor disabilities acquired early in life. The chapter concludes by some directions for further research on this topic.

Chapter 1

Review of Literature

One of the most contentious questions that a researcher would encounter while researching on disability is to answer, ‘What is disability?’ This is because disability has been understood differently by different people across time and space (Ghosh, 2012). One of the reasons for this complexity is that disabilities can be a result of a number of factors. It may be congenital (like most intellectual disabilities), acquired in childhood (due to micronutrient deficiencies, malnutrition or infections) or in later life (due to accidents, injuries or advancing age) (Addlakha, 2008). Disabilities can be characterized by episodic upsurge of symptoms and / or progressive degeneration (like schizophrenia, multiple sclerosis and Alzheimer’s disease) or they can be static (like loss of a limb due to an amputation), hidden (diabetes and epilepsy), visible (blindness and leprosy), temporary (like mild fractures) or permanent (spinal cord injury sustained in an automobile accident). Disabilities can also be graded from mild to severe (Ibid). Additionally, the experience of disablement varies for different persons located in different socio-economic and cultural contexts. Thus, disability is a complex experience and it needs to be understood by taking into consideration the interconnected components of medical limitation(s) and social prejudice (Addlakha, 2008).

This chapter reviews the existing literature on disability, keeping in view the focus of this study. The chapter is divided into four sections: Section I elaborates on the sociological perspectives on disability and the birth of the disability movement and disability studies in the United Kingdom,[6] followed by a discussion on the different models of disability as developed by disability scholars as well as the role played by the United Nations. Section II elaborates on the critique of disability studies as

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[6] The literature that has developed in the UK has been extensively reviewed in this study because (1) this has played a significant role in changing the perception about disability and persons with disabilities in academics and social policies in different countries all over the world, and (2) much of this literature is easily accessible either in the Disability & Society Journal (previously Disability, Handicap & Society) or in the archive of the Centre of Disability Studies, University of Leeds. I understand that the civil rights movement in the USA had encouraged the growth of disability studies in the USA in the 1960s (Gleeson, 1997), but because this literature is not easily available I have decided to skip its review in this study.

presented by majority world theorists. Section III elaborates on disability in the specific context of India. Section IV elaborates on some of the themes that are specific in the context of this study.

Section I

Sociological Perspectives on Disability

Cartesian dualism has played a significant role in hindering the study of the body in sociology and other social sciences disciplines. As a result, sociological studies on physical impairment have been very limited until about the 1980s (Hughes & Paterson, 1997). Prior to the development of the *social model of disability*, sociologists had developed two ways of understanding disability and chronic illness that were influenced by two different sociological traditions. The first among these is associated with the *functionalist* school of thought that looks at society as a biological organism in which the whole is made up of interconnected parts. This integration is a result of the general agreement on values and norms that are central to the society (Health Knowledge: Education, CPD and Revalidation from Phast, n.d.). Medical sociologist and a prominent functionalist thinker, *Talcott Parsons* considered illness as a social phenomenon instead of a purely biological condition. He had developed the *sick role* theory which considers health as an essential precondition for the smooth functioning of society. In this theory, Parsons outlined two major rights and two major duties of the sick person. According to him, the sick person is exempted from any responsibility for his/ her illness as it is beyond his/ her control. This incapacity also exempts the sick individual from his/ her normal role and task obligations. This legitimacy, however, is dependent on the recognition on the part of the sick person that sickness is an undesirable state of being and there is an obligation to get well. S/he is also under obligation to seek technical support and to cooperate in the process of getting well (Segall, 1976).

This theory has been influential because it shows that a sick person is an integral part of a larger social context. However, it has been critiqued for a number of reasons. Some have argued that the concept of sick role does not capture the subjective interpretation of illness by the sick person, but instead articulates the views of those who are credited with the responsibility of recovery, that is, the medical profession (Barnes & Oliver, 1993). Others have pointed out that it is not universally applicable to all patients as it is not always possible to incorporate the sick role. For instance, some individuals may be denied the sick role if a clear cut diagnosis of their condition has not been made, even though they have been suffering from chronic pain for a long period of time (Giddens, 2006). This theory also does not take into consideration other factors such as race, class and gender which can play a big role in affecting whether and how readily the sick role is granted (Giddens, 2006). Furthermore, the sick role has also been critiqued because it is not compatible with the social realities of modern societies, where there is an increasing stress on lifestyle and health. This means that individuals are held accountable for their own well-being, which is contradictory to the first premise of the sick role that the individual should not be blamed for his/ her illness. Another thing that is very prominent in modern societies is the shift from acute infectious diseases to chronic illnesses, which also makes the sick role redundant (Giddens, 2006).

Disability scholars have argued that the sick role does not distinguish between illness and impairment as even though a person is expected to occupy the sick role for a brief period of time, similar exceptions are also applied to persons with disabilities (Barnes & Oliver, 1993). Over the years roles have been developed to incorporate the experiences of persons with disabilities. These include the *impaired role* and the *rehabilitation role.* The former is used to refer to an individual whose physical condition is not likely to change because of which he/she is not able to meet one of the preconditions of the sick role, which is to ‘get well’ soon. Persons who occupy this construct are considered to have given up the idea of recovery completely, because of which they are not expected to cooperate with medical treatment to regain their health. The flip side of this role is that these persons are treated as ‘second class citizens’, who have accepted dependency on others (Sieglar & Osmond, 1974, cited in Barnes & Oliver, 1993). In the rehabilitation role a person is expected to accept and learn to live with his/her impairments by exploiting their remaining abilities. Like in the sick role, persons with disabilities in the rehabilitation role are not excused from social expectations or responsibilities. They are held responsible for their own recovery, and for this they are dependent upon rehabilitation professionals for bringing them back to ‘normality’ and for helping them to psychologically accommodate the ‘disabled’ identity (Safilios-Rothschild, 1970, cited in Barnes & Oliver, 1993).

These roles have been critiqued by disability scholars for being essentially determinist; for ignoring the social, political and economic factors; and for undermining the subjective interpretations of impairment from the perspective of the impaired individual (Barnes & Oliver, 1993). According to Oliver (1983, cited in Barnes & Oliver, 1993), such constructs are the product of the ‘psychological imagination’ of non-disabled people’ assumptions about what it is like to experience impairment. Oliver (1986, cited in Barnes & Oliver, 1993) has referred to this individualistic approach where the awareness of impairment is considered a loss as the ‘*personal tragedy theory*’ (. Barnes & Oliver (1993: unpaginated) have further stated that,

> [o]ne important factor explaining the continued ideological hegemony of ‘personal tragedy theory’ is its professional expediency, both at the individual and at the structural levels. If individuals fail to achieve the anticipated professionally determined rehabilitation goals then this failure can be explained with reference to the disabled person’s perceived inadequacy – whether it be physically or intellectually based or both. The ‘expert’ is exonerated from responsibility, professional integrity remains intact, traditional wisdom and values are not questioned, and the existing social order remains unchallenged (Barnes, 1990).

The second school of thought that sociologists have used to understand disability and chronic illness during the 1960s is *symbolic interactionism*. Symbolic interactionists study the ways people understand the social world and the meanings they assign to it (Giddens, 2006). They examined illness from the perspective of patients, and implicitly challenged the then dominant ‘sick role’ conception that gave primacy to the medical perspective and the functionality and complementarity of the doctor-patient relationship. In contrast, symbolic interactionists see patients as active agents and the doctor-patient relationship as containing a ‘clash’ of perspectives (Conrad & Bury, 1997). Through their emphasis on meaning, identity and the process of labeling (Barnes & Oliver, 1993), symbolic interactionism has been used to understand how people experience illness/ disablement themselves or perceive the illness/ disablement of others (Giddens, 2006). Goffman’s work is one of the pioneering works that has come out from this perspective. According to him, an individual’s personality is shaped from continual social interactions with other individuals, where attitudes are formed on the basis of perceived positive and negative qualities of others (Jary &

Jary, 1991, as cited in Gleeson, 1997). In Goffman's view, disability is understood as a '*stigma*', that is, "*a negative social attribute or sign* [which] *emerges from the ritualistic interaction of actors in society*" (Gleeson, 1997: 184). According to him, therefore, a disabled personality is molded by infinite stigmatizing encounters (Abberley, 1991, as cited in Gleeson, 1997). This perspective has largely dealt with empirical inquiry, explicitly detailing the strategic handling of symptoms and disabilities, but the problematic nature of such behaviors and their deeper implications have been left unexplored. One of the biggest criticisms of symbolic interactionism is that it focuses too much on the descriptive categories of interaction at the expense of wider cultural and structural analysis (Bury, 1982).

In the 1970s and 80s, sociologists from the sub-discipline of *medical sociology* set out to correct this lacuna. One of the groundbreaking works of this period is Strauss & Glaser's book *Chronic Illness and the Quality of Life* (1975), which outlined the territory of what sociology of illness experience might be like. Strauss & Glaser (1975) had focused on the subjective experience of living with a chronic illness and how people managed it in their everyday lives. They had stressed that chronic illness needs to be understood in the specific context of people's lives. They also recognized that chronic illnesses have certain common dimensions, but they stressed that in any sociological account, it is important to recognize that different illnesses affect people's lives in different ways (Conrad & Bury, 1997). Following their work, many sociological studies have been conducted in both the UK and the USA on specific disabling illnesses that have documented both the problems that people face and the active steps they take to overcome these problems (Bury, 1996).

According to Pierret (2003), who had reviewed the work published in the journal *Sociology of Health and Illness* from its inception in June 1979 up to its 25th anniversary, research in this field can be classified into three themes. In the initial phase, sociologists had focused on the theme of understanding the subjectivity of the patients and the meanings they attached to their experiences of illness through metaphors and mental representations that they develop after learning about their conditions. Such studies have focused on the notions of stigma, sense of shame and loss of self (Pierret, 2003). Such an inductive analysis paved the way for moving from the level of the individual, to the institutional level. A second theme had focused on how chronic illness upsets a patient's interactions with family members and people at the workplace. Such studies have been grouped under the label of coping actions and strategies. A third theme had focused on the connection between the illness experience and the social structure, primarily how the former is affected by the latter, although such studies are far less in number (Ibid). According to disability scholar, Colin Barnes (2003), such studies have great potential to enhance our knowledge about the experience of persons living with chronic illness, along with its social and economic implications for them and their families. Such studies, however, have been vehemently critiqued by disability scholars for individualizing the experience of disability by primarily focusing either *"on the physical and psychological consequences of the condition, or the complexity of the relationship between the disabled individual and their social environment"* (Barnes, 2003: 3). Disability scholars have further critiqued such studies for never seriously questioning the dominant 'personal tragedy theory' of disability and for undermining the achievements made by the disability movement in the UK (Barnes & Oliver, 1993; Shakespeare & Watson, 1997; Barnes, 2003; Thomas, 2004a). We would turn to these debates at a later section in this chapter.

Due to the political unacceptability of the implications of functionalism and interactionism, as noted above, sociologists committed to the liberation of persons with disabilities have extensively drawn from *Marxism* (Abberley, 1997). Although Marxian theory and practice have conventionally ignored or trivialized all other forms of social oppression besides that which was dependent on class relations, in the recent years, several disability theorists from Britain such as Finkelstein (1980), Oliver (1996) and Gleeson (1997) have explored *historical materialism* as a social theory to understand the origin of disablement in Western societies (more specifically in Britain) (Gleeson, 1997). According to Abberley (1997), this has happened partly because of the theoretical and political backgrounds of the sociologists involved. The historical materialist approach recognizes that,

> … all social relations are products of the practices which humans pursue in meeting their basic needs for food, shelter, affective ties, movement and the like. The social practices of each community are seen as transforming the basic materials – both physical and biological – received from previous generations (Bottomore et al., 1983). These basic, historically-received materials are known to materialism as 'first nature', and include everything from the built environment to the bodies social actors receive from previous generations. When these materials are then taken and remade by a succeeding society they become known as 'second nature' (Gleeson, 1997: 193).

According to Gleeson (1997), the materialist framework provides a distinct conception of disability which is based on the twin conception of first and second natures. Disability theorists have distinguished between impairment and disability, and have defined the latter as a form of social oppression which any society might produce in its transformation of first nature. In his opinion, the social construction of physically impaired people as persons with disabilities arises

> from the specific ways in which society organizes its basic material activities (work, transport, leisure and domestic activities). Attitudes, discourses and symbolic representations are […] critical to the reproduction of disablement, but are themselves the product of the social practices which society undertakes in order to meet its basic material needs (Gleeson, 1997: 194).

In this understanding, therefore, impairment is understood *"through its socialization as disability or some other (less repressive) social identity"* (Gleeson, 1997: 194). According to Gleeson (1997), the materialist position does not ignore the real limits that impairment places upon individuals, but it consciously and politically separates "the oppressive social experiences of disability from the unique functional limitations (and capacities) which impairments can pose for individuals". Disability therefore is not a natural human, but it is what happens to impairment "*as each society produces itself sociospatially*" (Gleeson, 1997: 194).

Vic Finkelstein (1980) was one of the pioneers to use the framework of historical materialism to understand the causal factors that gave rise to disablement with the advent of industrial society. He had used this framework to develop an evolutionary model which is embedded in terms of three phases of historical development. *Phase 1* is parallel to the feudal society of Britain before the advent of industrial revolution in which the economic base was agriculture and small scale industry. According to him, this phase did not exclude persons with disabilities from the process of production, even though they were regarded as individually unfortunate. *Phase 2* is parallel to the capitalist society and the progression of industrialization when the place of work shifted from the home to the factory. As a consequence of this, many persons with disabilities faced barriers that exclude them from participating in the production process. This subsequently resulted in their segregation in all kinds of institutions. *Phase 3* is parallel to the present day, which in Finkelstein's view

> …will see the liberation of disabled people from the segregative practices of society largely as a consequence of the utilization of new technologies and the working

> together of professionals and disabled people towards common goals (Oliver, 1990: unpaginated).

Finkelstein's evolutionary model has been critiqued by Mike Oliver (1990) who argues that even though it helps in explaining how the emergence of capitalist society affected persons with disabilities in Phase 2, it is an oversimplification of what had happened prior to the rise of capitalist society. According to him, Finkelstein had constructed an idealized community in Phase 1, which treated persons with disabilities more compassionately. He argues that although the advent of capitalism brought about qualitative changes in social relations, it is difficult to determine the exact impact of these changes on the lives of persons with disabilities as there is no evidence of this experience in recorded history (Oliver, 1990).

According to Oliver (1990), the nature of disability can be understood by taking into consideration changes in both the mode of production as well as the mode of thought prevalent at a particular point of time, and the relationship between the two. The rise of capitalism, according to him, broke down traditional social relations, and gave rise to new problems for social order, for which institutionalization was considered to be the foremost tool for ensuring social control. During this period there was a rapid increase in the number of institutions such as prisons, asylums, workhouses, hospitals, industrial schools and colonies. These institutions were a highly successful endeavor as they personified both repressive and ideological mechanisms of control (Althusser, 1971, cited in Oliver, 1990). Through these institutions, it was possible to separate *"those who would not from those who could not conform to the new social order"* (Oliver, 1990: unpaginated). These changes enabled the seclusion of persons with disabilities in specialist institutions of one type or another (Ibid). The Poor Law Amendment Act of 1834 also played an important part in the process of separating people who were reluctant to work vis-à-vis those who were incapable to work. Even though a majority of persons with disabilities during this period, much like the feudal period, lived in the family setting, what changed, however, was that disability now became a matter of shame. It was especially hard for working class families to handle the problems of having a disabled family member systematically segregated within them, as they were already under a lot of pressure in the new capitalist order. This system of segregation within the family and the institution remained intact well into the twentieth century as the state became more interventionist and the welfare state came into existence. In the second half of the twentieth century there has been a de-institutionalization movement as a result of which many people who had lived in the institutions earlier had returned back to their communities (Ibid).

Gleeson (1993, as cited in Gleeson, 1997) has also used this framework to argue that feudal English society was less disabling towards people with impairments due to two reasons, first, the narrow realm of physical interaction during that period, and second, the fairly weak presence of commodity production. According to him,

> "the growth of commodity relations in late feudal English period […] slowly eroded the labor-power of impaired people. Market relations and the commodification of labor introduced a social valuation of work […] into peasant households which had heretofore been relatively autonomous production units. The increasing social authority of the law of value meant the submission of peasant households to an abstract external force (market relations) which appraised the worth of individual labor in terms of standards of average productivity standards" (Gleeson, 1997: 194-195).

This competitive social appraisal of individual labor-power meant that people who were 'slower', 'weaker' or more flexible were devalued in terms of their potential for paid work (Gleeson, 1997). This gradually resulted in the production of disabling environment in Britain as well as its colonies. The advent of the industrial city in the late 18th century solidified the socio-spatial oppression of persons with disabilities which had begun in the late feudal era. One shared, but disabling, factor of the industrial city was the new separation between home and work which did not exist in the feudal period. This resulted in the disablement of physically impaired individuals in their daily lives. Moreover, industrial workplaces were designed in such a way that it further led to the disablement of 'uncompetitive' workers, including persons with physical impairments (Gleeson, 1997). The escalation of mechanized forms of production led to the standardization of productivity, which assumed the body of a 'normal' worker, while assigning everyone else as disabled. These changes eventually resulted in a section of labor, who were "*incarcerated in a new institutional system of workhouses, hospitals, asylums, and (later) 'crippleages'*" (Gleeson, 1997: 195).

These disability scholars, therefore, have tried to provide a materialist explanation for the disablement of persons with disabilities from pre-modern to modern to capitalist era largely through the experiences of people with impairments in Britain. Among all of them, Gleeson (1997) is the only one who had acknowledged that a vast continent of human history has remained unexplored by materialist scholars of disability.

According to him, there is *"a pressing need for empirically-grounded research on the social experience of disabled people in nearly all historical societies."* (Gleeson, 1997: 196) This is necessary, in his view, if materialism does not wish to echo the mistakes that traditional social sciences have made, that is, offering ahistorical and hypothetical accounts of disablement (Gleeson, 1997). Gleeson (1997) has also reasoned that historically grounded research is required to understand the particular subtleties of capitalism which have oppress persons with disabilities, while at the same time it is also necessary to reveal the exact ways in which impairment was experienced in different social formations. The aim of the latter is very crucial, according to him, as capitalism has not been the sole cause of disablement in human history (Gleeson, 1997).

Abberley (1997), however, found it extremely problematic to use the Marxian model of human beings for the emancipation of persons with disabilities. This is partially due to the effectiveness of Marxism as a social theory of impairment and the ensuing suggestion that the elimination of capitalism would eventually lead to the withdrawal of the material basis of disablement. In "*The Condition of the Working Class in England"* (1844/5), Engels had made the most explicit reference to impairment. He had argued that the impairment of the working class people was directly a result of the long working hours. He also condemned

> …a state of things which permits so many deformities and mutilations for the benefit of a single class, and plunges so many industrious working-people into want and starvation by reason of injuries undergone in the service and through the fault of the bourgeoisie (Engels, 1969: 194, as cited in Abberley, 1997: 29).

Engels also mentioned that in this way the system was destroying the people in the working class both physically as well as mentally (Ibid). According to Abberley (1997), such a concern has propaganda value that impairment is one of the things that socialism would abolish. In his paper, Abberley (1997) did not wish to dispute the accuracy and relevance of these arguments, rather what he pointed out was that for real persons with disabilities, such an analysis of linking impairment with capitalism to show the inhumanity and irrationality of the latter made no sense. What such a conceptualization, however, implies is that with the withering away of a state that progressively abolishes the injurious consequences of production for profit, persons with disabilities would also wither away from society. Abberley (1997) has two objections to such a proposition: first, while socially produced impairments may reduce, it is implausible that the rate of impairment would ever be reduced to zero; and second, it is questionable whether such a state of affairs is at all appropriate for persons with disabilities given its eugenicist undertone. He urges for disability scholars to understand the limitation of Marxian theory to offer concepts which can be successfully used to promote the development of a liberative social theory of disability (Ibid).

The above discussion has tried to show the sociological perspectives on disability and chronic illness. The perspectives that were considered include the functionalist perspective, symbolic interactionism and historical materialism. While disability scholars have been critical of the former two perspectives and have extensively used the third perspective in their understanding of disability as oppression, Abblerley's (1997) critique enlightens us that the Marxian perspective on disability has its own limitations. With this understanding let us now look at the genesis of the disability movement in the UK.

Genesis of Disability Movements in the UK

The origins of the disabled people's movement in the UK can be found in the late 19th century with the formation of two disabled people's organizations (viz. the British Deaf Association and the National League of the Blind) (Pagel, 1988, as cited in Barnes & Oliver, 1993). The movement, nonetheless, only found momentum in the 1960s when a group of disabled residents of residential institutions struggled for their autonomy (Finkelstein, 1991), and the creation of the Disablement Income Group (DIG) in 1965 (Barnes & Oliver, 1993).

Residential Institutions: In the past, most persons with disabilities in industrial societies received care in residential institutions. Morris (1991) defined institutionalization as "*an experience of powerlessness which can grossly multiply the effects of our physical limitations*" (unpaginated). According to Finkelstein (1991), incarceration of persons with disabilities in residential homes has been practiced for such a long time that it was considered a legitimate way of 'caring' for them. He stated that this was normalized to such an extent that founders and supporters of such institutions have received numerous accolades from civic and voluntary authorities for helping the ‘unfortunate disabled’. There was no awareness whatsoever that it could be profoundly undemocratic for able-bodied people to systematically remove persons with disabilities from their communities to live a life of isolation in these institutions. In contrast, persons with disabilities have regarded institutionalization with considerable misgivings. They have not only complained about the quality of their lives in these institutions but have also felt extremely distressed by their lack of control over how these institutions function (Finkelstein, 1991). Due to these reasons, residential institutions have been a dynamic site where persons with disabilities have struggled for their basic citizenship rights. They had demanded for, first, the right to control their personal lives, and second, the democratic right to have a voice in the way the residential homes function (Ibid).

Finkelstein (1991) further elaborated that the management of institutional care was placed in the hands of able-bodied ‘experts’, who, by virtue of their preconceived notions considered persons with disabilities to be victims of personal tragedy. These experts, according to him, considered removing persons with disabilities from the able-bodied society where they were unable to cope with the able-bodied environment as an act of kindness. In such a situation, requests from the residents to have a say in the running of the management of the institution was usually met with blank incomprehension (Ibid).

In this context, it is imperative to review Miller and Gwynne’s (1972, cited in Morris, 1991) controversial study where they had argued that the main purpose of residential institutions was to assist the inmates in their switch from ‘social death’ to ‘physical death’. Their contention was that if a physically impaired person had to enter an institution, this was because he/ she had failed to occupy or retain any meaningful social role according to the societal norms that offers status to the individual. This, according to them, can be validated by the fact that those who entered these institutions rarely left from there, unlike criminals or even psychiatric patients (Morris, 1991). This, for them, is equivalent to being socially dead. The institution, for them, is a kind of limbo where persons with disabilities are sent during their interval between their social death and physical death (Morris, 1991). Morris (1991) has argued that while many persons with disabilities would agree with this view, many others would reject it by insisting that social death is mainly due to the reaction of non-disabled world towards disability, rather than an inevitable consequence of functional limitation, regardless of its severity.

Formation of Disablement Income Group: By the 1960s, some of the residents started moving out of the institutional setup into their own homes in the community. By this time, they were certain that the setting up and maintenance of residential homes was a powerful indication of the chief attitude of the society that disability means social death (Finkelstein, 1991). Due to this, they realized the importance of the movement to provide safe community based alternatives as a necessary factor in securing the citizenship rights of persons with disabilities (Finkelstein, 1991). To achieve this goal they became actively involved in joining and creating organizations of persons with disabilities which they felt could in some way promote the assimilation of persons with disabilities into the community (Finkelstein, 1991).

During this period, an organization that attracted much responsiveness was the Disablement Income Group (DIG) (Finkelstein, 1991). Formed in 1965 by two women, *Megan Duboisson* and *Berit Moore*, in Britain, DIG was concerned about general social rights of persons with disabilities and the manner in which disabled housewives were disqualified for any disability benefits of that period (Finkelstein, 1991; Finkelstein, 2001a). In that decade, DIG became the largest mass organization of persons with disabilities in the world. Over time, however, its control went over to the hands of men, including some male academicians, who changed the purview of the organization into a "narrow parliamentary lobbying group wholly focused on 'benefits'" (Finkelstein, 2001a: 3). This change meant that the ordinary members had no clear roles within the organization, due to which its membership began to dwindle (Finkelstein, 2001a).

Inspiration from America's Independent Living Movement: In the USA, some of the earliest formal organizations[7] for persons with disabilities were organized between the two World Wars. These organizations mostly catered to the needs of the members of their own group rather than more widespread disability issues. Other organizations[8] were established about 20 years following the Second World War. These

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[7] These organizations include the Disabled American Veterans (DAV) and the National Federation of the Blind (NFB) (Scotch, 2009).

[8] These organizations include Paralyzed Veterans of America, the National Association of the Deaf and the American Council of the Blind (Scotch, 2009).

organizations had different degrees of political participation, but none were concerned with the broader issue of civil rights for all persons with disabilities (Scotch, 2009). All this, however, began to change by the late 1960s as several changes in the society were affecting the lives of persons with disabilities. These changes include, first, improvement in medical technology that prolonged the lives of persons with disabilities with a range of medical conditions/ injuries who would not have survived previously. For these growing numbers of adults with disabilities, physical impairment was proving to be less of an impediment than the barriers they faced due to stereotyped attitudes of the society and architectural constraints. Second, many individuals who had acquired their impairments in their childhood, adolescence or early adulthood due to infectious causes, accidents or the Vietnam War, had a clear memory of themselves as non-disabled and due to this they had not incorporated an image of themselves as dependent on others. They wanted to live as ‘normal’ adults and expected to fully participate in economic and social activities, which was also being made technologically possible. Even for those who had congenital disabilities, their parents had usually stressed on self-confidence and achievement, which encouraged persons with such disabilities to think about themselves as capable of participation (Scotch, 2009).

This aspiration for participation was also encouraged by the political climate of that period. In the 1960s, several groups of minorities and activists were seeking greater participation in social institutions and more autonomy and control over their lives. In such a context, a number of persons with disabilities who had participated in these movements got the inspiration to view their identities in the same political sense as the other groups (Scotch, 2009). They also realized how a number of strategies used by the other movements could be adopted for their own liberation. While models of change-oriented activism did not assure success, it was a good method for getting support among a constituency and among the public in general, and for using that support towards persuading governmental and institutional decision-makers. The prospect of integration into the mainstream of society encouraged persons with disabilities to form new organizations at the local and state levels and to restructure surviving groups, which included individuals with a range of disabilities (Ibid).

The Independent Living Movement (ILM) deserves special attention here. The ILM emerged in the 1960s and was an outcome of the campus culture of American universities. During this period, these universities had initiated several self-help programmes to facilitate students with severe impairments to attend mainstream courses. As such facilities were hardly available outside the university campuses, it encouraged some disabled students to develop their own services under the banner of Centers for Independent Living (CILs) (Barnes, 2012). The first CIL was established in Berkeley, California in 1972 (Barnes & Oliver, 1993). Unlike other services *for* persons with disabilities, the CILs were self-help organizations that were *run* and *controlled* by them (Barnes, 2012). The Berkeley CIL provided a range of services such as peer counseling, advocacy services, transport, personal assistance services and training in independent living skills and community based living (De Jong, 1979 as cited in Barnes & Oliver, 1993). These were designated to enable people with impairments for a way of life of their own choice within the local community, instead of apart from it (Barnes, 2012). In the years that followed, similar CILs and organizations were also established in other parts of the USA, Canada and Europe (Driedger, 1989; Evans, 1993, as cited in Barnes & Oliver, 1993).

The activities of the ILM in the USA were not merely restricted to establishment of CILs. Similar organizations were also involved in monitoring federal legislation for people with disabilities including the introduction of the Americans with Disability Act, which is considered as the most inclusive anti-discrimination policy ever introduced during that period (West, 1991, as cited in Barnes & Oliver, 1993).

Formation of UPIAS: In Britain, the establishment of many disability organizations in the 1970s and their fiasco in securing a wide-ranging disability resulted in the establishment of Disability Alliance (DA), an umbrella organization, in 1975 (Barnes & Oliver, 1993). The DIG and DA were mainly concerned about the economic needs of persons with disabilities, largely due to the influence of non-disabled academics and professionals (Ibid). According to Barnes & Oliver (1993), *"this approach was rooted in the traditional medical view that persons with disabilities are socially dependent on the non-disabled community"* (p: unpaginated).

Disheartened by this approach which was mainly under the control of non-disabled 'experts', Paul Hunt, Vic Finkelstein and other like-minded disabled activists set up the Union of Physically Impaired against Segregation (UPIAS) in Britain in 1974 (Barnes, 2012). Hunt, who had lived in the Cheshire Homes for a considerable period of time throughout his childhood and adulthood, had significant experience of organizing and mobilizing persons with disabilities. Finkelstein, on the other hand, had supported the anti-apartheid struggle of South Africa. When Finkelstein and his wife came to Britain, they met Hunt and his wife, and together they realized that they have a common agenda: to change the oppressive system that disable persons with impairments instead of appealing to the prejudiced to stop their discrimination (Finkelstein, 2001a). They realized the need for a new organization that would mobilize persons with disabilities at the grassroots level to fight against oppression. Eventually Hunt wrote a series of articles to the press asking like-minded persons with disabilities to join him in establishing a new organization. The UPIAS was formed through the exchange of ideas from those who wrote back to him. In order to prevent what happened to the DIG, the membership to the UPIAS was restricted only to persons with disabilities initially. The main agreement among the members of UPIAS was that *"the oppressed [will] have to organize themselves, in their own interest, for the transformation of society"* (Finkelstein, 2001: 4).

During the 1960s and early 1970s, the popular concern among disabled activists was to campaign for a national income group, which Finkelstein terms as the *compensatory approach.* The intrinsic aim behind this was that persons with disabilities should be provided with a statutory income in order to compensate for their 'personal defects'. The argument of UPIAS ran counter to this, which was that *"the central issue is that of oppression not compensation. We don't want to be compensated for being oppressed! We want people to stop oppressing us!*" (Finkelstein, 2001a: 4). According to Finkelstein (2001a), there is a huge difference in the perspectives of the two interpretations. While the first considers persons with disabilities as victims of 'personal tragedy' and places them in a dependent position vis-à-vis the able-bodied society for state charity, the central issue for the second approach was that of oppression. For this reason it is claimed that the able-bodied society should change because it is oppressive to persons with disabilities. This view of UPIAS was very much in contrast with the other established organizations *for* and *of* persons with disabilities in the late 1960s and early 1970s. In its manifesto, entitled *Fundamental Principals of Disability* (1976), the UPIAS asserted that:

> In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by way we are unnecessarily isolated

> and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS, 1976: 3-4).

Formation of BCODP: Some of the other organizations that were formed in this period include ‘The Liberation Network’, which functioned between 1979 and 1983 and ‘Sisters against Disability’, an early movement of women with disabilities. The common aim of all these organizations was securing equal rights for persons with disabilities and the removal of negative discrimination in all its forms (Davis, 1993, as cited in Barnes & Oliver, 1993). Later these goals were adopted by 10 organizations that came together in 1981 to form the British Council of Organizations of Disabled People (BCODP). From the very beginning it had adopted the UPIAS definition of disability (Campbell & Oliver, 1996, as cited in Barnes, 2012).

In the 1980s, self-organization and developments at the international level intensified the campaign for equal rights in Britain. In 1985, several disability organizations controlled and run by disabled (such as BCODP) and non-disabled persons (such as Royal Association for Disablement and Rehabilitation [RADAR] and the Spastics Society) came together to form Voluntary Organizations for Anti-Discrimination Legislation (VOADL). This is an important event because its establishment gave a strong indication of the increasing strength of the disabled people’s movement in Britain. Despite this seeming unity, there still existed a number of important differences between the fundamentally paternalistic approach of the traditional organizations for persons with disabilities and the emancipatory philosophy of BCODP (Oliver & Barnes, 1991, as cited in Barnes & Oliver, 1993).

The BCODP and its member organizations have been at the center of the campaign demanding equal rights for persons with disabilities and have produced a number of policy initiatives that have improved the lives of persons with disabilities in Britain. Such initiatives have resolutely established BCODP as the only truly representative voice of persons with disabilities in Britain (Barnes & Oliver, 1993). This success of BCODP has subsequently encouraged growing numbers of persons with disabilities to assume a collective disabled identity and take a more direct approach to political participation. The encouragement for such radicalization has mainly come from the USA, particularly the strategies adopted by the Civil Rights Movement and the ILM. In the early days of the British disability movement, the overprotectiveness of the welfare state and the lack of a strong British Civil Rights tradition caused persons with disabilities to be careful in their choice of strategies. But this scenario has changed drastically over the last few decades and increasing numbers of persons with disabilities have taken to the streets to protest against institutional discrimination in all its forms. In order to bring the attention of the masses to the injustices they suffer, persons with disabilities also risked public ridicule, arrest and even imprisonment (Barnes & Oliver, 1993).

In the 1990s, however, there came about several changes in the world and in the UK, which turned the focus of the BCODP from grassroots work to parliamentary lobbying that subsequently undermined the disability movement (Finkelstein, 2007). According to Finkelstein (2007), during this period the BCODP gave more importance to the campaign for anti-discrimination. Since all major political parties of that period were in favor of a free market to solve the problems in health and social services, persons with disabilities in Britain were left with no other option but to *"suck up to the parliament in the hope that they will not be forgotten"* (Finkelstein, 2007: 4). As persons with disabilities did not have enough individual income to buy services or use important sectors of the market to solicit their customs, that is why they had to *"beg that* [their] *human rights are recognized and policed"* (Finkelstein, 2007: 4). According to Finkelstein (2007) this is the primary reason why in the 1990s, there emerged several meaningless social models of disability that shifted the emphasis on 'social rights'. Subsequently it was a simple step *"to interpret the social model of disability as a 'rights' model"* (Finkelstein, 2007: 4). He has been against this rights approach because within it, the "*parliament grants legal rights to those that it* ***defines*** *as 'disabled'"* (Finkelstein, 2007: 5, emphasis in original). The focus of this approach, therefore, is to isolate the characteristics of the individual instead of the nature of the society and then to make selected 'concessions' to those defined as such. This is in sharp contrast to the main emphasis of the UPIAS, which was to ensure that persons with disabilities are integrated in all areas of society (Ibid).

The above section made an attempt to provide the background which enabled the disabled people's movement in the UK to emerge. As can be seen from the above discussion, by adopting a collective disabled identity, the movement was able to bring about significant changes in the lives of persons with disabilities at the grassroots level. However, things began to change from the 1990s, with the change of the political atmosphere that eventually narrowed down the demands of the earlier vibrant disability movement of radically changing the environment to merely protection of human rights.

Emergence of Disability Studies as a Discipline

Disability studies is a theoretical and research approach that has drawn extensively from the experience of the disability movement (Shakespeare & Watson, 1996). Disability studies perspective is inspired by the UPIAS document *Fundamental Principles of Disability* (1976) that redefined ‘disability’ as something that people with impairments experience in a society that is prejudiced towards any biological flaw. Inspired by this definition, Oliver had coined the term *social model of disability* in the early 1980s. Unlike the traditional view of disability based on the medical approach (Chander, 2013), in disability studies, disability is understood as an outcome of the twin processes of discrimination and prejudice that limit people with impairments. It is a structural analysis which is based on the idea that persons with disabilities are an oppressed group, where disablement is a collective experience (Shakespeare & Watson, 1996). The following sub-section elaborates on the models of disability that are used in disability studies.

The Models of Disability: In disability studies, the lived experiences of persons with disabilities are described by different models (Ghai, 2003). These models represent socio-cultural assumptions about disability and persons with disabilities in various periods of human development, along with the ways they have been subjected to different forms of stigmatization and discrimination (Ghosh, 2012). These models were developed in the minority world, where persons with disabilities took the lead in demanding equal rights (Ibid). Mike Oliver is credited as one of the pioneers on the discussion of models of disability (Oliver 1990). He conceptualized these models as the binary distinction between, what he termed as, ‘individual’ and ‘social’ models of disability. This idea of the two models was inspired from UPIAS distinction between ‘impairment’ and ‘disability’ (Oliver 1990). The UPIAS defined impairment as *“lacking part or all of a limb, or having a defective limb, organ or mechanism of the body”*, and disability as *“the disadvantage or restriction of activity caused by a* *contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities"* (UPIAS, 1976: 3-4). Oliver developed these two models in order to make it easy for professionals, who had limited idea about disability issues to understand (Oliver, 1990).

The individual model encompasses several models like the moral model, the charity model, the personal tragedy model and the medical model (see Bhanushali, 2007; Ghosh, 2012). The two fundamental tenets of the individual models are: firstly, the 'problem' of disability is located within the individual, and secondly, the causes of this problem originate from the functional or psychological limitations which are assumed to arise from disability (Oliver, 1990). Oliver considers medicalization as a significant component of this model (Ibid). This is because disability is often looked at as a medical deficit, and medical professionals frequently dominate over the lives of persons with disabilities (Ghosh, 2012). In contrast, the social model of disability is a rejection of all the tenets listed above, and instead locates the problem of disability within the society (Oliver 1990).

The following section elaborates on the medical and social models of disability.

The Medical and Social Models of Disability: The medical model defines disability as *"the presence of a physical or cognitive difference that deviates negatively from a 'mundane' norm"* (Koch, 2001: 370). This model explains physical, sensory or cognitive disabilities in terms of a medical etiology and emphasizes on the causal relationship between the origins and outcomes of various types of disabilities (Ghosh, 2012). The focus of this model, therefore, is not the individual per se, but the particular body part which is not functioning 'normally' (Ibid). Cure and overcoming the disability are the central features of this model, which are to be sought by the individual who is afflicted by it (Ghai, 2003).

The medical model has been criticized for giving undue emphasis on clinical diagnosis, which in turn provides a partial and inhibiting view of the individual (Brisenden, 1986). It is argued that the problem with this model is that it not only determines the kind of treatment that is suitable for persons with disabilities, but also the type of life that they are supposed to lead (Ibid). According to Oliver (1990), disability is only a social state, and not a medical condition, because of which medical interference and control over disability is inappropriate. He further argues that doctors play a crucial role in the lives of persons with disabilities in stabilizing their initial condition and treating their illnesses. However, it is absolutely wrong when they use their medical expertise and skills to treat disability rather than illness, which, according to him, are two different things. It is wrong on two counts: firstly, as a result of the powers vested on them as experts, doctors are able to make decisions about the lives of persons with disabilities that have caused much harm to the community; and secondly, the ideology of normality, upon which the medical and rehabilitation enterprises are founded, have little regard for the pain and suffering of these individuals in their endeavor to restore normality or as near normality as possible (Oliver, 1990). The second point has also been highlighted by Barnes (2003) that *"the promise of miraculous treatments and cures by medical and rehabilitative professionals and the media"* (p: 11) may result in raising the expectations of persons with disabilities, which in turn may lead to psychologically debilitating consequences for them. He had cited the example of an ex-policeman, Philip Olds, who had acquired a spinal cord injury. Olds had committed suicide after a prolonged period of 'rehabilitation' when he understood that a 'revolutionary' new technique that was supposed to enable him to walk turned out to be a failure. According to Oliver (1990), persons with disabilities are increasingly rejecting the prescriptions of 'normalizing' society, along with different professional activities that attempt to support it.

The social model of disability, on the other hand, was developed by academicians and activists who are disabled themselves, and is a complete antithesis of the medical model (Lang, 2001). The important tenets of this model are: firstly, it does not refute the importance of appropriate medical and rehabilitative interventions in relation to disability, instead, it demonstrates the drawbacks of this approach in the cause of empowerment of persons with disabilities; secondly, the model makes a conscious effort to shift the attention away from the functional limitations, physiological and cognitive impairments of the individuals, to the ability of the society to systematically oppress and discriminate them (Lang, 2001; Barnes, 2003; Barnes, 2012). This model, therefore, provides insights into the disabling aspects of modern society with the aim of developing sound policies so that such aspects can be removed (Barnes, 2012). It is strongly influenced by Marxist and feminist paradigms within sociology. With such a conceptualization of disablement, this model has brought about a paradigm shift within sociology (Shakespeare & Watson, 1996). Furthermore, the model has played a critical role in the emergence of groups of persons with disabilities and the growth of a positive disabled identity (Ibid).

Debates surrounding the Social Model of Disability: The social model understanding of impairment and disability had a great impact on the mobilization of persons with disabilities in Britain during the 1980s and 1990s. It has been very important for the disability movement in Britain in two important ways: first, it enabled the identification of the political strategy for the movement, namely, removal of barriers, instead of pursuing a strategy of medical cure or rehabilitation; secondly, the model had a great impact on persons with disabilities themselves (Shakespeare & Watson, 2002). The importance can be deciphered from the words of Liz Crow (1996), who wrote,

> My life has two phases: before the social model of disability, and after it. Discovering this way of thinking about my experiences was the proverbial raft in stormy seas. It gave me an understanding of my life, shared with thousands, even millions, of other people around the world, and I clung to it (p. 55).

The social model gave Crow the explanation that she was seeking for a number of years. Most importantly, it gave her the ‘revolutionary’ understanding that, *“if all the problems had been created by society, then surely society could un-create them”* (Crow, 1996: 55). She further writes that this model has given persons with disabilities a vision to free themselves from oppression, and has played a central role in upholding individual self-worth, collective identity and political organization (Crow, 1996).

Jenny Morris, an active member of the women’s movement in Britain, acquired her impairment at the age of 33 years, after an accident (Morris, 1991). It did not take her long to realize that her new experience had little room within feminist ideas or the women’s movement. She considers herself fortunate that the disability movement was active in Britain at that time, which gave her a political outlook to comprehend her personal experience (Morris, 2001). According to Morris (1998),

> [t]he social model of disability has given us the language to describe our experiences of discrimination and prejudice and has been as liberating for disabled people as feminism has been for women (p. 3).

In spite of the positive role played by the model, from the 1990s, an increasing number of disability scholars, informed by the feminist and post-modernist debates, have raised the internal critique about leaving out the body from the experience of disablement. Some have argued that this model works well on a grand scale to challenge discriminatory social structures and shows the requirement for civil rights legislation to protect the rights of persons with disabilities. However, it lets them down at a personal level (Crow, 1996). According to Shakespeare and Watson (2002), the 'strong' version of the social model uses a very rigid dichotomy between the private and public lives of persons with disabilities. Although in their private conversations, most activists talk about experiences of aches, pain and urinary tract infections, which are at odds with the 'strong' social model, they refute the significance of the body while they are out campaigning. Shakespeare & Watson (2002) argue that this inconsistency is wrong. In their words,

> … if the rhetoric says one thing, while everyone behaves privately in a more complex way, then perhaps it is time to re-examine the rhetoric and speak more honestly (pp. 7-8).

The binary distinction is a product of the fear of articulating any negative feelings about the bodies of persons with disabilities, as it may result in passing a wrong message that their lives are not worth living. However, Morris (2001) considers it foolish to deny the distressing experiences of the body. Some have argued that the divide that categorizes people into disabled and non-disabled is problematic, as: firstly, a division between persons with and without disabilities cannot be made on the basis of impairment, as many non-disabled persons can also have impairments (like short or long sightedness); and secondly, the divide cannot be sustained on the basis of oppression as many persons with disabilities can be oppressors themselves (like they can be racist or sexist), and non-disabled persons can be oppressed due to different factors like poverty, racism and sexism (Swain & French, 2001).

According to Crow (1996), the focus of the social model is so absolute that it runs the risk of supposing that impairment plays no part in shaping the experiences of persons with disabilities. Very often impairment has been presented as an irrelevant, neutral or even positive aspect of their lives, but the complexities and contradictions associated with it are never openly discussed. She argues that "*the experience impairment is not always irrelevant, neutral or positive* [as] *it is the very reason used to justify the* *oppression that we are battling against"* (Crow, 1996: unpaginated). This denial can sometimes also lead to unfortunate consequences like neglecting the need to take appropriate action on impairment or impairment prevention (Shakespeare & Watson, 2002).

Impairment can be salient for many persons with disabilities (Shakespeare & Watson, 2002). Due to the failure of the model to take into account experiences of pain, fatigue, depression and chronic illness, many persons with disabilities may not be willing to identify with the disability movement. Since impairment is a heterogeneous experience, it affects the lives of persons with disabilities differently, and can also generate different reactions from the wider socio-cultural settings. All these factors have different individual and psychological impacts as well as social and structural impacts (Ibid). According to Shakespeare and Watson (2002), people are disabled both by their bodies and the barriers they face, due to which both social theory and disability movement should take this into consideration.

Morris (2001) mentions that to refute the mainstream notions about persons with disabilities, the social model *"sometimes colludes with the idea that the 'typical' disabled person is a young man in a wheelchair who is fit, never ill, and whose only concern is the physically inaccessible environment"* (p: 9). This, according to her, runs contrary to the facts that

> … the largest group of disabled people are those with […] cognitive impairments, and most disabled people with a physical impairment are women, are over the age of 60, have a chronic or progressive condition […], and feel unwell a lot of the time, and if they use a wheelchair they only do so occasionally (Morris, 2001: 9) .

She also fears that if persons with disabilities do not incorporate the personal experience of impairment into their politics, then the non-disabled world would continue to define their experiences for them, which further runs the risk of alienating and disempowering persons with disabilities (Morris, 2001).

Crow (1996) also points out the fundamental difference between the disability movement and other civil rights movements, which cannot be ignored. She states that embodiment need not necessarily be unpleasant or difficult for the other groups, but it is not so for persons with disabilities. Recognizing this difference would not mean that the struggle against disability is any less important than the struggles of other groups, but it is to acknowledge that the personal struggles of persons with disabilities with their bodies will remain even when the disabling barriers cease to exist (Ibid).

Additionally, it has been argued that the binary distinction between impairment and disability is unsustainable (Morris, 2001; Shakespeare &Watson, 2002). This is because it is not always apparent which restrictions are caused by impairment and which by disability (Ibid). According to Hughes & Paterson (1997) the social model separation between body and culture, impairment and disability has produced a cartesianized subject, which although is very helpful in establishing a radical politics of disability, sits uneasily in the contemporary world of identity politics. The social model by conceptualizing the body in purely biological terms, follows the traditional, Cartesian, western, meta-narrative of human condition, and in this way seems to converge with the biomedical understanding of the body as a pre-social, inert and physical object (Hughes & Patterson, 1997). Impairment, according to them, is an irresistible feature in the lives of persons with disabilities. But in spite of this, it remains 'theoretically embryonic' in disability studies literature. By ignoring to recognize the importance of impairment, Hughes & Paterson (1997) have argued that the social model *"actually concedes the body to medicine and understands impairment in terms of the medical discourse"* (p: 326) even though it is critical of the medicalization of disability. It has been argued that although the binary division between impairment and disability de-medicalizes disability, it concurrently leaves the body in the exclusive domain of medical interpretation. In this way, the relationship between persons with disabilities with their bodies is mediated by medicine and treatment, while any connection of the body with policy and politics is severed (Hughes & Paterson, 1997). In order to correct this lacuna, according to them, the social model has to be critiqued for its 'dualistic approach' and to establish that "the impaired body is part of the domain of history, culture and meaning" (p: 326), and not bereft of it as medicine would have one believe (Hughes & Paterson, 1997). Impairment is always already social, and due to this reason, an appropriate social theory of disability should include all the dimensions in the lives of persons with disabilities, including *"bodily, psychological, cultural, social and political, rather than claiming that disability is either medical or social"* (Shakespeare & Erikson, 2000, cited in Shakespeare & Watson, 2002: 19). Hughes and Patterson (1997) have suggested the use of the theoretical perspectives of post-structuralism and phenomenology to correct this lacuna.

Finally it has been argued that disability politics rests on a fairly unreflexive acceptance of the distinction between disabled / non-disabled. This is problematic because many persons with disabilities do not identify themselves as disabled, and instead seek access to a mainstream identity (Shakespeare & Watson, 2002). It is also difficult to define who is a disabled person and who is not because different societies treat particular groups of persons with impairment in different ways. Along with this, the social model has also not been very effective in reconciling multiple identities, such as the dimensions of gender, race and sexuality, within or outside disability (Ibid). Shakespeare & Watson (2002) have argued that some people may identify themselves in terms of their alternate identities, or may strategically identify with either one of their identities depending upon the context.

Criticisms of Disability Studies: Disability studies as a discipline has faced numerous criticisms over the years. Some of the major criticisms include the atheoretical nature of the discipline and the ignorance of the experience of impairment among others. Several disability scholars have blamed the overemphasis on the social model as being the primary reason for the theoretical deficit of the discipline (Shakespeare & Watson, 1996; Gleeson, 1997; Hughes & Paterson, 1997; Thomas, 2004c). Gleeson (1997), on the other hand, is of the view that the atheoretical nature of disability studies is related to its cross-disciplinary character. For him, the boundless character of the discipline has the advantage that it allows flexibility to integrate the random division of disciplines that are institutionalized in Western academics. At the same time, however, it makes the discipline a difficult theoretical terrain to appraise. According to him, this is due to two reasons: first, is the disciplinary backgrounds of the majority of contributors in disability studies, who are either social workers or advocates, due to which the field of disability studies has remained dominated by policy discussions; and second, is the failure of the social sciences more generally to consider impairment as an important issue to be studied (Gleeson, 1997). Gleeson (1997), however, has noted that the tilt towards policy making in disability studies is both its strength and limitation. Stressing on this point, he had said that even though the assertions in disability studies are theoretically unsophisticated, they are firmly embedded in the everyday world of social practice and are marked by a direct understanding of the oppression that persons with disabilities experience. One of the merits of the highly politicized nature of the discipline is that it promises great potential for a more theoretically-informed praxis (Gleeson, 1997).

Others have pointed out that by failing to look at the body, disability studies has failed to do justice to the corporeal experiences of persons with disabilities (Shakespeare & Watson, 1996). According to Shakespeare & Watson (1996), if disability studies wishes to continue in its role in the development of the disability movement, then it must embrace the body in some way. They realize that many disability studies scholars are fearful of this move as it might weaken the disability movement, but they reason that it is a very important issue that cannot be left in the hands of medical sociologists. Due to this neglect of the everyday experiences of persons with disabilities, disabled sociologists like them had turned to the sub-discipline of *sociology of the body*, but there also they faced disappointment due to its overtly theoretical nature, with little or no empirical studies and no connection to social movements or political initiatives (Ibid). They have further stated that the acceptance of embodiment and impairment is a necessary development for disability studies which would further increase its relevance to the everyday lives of persons with disabilities. But they have put forth that a truly embodied sociology that is devoid of *"the dangers of biological determinism and the reductionism of social constructionism could form the basis of a more complete theoretical and political strategy"* (Shakespeare & Watson, 1995, cited in Shakespeare & Watson, 1996: unpaginated).

Following the argument made by Zola, Shakespeare & Watson (1996) have argued that impairment is ubiquitous as persons with and without disabilities experience impairment and limitations, which is why both the groups cannot be distinguished from one another on the basis of impairment. According to them, if this is accepted, then it lays the ground for furthering our understanding on how nondisabled people "maintain their bodies as unproblematic" (Shakespeare & Watson, 1996: unpaginated). What they are arguing for is basically a lay perspective on the body which would make it possible to theorize impairment from the 'bottom-up' (Ibid).

Medical sociologists, Michael Bury and Ruth Pinder who have been criticized for their work on chronic illness have also counter-criticized disability scholars for negating the experience of the body. Bury's (1982) work had tried to understand how chronic illness disrupts the structures of everyday life and the forms of knowledge that reinforce them. Chronic illness, according to him, brings to consciousness the worlds of pain and suffering and sometimes impending death, that is, experiences that are normally considered to be distant possibilities or predicaments that others suffer from. Furthermore, the experience of chronic illness changes the nature of relationship between individuals, their families and the wider social networks (Bury, 1982). According to him, the development of chronic illness such as rheumatoid arthritis is a form of *biological disruption* that (1) disrupts taken-for-granted assumptions and behaviors, (2) forces one to reevaluate his/ her biography and self-concept, and (3) forces one to mobilize the resources available to them to face the altered situation (Ibid). His work, therefore, had tried to understand, firstly, the particular background in which illness takes place, and secondly, the cultural exchanges by professionals and lay persons (Pierret, 2003). According to Pierret (2003), this framework has served as the reference point for other studies on chronic illness that were conducted subsequently. His study, however, did not give much importance to the larger social structure in which chronic illness takes place (Ibid). Bury's work has been critiqued for ignoring the disabled people's movement, the social model of disability and its impact on social policy and social research outside of sociology (Barnes & Oliver, 1993). Thomas (2004c) has accused Bury of individualizing the experience of disability by reinforcing the view that 'disability' is primarily caused by 'impairment' while ignoring the social and cultural factors completely. In his later works, however, Bury has clarified that sociology has long recognized that not all restrictions of activity are caused by physical factors, but some are caused by social and cultural causes (Bury, 2000 as cited in Thomas, 2004c). Thomas (2004c) concedes that even though he accepted disability to be caused by both biological as well as social factors, he laid more stress on the former. Further, Bury (2000) did acknowledge the significance of the social model in changing wider social and sociological thinking about disability, but in spite of this, he finds it untenable due to its denial of any causal connection between disability and impairment. He considers this as an unhelpful 'oversocialized' and overly political view (Thomas, 2004c).

Ruth Pinder’s work on persons with arthritis has also been critiqued by disability scholars (see Shakespeare & Watson, 1997). In her papers, Pinder (1995; 1996) had used detailed case studies of people with arthritis in order to examine how they manage or fail to manage in the workforce. In both the papers she has used the case studies of two informants, one who is able to manage at the workforce, and the other who has not been able to do so. Pinder (1997) had argued that even though the social model of disability was able to account for some of the experiences of her research participants, it wasn’t able to do so in the case of other experiences. This, however, was not appreciated by disability scholars Shakespeare & Watson (1997), according to whom, the sole purpose of Pinder’s two papers was to attack the social model of disability. They argued that the social model has been invaluable for persons with disabilities in Britain and elsewhere, which has led to both social improvements and individual empowerment (Ibid). In a reply to Shakespeare & Watson (1997), Pinder (1997) had stated that she appreciates the contribution of the social model as a tool for the disability movement, but she argued that the attempts to treat the two as separate entities overlooks the complexities that exist in the lives of persons with disabilities. She further argued,

> …if we want to fully understand the ambiguities of lived experience, we need to come to grips with the many interlocking webs of significance in which impairment and disability are embedded. On their own, neither tells the whole story. The picture I have tried to paint is a holistic one, avoiding both the ‘undersocialising’ of an individualistic psychologising approach and the ‘oversocialising’ of a more deterministic analysis (Williams, 1996). I stand by these arguments (Pinder, 1997: 275).

Disability, Chronic Illness and the Body: There could be several reasons for the lack of acceptance of studies on chronic illness by disability scholars. According to Wendell (2001), who has M.E.[9], there is a two-way relationship between disability and chronic illness. But in spite of this disability movements have been reluctant to identify disability with illness. She argues such a stance is understandable given the troubled past of persons with disabilities as a community (see Wendell, 2001). According to Wendell (2001), such factors have motivated disability activists and other persons with disabilities to detach themselves from chronically ill persons. She, however, has pointed out that this is problematic as some people with disabilities are

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[9] M.E. refers to myalgic encephalomyelitis, which is a debilitating illness that affects the muscles and the nervous system. Its cause is still not known, although it usually begins with a severe viral infection like influenza (Wendell, 1993).

‘unhealthy’, who constantly suffer from declining health, psychological problems and even the threat of death that social justice cannot eliminate. Due to such reasons, some persons with disabilities want a cure for their conditions, ‘*not as a substitute for curing ableism, but in addition to it’* (p: 18). Echoing the concerns of other disability scholars, Wendell (2001) also stated that it is dangerous to accept such facts as it might provide support to the individualized and medicalized representation of disability. Due to this reason, disability activists find it much safer and more comfortable to focus on ‘healthy’ persons with disabilities (Wendell, 2001).

Similarly, Wolfe (2002), who is also a long-term M.E. sufferer, has also argued that it is much easier for the disability activists to raise issues that are unambiguous in nature, so that they can convey a plain message,

> …that disability does not equate with tragedy and exclusion from mainstream life, and that a society which accommodates disabled people can transform their lives (Wolfe, 2002: 259).

Therefore, raising the issues of bodily pain and weakness can be considered incompatible to the major objectives of the disability movement. It is more likely for political movements to succeed if they are based on commonalities of experience. In such a scheme, raising the concerns of persons with chronic illness into the disability movement can be considered dangerous because of the risk of fragmenting it beyond any usefulness. This, however, has another important drawback which is that potential activists might be currently excluded from the movement. This is the reason why it is necessary to develop alternative methods of participation to encourage more people to join the movement (Ibid).

For the able-bodied society, persons with disabilities represent failure in many ways (see Wendell, 1989). ‘*Disabled heroes*[10]’ (or the SuperCrips), however, are an exception as they symbolize heroism against all odds (Ibid). According to Wendell (1989), the image of the disabled heroes is comforting for the able-bodied because they reassure them about the possibility of transcending the body. Disabled heroes are recognized by the society for their physical strength and endurance. Examples include amputee and wheelchair athletes. Wendell (1989) has argued that while disabled

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[10] Disabled heroes or *SuperCrips* are people with visible physical disabilities who receive public attention because they have been able to accomplish extra-ordinary things that are sometimes even impossible for the able-bodied people (Wendell, 1989). Examples include Helen Keller and Stephen Hawking (Ibid).

heroes can be inspiring and reassuring for persons with disabilities, they may give a false impression that all persons with disabilities are capable of overcoming their bodies. This is problematic because disabled heroes usually have access to extraordinary social, economic and physical resources which may not be available to other people with disabilities. Besides, certain disabilities reduce the energy and stamina of the person, that makes it impossible for them to perform physical heroics. According to Wendell (1989),

> [t]he image of the disabled hero may reduce the "otherness" of a few disabled people, but because it creates an ideal which most disabled people cannot meet, it *increases* the "otherness" of the majority of disabled people (p: 117; emphasis in original).

Wolfe (2002) has also argued that no fixed boundaries can be drawn between those who are characterized as sick and those who are referred to as disabled. She further stated that disability activists have prioritized the social accommodation of the disabled body, instead of medical attention. In this way, cure and prevention of disability are not seen as compatible to accommodation, as the former holds the promise of a society where people only have flawless bodies. This is problematic because seems to suggest that only the physically 'perfect' should be conferred full membership in society. Consequently, this may make the social integration of people with uncorrected impairments even more precarious (Wolfe, 2002). Furthermore, scientific medicine for the cure of disability may be politically divisive for the disability movement, as different groups of persons with disabilities might compete for the same scarce funds, instead of building links with other groups on the basis of the shared experience of social marginalization (Zola, 1983, cited in Wolfe, 2002).

Wolfe (2002) had further stated that even though disability activists are skeptical about medical intervention, only a few of them would advocate for the complete abandonment of cure. Additionally, it is also nearly impossible to make a straightforward distinction between those bodily states that require medical remedy and those that require accommodation by means of social change. People with different impairments may respond to the possibility of cure with different degrees of enthusiasm or resentment (for instance, Deaf people vis-à-vis other people with impairments), and it is difficult to point whether either one group is correct in their demands or not, because these demands are made in a particular social context where specific material constraints exist (Wolfe, 2002). Moreover, for persons with disabilities or chronically ill persons, cure and accommodation are not mutually exclusive strategies because

> *[i]f this dichotomy were to be sustained, it would* [mean] *that people that people who regard cure as the optimal solution to their pride are not entitled to claim changes in the social arrangements which will foster their social integration* (Wolfe, 2002: 260).

This is problematic because cure for certain conditions may not exist at all, or might be very slow in coming. In contrast to certain impairments discussed by disability activists, studies have shown that the occurrence of chronic illness could be a tragedy for both the person as well as others who are close to him/ her, for which they will eventually have to seek medical help. Many of the problems that such people face are a result of their bodily condition, which no amount of social accommodation can compensate. This, however, does not mean that change in the social arrangement does not make an impact on the experience of illness (Ibid).

She further stated that in Western societies, there are numerous biomedical as well as alternative discourses on health and illness, by following which a person can avoid or remedy his/her condition. According to Wolfe (2002), this indicates that there is a growing impatience around the sick body because of which there is

> … little social legitimation for accepting illness as a regrettable, but sometimes unavoidable, part of life, or even allowing the body, once ill, time to recover (p: 261).

Therefore, people with chronic illness live and suffer in a social context where illness is regarded as a ‘deviation’ from a normal state of good health. The problem that might occur for such people is that sometimes they might be accused of seeking attention or of avoiding normal social responsibilities and relationships. In this regard, the problem with the disability movement is that it does not with issues of controllability of the body. On the other hand, its message is directed towards those whose bodies can be controlled, that is, bodies which can be subsumed into the social (Wolfe, 2002). In Wolfe’s (2002) opinion, disability studies plays a crucial role, albeit unintentionally, to marginalize and stigmatize people who are chronically sick. She further argues that suffering should not be considered unspeakable or shameful as this fruther complicates the situation for the sufferer. Instead, it should be recognized that people who live with chronic illness require social recognition, inclusion and support (Ibid).

Bringing back the Body/ Impairment to the Social Model of Disability: The absence of impairment from the social model did not go unnoticed, and from the mid-1990s onwards a number of disability scholars have tried to bring back impairment in their writings. The main aim of these scholars was to encapsulate the experience of disability in a more comprehensive manner. Few of these scholars urged for renewed models of disability that would expand the existing social model, while others have called for a complete rejection of the social model in favor of newer theories. This section would elaborate on the arguments of some of these scholars.

Liz Crow: The Renewed Social Model

Crow (1996) was among the pioneers who called for a renewed social model of disability. In her paper, *"Including all of Our Lives: Renewing the Social Model of Disability"*, Crow (1996) states that the dominant perceptions construct impairment as a personal tragedy by invoking personal inadequacy or functional limitations. Such interpretations do not look at the difficulties imposed by the society, and is a prime factor responsible for the attitudes and actions that disable persons with disabilities. Crow (1996) argues that such an interpretation rarely resonates with the lived experiences of persons with disabilities, but in spite of this, the same perceptions are used to undermine the work of the disability movement, and create fear in the minds of non-disabled people. Such interpretations, according to her, work to segregate persons with disabilities from non-disabled people, and also from each other. In her words,

> …impairment, at its most basic level, is a purely objective concept which carries no intrinsic meaning. Impairment simply means that aspects of a person's body do not function or they function with difficulty. Frequently it is taken a step further to imply that the person's body, and ultimately the person, is inferior. However, the first is fact; the second is interpretation. If these interpretations are socially created then they are not fixed or inevitable and it is possible to replace them with alternative interpretations based on our experience of impairment (Crow, 1996: 60).

According to Crow (1996), a new approach is required that would allow people to apply their own meanings to their experiences of impairment, which would add a new layer of personal, subjective interpretation to the objective concept of impairment. She contends that knowledge about their impairment would empower persons with disabilities to identify their specific needs, which is a precursor to accessing existing information and resources. This would enable them to confront disability, and its impact upon people with impairments (Ibid).

To incorporate this approach, Crow (1996) forwards a renewed social model in order to understand the experience of disablement in all its complexities. According to her, this model should work on two levels: firstly, it should provide a complete understanding of disability and impairment as social concepts; and secondly, acknowledgement that an individual’s experiences of their body may vary over time. She states that the existing social model understanding is that once the disabling barriers cease to exist, persons with impairments will no longer be socially excluded. According to Crow, this may not be the case, as impairment and disability are related in many ways. The renewed model, according to her, would broaden and strengthen the existing model, as it would also include people who feel pain and other negative experiences with connection to their bodies.

John Swain and Sally French: The Affirmative Model

According to Swain and French (2000), even though the social model is incompatible with the personal tragedy theory of disability, it fails on two counts: first, being a member of an oppressed group within society need not prompt a non-tragic view of impairment; and second, by separating impairment from disability, it leaves the probability that even in an ideal world where persons with disabilities have gained full civil and political rights, impairment can be seen as personal tragedy. In their paper, “*Towards an Affirmative Model of Disability*”, they state that non-disabled people readily accept, even though superficially, that barriers create participation restrictions for persons with disabilities, but they feel much threatened and challenged when they find that a wheelchair user could be pleased and proud to be the person s/he is. They argue that the affirmative model, which is essentially a non-tragic view of disability and impairment, is far more problematic. This model views disability as a positive personal and collective identity, and is grounded in the virtues of being impaired and disabled (Swain & French, 2000).

According to Swain & French (2000), the argument forwarded by them is different from other critiques of the social model in two ways: firstly, the criticism that ‘pain and chronic illness’ are not included in the social model has somewhat distorted the debate as, according to them, these experiences are not just limited to persons with disabilities; and secondly, this debate has regularly equated impairment with personal tragedy. They maintain that the writings and experiences of persons with disabilities show that having an impairment can have certain benefits, like giving up paid employment and pursuing something of interest, if they have sufficient resources, allowing them to escape class oppression, abuse and neglect by virtue of having an impairment. Since it becomes difficult for persons with disabilities to meet the expectations of the society, it can be altogether avoided, like young women will not be pressurized to form heterosexual relationships, marry or bear children. Additionally, their own experience of disablement can help them empathize with the oppression of others. They argue that by embracing an affirmative model persons with disabilities can assert a positive identity of not only being disabled but also impaired (Swain & French, 2000).

Tom Shakespeare and Nicholas Watson: Embodied Ontology

According to Shakespeare and Watson (2002), the social model had become so powerful in Britain that it is its very success that has now become its main weakness. In their paper, "*The Social Model: An Outdated Ideology?*" (2002) they have urged the necessity of a more sophisticated model in order to explain the experiences of persons with disabilities more effectively. They have devised the following five points for this new approach: (i) disability is a complex experience, because of which it is difficult to disentangle impairment from disability, but this need not be seen as debilitating; (ii) disability should not be reduced to either medical condition or social barriers; (iii) it is important to distinguish between interventions at the individual and societal levels, while recognizing that neither can be substituted by the other; (iv) meta-narratives about disability should be abandoned, in favor of responses that are context-specific; and (v) disability studies and politics should not take for granted that they already know the disabled subject. Shakespeare and Watson (2002) suggest an alternative ontology of disability by incorporating these five points, will be helpful not only for disability studies, but also other social sciences in conceiving the body. They argue that no one's body works perfectly, as everyone is impaired in some way. However, this truth has been obscured by the western tradition of the mind / body dualism. According to them, accepting the ubiquity of impairment and physical limitation will provide a different definitional strategy for disability studies (Ibid).

Shakespeare and Watson (2002) have proposed the theory of embodied ontology, which argues that there is no qualitative difference between persons with and without disabilities, because all human beings are impaired. Impairment is not the central component of disability, but is the inherent nature of humanity. Furthermore, they state that while all human beings are impaired, not all are oppressed in the same way. Only a small minority of the population face additional disabling processes of society. Their central argument is that instead of breaking the connection between impairment and disability, disability scholars should expose the link between impairment and embodiment, since part of the resentment towards persons with disabilities lies in the tendency of non-disabled people to negate their own vulnerabilities and weaknesses onto persons with disabilities who are subsequently excluded and ignored (Ibid).

Criticisms of these New Models: Some of these critics of the social model were counterattacked by disability scholars and activists, who were opposed to the idea of exploring the personal experience of impairment (Miceli, 2010). Finkelstein (2001b) is critical of the 'rectifiers' of the social model for promoting the negative experiences of the body, citing that this approach was earlier used by the medical profession to explain disability in purely medical terms. Finkelstein acknowledges that impairment is a prerequisite for disability, but he maintains his earlier stance that, *"disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group"* (Finkelstein, 2001a: 1). Finkelstein has also pointed out that Oliver's radical social model has been bent out of proportion, and is often confused with the 'rights' campaign agenda for legal safeguards. He also laments that a lot of people discuss the social model of disability as if it were an explanation, definition or theory reducing it to a sterile formalistic version (Finkelstein, 2001a). He states that,

> [n]owadays many people have come to think about the 'social model of disability' as if it explains our situation. Hard, perhaps, to accept but models do not *explain* anything. Models should not be confused with theories or hypothesis, which *do* attempt to reveal the inner, or hidden, laws governing the nature of things and relationships. Models, on the other hand, work best when they are used as tools to give us insight into situations which otherwise are difficult to *begin* explaining. We construct models because without them we may remain unable to detach ourselves from a fruitless way of interpreting a situation or problem (Finkelstein, 1996: 1, emphasis in original).

According to him, instead of accessing 'rights' within a competitive market society, the social model of disability, demands the creation of a society that facilitates persons with disabilities to be 'human'. He further argues that the society is built on a competitive market foundation and it is the social system that disables persons with disabilities (Finkelstein, 2001a).

In a series of articles over the last two decades, Oliver (1996; 2004; 2013) has responded to the critiques of the social model of disability. According to him, there are five main criticisms of the model (Oliver, 2004). Following are these criticisms, and his responses to them.

1. The social impairment negates the realities of impairment: Oliver (2004) has responded to this criticism by stating that the main objective of this model was not to explain how impairments hinder persons with disabilities, but instead how social barriers restrict the mobility of persons with disabilities.
2. This model has denied the subjective experience of pain of impairment and disability: According to Oliver (1996), the social model does not actually deny such experiences, but it consciously shifts the attention to issues that can be transformed through collective action.
3. Other forms of oppression such as racism, sexism and homophobia do not find space within the social model: Oliver (1996; 2004) accepts that such issues have not been addressed by the social model. But he argues that it does not mean that these can never be incorporated. He puts forth that the critiques of the social model would do much good if instead of critiquing the social model for its perceived failures, if they would make an effort at applying these different forms of oppression into practice (Oliver, 2004).
4. Cultural values create the disabled 'other': For postmodernist disability scholars, persons with disabilities actually become disabled through cultural values that position them as the 'other'. As such they downplay the role of physical and environmental factors (Oliver, 2004). Oliver (2004) has argued that while the social model does not disregard cultural values, postmodernist ideas of representation are inappropriate in a world where a vast majority of persons with disabilities are living in abject poverty and are struggling for their bare minimum.
5. Social model is inadequate as a social theory: Oliver has responded to this criticism by stating that he and others who were part of the early discussion of the model never claimed that it was equivalent to a theory of disability.

> Models are used to aide understanding of a phenomenon, rather than to provide an explanation (Oliver, 2004). The social model of disability cannot replace the need for a social theory of disability, which must include a theory of impairment (Oliver, 1996).

According to Oliver (2013), the years he has pointed out that

> …focusing on impairment and difference will only de-politicize the social model and will not lead to the development of any approaches or alternative models that are likely to be useful in developing campaigns to improve or defend the lifestyles of disabled people (p: 1025).

His predictions came true, according to him, when the global economy started slogging in 2008 which led to unintended consequences for a vast majority of the population of the world, including persons with disabilities. During this period, the strategy of emphasizing on impairment and difference proved to be ineffective in safeguarding the interests of persons with disabilities. According to him, the government has incorporated the criticisms of the social model by bringing impairment and difference back into their economic and social policy, while at the same time ignoring the barriers that persons with disabilities still face (Oliver, 2013). He laments that the disability movement which was once united around the issue of barrier removal has now split, and has almost disappeared. This in turn has left persons with disabilities at the mercy of the government and big charitable organizations which have their own vested interests. Due to this reason, in their campaigns, persons with disabilities have moved back about 30 years or so where they portray themselves as victims of personal tragedy. He ends this paper by blaming those scholars who have disregarded the social model but at the same time have failed to replace it with something more meaningful (Oliver, 2013).

Barnes (2012) has also argued that the importance of the social model has been weakened through the influence of post-moderninst/ post structuralist perspectives within social sciences more broadly, and disability studies in particular. According to him, the gradual de-radicalization of social sciences and withdrawal from radical theories that pose a direct challenge to the neo-liberal worldview are related to the transition of the political scenario in the UK, the USA and USSR in the 1980s. A similar shift is also visible in disability studies in the work of several disability scholars, where they have shifted their focus from the radical approach of relating disablement with the material conditions to a politically benign focus on culture, language and discourse. According to Barnes (2012), the criticism of the social model serves no meaningful or practical value, but only reinforces the traditional bias of changing the individual rather than the society, which has been appropriated by policymakers. He reiterates that the social model dichotomy of disability and impairment is a pragmatic one which does not refute the claim that some impairments create hindrances for people to function independently or that they fall sick at different points of life, when medical interventions are necessary. But how people deal with their impairments is determined by their access to a range of social and material resources (Barnes, 2012).

This section gave an overview of the criticisms of the social model, followed by its counter criticisms by the proponents of the social model. Despite the criticisms, it has to be appreciated that the social model brought about a radical way of thinking about disability. This thinking has also been applied to the process of conducting disability research. The following section elaborates on this aspect.

From Theory to Research: Doing Emancipatory Research

Even though since the 1950s several social scientists, particularly sociologists, have conducted ‘disability’ research, these studies have been critiqued by disability scholars for basing their arguments on the traditional conception that persons with impairments are ‘disabled’ by their physical restrictions (Barnes, 2001; 2003). This notion began to change from the late 1960s and early 1970s with the consciousness rising among persons with disabilities in the USA and the UK and the redefinition of disability by the UPIAS that subsequently led to the development of the social model of disability. Together with this, there was also a growing disenchantment with traditional social research strategies amongst researchers working in the majority world, black writers, feminists and educationists that led to the advent of literature on ‘critical social research’ and/ or action research, that positively allied itself with oppressed groups (Barnes, 2001; 2003). All of these developments contributed to the thinking behind the emergence of the *emancipatory research paradigm* (Ibid). Like the social model, Oliver has been credited for coining the term ‘emancipatory disability research' to refer to a radical new approach to researching disability (Barnes, 2001).

According to Oliver (1992), conventional social science research, both positivist as well as interpretive, has failed to illuminate the experience of disablement due to the failure of the social relations of research production which provides the structure within which research is undertaken. These social relations, he further writes, is built upon a firm distinction between the researcher and the researched, based on the belief that it is the researchers who have expert knowledge and skills to decide not only the topics that are researched, but also have control over the whole process of research production (Ibid). The central aim of the emancipatory research paradigm, on the other hand, is *"the recognition of and confrontation with power which structures the social relations of research production"* (Oliver, 1992: 110), and placing control in the hands of the researched and not the researcher (Oliver, 1997). The three fundamentals upon which this paradigm must be based, according to Oliver (1997) are reciprocity, gain and empowerment. According to Oliver, while reciprocity is a worthwhile aim in conducting research, within existing social relations of research production, very often researchers do not reveal as much about themselves as they expect their research participants to reveal. Taking the example of the book that he co-authored with Jane Campbell, *Disability Politics in Britain: Understanding our Past, Changing our Future"* (1996), Oliver (1997) argued that undeniably he and his co-author have gained the most from the research as now they have an extra publication in their names, from which they would receive royalty cheques, while at the same time he feels that they have gained a better understanding of their own personal biographies and their collective history, and the relationship between the two. He is hopeful that the participants of the research may have also gained similarly from their research (Ibid). In the case of empowerment, Oliver (1997) feels that it is a false question. This is because *"empowerment does not exist as the gift of few who have it to be delivered to those who do not; people can only empower themselves"* (Oliver, 1992: 111). The aim of emancipatory research, therefore, "*is not how to empower people but, once they have decided to empower themselves, precisely what research can then do to facilitate this process"* (Ibid). For this purpose, *"researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose"* (Ibid). Oliver has further stated that simply basing research on these fundamentals does not make research emancipatory, but what is necessary is to change the existing social relations of research production to make emancipatory work possible (Oliver, 1997).

Different disability academics have identified different core principles or characteristics of the emancipatory research paradigm (Stone & Priestley, 1999; Barnes, 2001; 2003). These principles are:

(1) Accountability: In disability studies, research conducted from the positivist and interpretive paradigms have been criticized for their failure in improving the material conditions of life for the disabled research subjects (Stone & Priestley, 1999). As a result of this, many have articulated that, researchers must be accountable to persons with disabilities and their organizations (Barnes, 2001; 2003). For this purpose it is important that the political standpoint of the researcher is tied to political action in order to effectively challenge oppression and assist the self-empowerment of persons with disabilities (Stone & Priestley, 1999). Barnes (2001; 2003), however, acknowledges that it is not very easy because professional researchers within the market led environment as well as in the university set up face different kinds of constraints which makes it difficult for them to maintain meaningful on-going relations with persons with disabilities and their organizations.

(2) The Social Model of Disability: Stone & Priestley (1999) and Barnes (2001; 2003) have envisaged replacing the dominant research paradigms with a new epistemology of disablement which is based on the social model of disability, that is, an epistemology that works with the aim of empowering persons with disabilities through the removal of disabling barriers.

(3) Personalizing the Political and Politicizing the Personal: This is one of the most controversial principles within the emancipatory paradigm as this has led to significant divergence amongst the core of disability research (Stone & Priestley, 1999). While a few authors have urged for the inclusion of personal experiences of impairment and disability as research data, others give more importance to collectivizing rather than individualizing experiences of persons with disabilities. Barnes (2001), however, disagrees with those who have argued that the social model precludes research on the personal experience of

disablement. According to him, such experiences need to be embedded firmly within an environmental and cultural context of the society which is organized as per the needs of people without disabilities (Ibid).

(4) Non-Disabled vs. Disabled Researcher: Emancipatory research can be especially difficult for researchers without an accredited impairment because many persons with disabilities within the disabled people's movement view social research conducted by those without disabilities with suspicion (Barnes, 2003). According to Barnes (2003), however, having a designated impairment does not automatically give one affinity towards people with disabilities, as emancipatory research is not about biology but about commitment of researchers to put their knowledge and skills in the hands of persons with disabilities and their organizations, for which it is not necessary to have an impairment (Ibid).

(5) Surrendering Objectivity: According to Stone & Priestley (1999), researchers must surrender their claims to objectivity by explicitly declaring their political commitment to the development of the disabled people's movement. According to Barnes (2001), all social scientists particularly those who endorse a politically sensitive or minority group perspective are accused of being politically biased and subjective. This can be countered, according to him, by plainly declaring the researcher's ontological and epistemological stance and by ensuring that their choice of research methodology and data collection strategies are logical, rigorous and open to scrutiny (Ibid).

(6) Choice of Methods: Even though emancipatory research paradigm is frequently associated with qualitative methods as opposed to quantitative methods, this association is regarded as problematic because there is no simple causal link between the use of qualitative data and the removal of disabling barriers (Stone & Priestley, 1999). Due to this some disability scholars have urged that researchers must use both qualitative and quantitative methods to satisfy the need of both macro-level and micro-level understanding of the oppression that persons with disabilities face (Ibid).

(7) Reversing the Social Relations of Research Production: Disability scholars have argued that for research to be emancipatory there must be a radical reversal of the social relations of production, whereby anti-oppressive

> practices must begin with the research production process itself (Stone & Priestley, 1999). All the same, it is also important to remember that as a group persons with disabilities are in an oppressed position vis-à-vis the able-bodied society, due to which it is inappropriate to consider the production of disability research as an activity that is distinct from the wider social setting (Ibid). According to Stone & Priestley (1999), only when persons with disabilities and their organizations are at the top of the research hierarchy, including control over research funding, can research be considered 'emancipatory'.

To summarize, the central aim of the emancipatory research paradigm is to empower persons with disabilities through the research process (Barnes, 2001). However, as can be seen from the above discussion, it is not very easy to undertake such kinds of research. According to Barnes (2001), no matter how comprehensive or rigorous a piece of research is, it is impossible to imagine that it would empower all persons with disabilities at the same time, because persons with disabilities are a heterogeneous group. In his opinion, emancipatory research must not be seen as a single project or projects but as a process that seek to erode the various forces that create and sustain disabling barriers in both macro and micro levels (Ibid). He further said that over a decade since Oliver coined the term emancipatory research till the time he wrote this paper, the space has been created within the research establishment for researchers to conduct emancipatory disability research implicitly, if not explicitly, if they wish to do so. He attributes this change to the growing disability movement in Britain along with the work of a small number of influential disability scholars many of whom are disabled themselves (Barnes, 2003).

Through his study on 35 people with a variety of physical, mental and sensory impairments, Kitchin (2000) attempted to understand the extent to which persons with disabilities are dissatisfied with academic research and tried to judge their opinion about who should conduct disability research. Since a majority of the research participants were working in the disability sector, they were already familiar with the field, and so were of the opinion that research on this topic is important and needed. But some of them were critical of the fact that most research remained only in the academic realm and failed to change the social relations in the real world. Due to this reason, several of the research participants expressed their frustration with academia that it was not aiding the disability movement. The findings also highlighted that many persons with disabilities find it very difficult to follow the research reports because of the style in which it is written, due to which Kitchin has argued that researchers must also utilize non-academic media to disseminate their findings. In the question of whether research has helped the disabled community, some were unsure because they had limited knowledge of current or past research, others were divided between those who thought that research has served the disabled community well, and those who thought that it has not.

According to Shakespeare (1997), the criteria that Oliver presents for emancipatory research are too strict. In his opinion, even though disability studies has evolved from the disability movement and there are major overlaps between the two, it would be wrong to see disability studies as only providing policy interventions or social analysis for political goals. He also states that Oliver is naïve or disingenuous to believe that his work benefited no one other than himself as his work such as *The Politics of Disablement* (1990) has had a major impact on the lives of persons with disabilities as well as the disability movement. He also argues that as an academic, Oliver could have conducted his research on any other topic, but he continued to research on disability and through this he developed the disability movement. According to Shakespeare (1997), academics should not be the spokesperson of the disability movement regardless of their expertise or their experience. Instead it is the organizations of persons with disabilities that represent their voices in the disability movement. In his opinion, academics have a valuable role to play in the development of understanding of the world as experienced by people with disabilities. By drawing parallels between disability academics, and gay, lesbian and feminist writers Shakespeare (1997) argues that while there have been tensions, the same kind of demands, suspicions and resentment are not made of academic writers in these other movements of identity politics. According to him, this could be because people with disabilities have been exploited by researchers in the past, or the relative poverty of most people with disabilities vis-à-vis the relative wealth of most academics, which is quite stark in comparison to researchers in other fields and their research participants. Shakespeare (1997), however, hopes that disability studies would continue to remain accessible to the non-academic readers with its commitment to document the lives and priorities of persons with disabilities (Ibid).

Stone & Priestley (1999) have also identified certain problems with the emancipatory research paradigm. They have argued that even though a lot has been said about the hierarchy of research production, much less has been talked about the constraints within which researchers operate. Regardless of their commitment to the emancipatory paradigm, the researcher is required to bow in several directions and in these relationships also power dynamics operate in an unequal fashion. Secondly, while it is important that disabled people are more involved with research production, it is more problematic to exactly determine the form and content of their involvement. It is important to take note that simply increasing the level of participation does not change or challenge the power relations of research production. Since participation need not necessarily lead to emancipation, it is important to consider how participation can best lead to control. Emancipatory research necessitates that persons with disabilities should have full ownership over the research process but it does not take into consideration that persons with disabilities are a heterogeneous group and different people with disabilities may have different kinds of power in their hands. Due to this heterogeneity, it can lead to a lot of problems in deciding to whom the power should be handed over to, as if the power is in the hands of the organizations, it might alienate individual research participants, while if it is devolved in the hands of the research participants it would be to assume that they want to take up the role of the researcher and activist. Such problems would also emerge in the process of data collection and analysis (Ibid).

According to Zarb (1992), however, changing the social relations of research production is not sufficient for facilitating the process of collective empowerment of persons with disabilities, as along with this, they must also have control over the material resources to undertake research. Until then, in his opinion, only participatory research is possible (Ibid).

Thus, the emancipatory research paradigm tried to bring about a radical approach to doing disability research. However, its practicality has been questioned over the years by different disability scholars. Besides these problems, the applicability of such a paradigm across cultures is questionable given the lack of awareness about the rights of persons with disabilities. In order to understand this better, the Section II elaborates on the experience of disability in the majority world.

Section II

Disability in the Majority World

From the above discussion it can be discerned that there is no universally agreed upon definition of disability, because the concept itself is shrouded in very many definitional riddles. Even though several attempts have been made to construct a universal language of disability, it has largely met with failure. This is because what it means to be a person with disability in a wealthy nation varies greatly from what it means to be labeled as one in the poorer countries of the majority world (Barnes & Mercer, 2005). Additionally, the category of disability itself is a western construct that has developed in a particular historical context in Europe (Whyte & Ingstad, 1995, as cited in Grech, 2009). Due to this, it has been extremely challenging to measure disability at a global level. This is because the approaches to measure it varies across countries which influence the results (World Report on Disability). However, defining disability is important for both measurement and policy purposes (Grech, 2009). According to the World Report on Disability (2011), the global prevalence of disability among the adult population is estimated to be between 15.6 and 19.4 per cent. This figure is gradually increasing worldwide due to wars, ethnic conflicts, HIV/AIDS, industrial injuries, road accidents, population growth, medical advancement and increasing life expectancy that make people more susceptible to old age related, chronic illness induced disabilities (United Nations Enable: Development and Human Rights for All, n.d.; Addlakha, 2010). It has also been estimated that about 80 per cent of the world's total population of persons with disabilities lives in countries of the majority world (United Nations Enable, 2008). In spite of this, it is important to note that most of these countries report lower disability prevalence rates than countries of the minority world (World Report on Disability, 2011). There are several possible reasons for it: first, since countries of the minority world have better health and support systems, there is a greater survival rate amongst people with congenital conditions and those who acquire their impairments later in life; second, life expectancy is considerably higher in these countries and the possibility of acquiring impairments increases with age; third, conditions such as dyslexia that are potentially disabling in technologically advanced countries, may not be disabling for people living in rural environments of majority world countries (Barnes & Mercer, 2005); and finally, many countries of the majority world collect data on a narrow set of individual-specific health impairments that generate lower prevalence estimates than those used in the minority world (World Report on Disability, 2011).

Notwithstanding these facts, the discipline of disability studies is dominated by western theorists, who largely focus on western industrialized settings. Due to this, much of the theorizing that is produced by the discipline has focused on the deprivations faced by persons with disabilities in the minority world, and is instilled with ideological, theoretical, cultural and historical assumptions (Grech, 2009). In contrast, the issues faced by persons with disabilities in the majority world have either been ignored, or have been added in a superficial manner in the mainstream disability studies literature (Priestley, 2001; Barnes & Sheldon, 2005; Grech, 2009). This has resulted in the exportation/ importation of ideas and models from the minority world to the majority world along with the implications about the presumed situation of persons with disabilities in the majority world countries from the perspective of scholars from the minority world (Ibid). This is done without any reference to the work of southern disability theorists or the southern setting (Meekosha, 2008). It has also been argued that disability studies literature emerging from the north assumes the south by not paying any attention to geography. It is only when the work is located outside of the northern metropole that disability scholars are expected to make their geopolitical position explicit (Ibid). The heterogeneity of the social, political, historical, cultural and economic contexts in the majority world countries and the ways in which these factors influence the lives of persons with disabilities in these countries, largely remain unacknowledged (Grech, 2009). Scholars from the majority world who use northern theory also face difficulties of ‘conceptual and theoretical fit’ and confusion of identity. However, they are left with little choice if they want to publish in mainstream disability studies journals (Meekosha, 2008). Meekosha (2008) has termed this process to be a form of *scholarly colonialism*. Let us know look at this issue more closely.

Scholarly Colonialism

In order to understand scholarly colonialism more deeply, we need to recall the early works of disability theorists such as Finkelstein (1989), Oliver (1990) and Gleeson

(1997), who have used a historic progression from pre-modern to modern to capitalist in order to explicate the emergence of social construction of disability (Meekosha, 2008). All of them, as seen above, have used the materialist explanation to understand disablement, largely through the experiences of persons with impairments in Britain. Such explanations have been critiqued by Meekosha (2008) who has argued that although this historic progression might be true for the northern industrialized western societies, it cannot be universalized and applied to all societies. This is because such kind of an understanding completely negates the history of colonization that had a deep impact on several societies of the majority world. Colonization involved structural, cultural, economic and political domination usually from the Northern European metropole over the South (Ibid). Even though in disability studies, ‘colonialism’ and ‘disability’ have come to denote many things (see Sherry, 2007), the relationships between disability, colonization and Global South are rarely discussed (Meekosha, 2008). This is despite the fact that disability issues in the majority world are intimately bound to colonization. For instance, the medical and charity models that are much prevalent in the majority world countries were instituted there during this period when church organizations and western medical professionals came to the fore through colonial humanitarian models (Grech, 2009). Such endeavors frequently separated persons with disabilities from their families and communities, and inflicted much suffering and destroyed traditional ways of caring for persons with disabilities (Ingstad, 2001, as cited in Grech, 2009; Meekosha, 2008). Additionally, the process of colonization involved the destruction of physical, emotional, psychic, economic and cultural life, in which appropriation of land of the indigenous people was a particularly important aspect of the disabling process (Meekosha, 2009). For instance, in Brazil, colonization paved the way for large plantations that were dominated by single crops which consequently destroyed the diverse and sustainable way of life that the population had led previously and reduced them to a state of enforced dependency (Scheper-Hughes, 1992, as cited in Meekosha, 2009). According to Meekosha (2008), because of such a history, the western differentiation between chronic illness, impairment and disability are inadequate to successfully explain the lived experiences of persons with disabilities in the majority world. She argued that we need a different set of methodologies and frameworks from those formulated in the northern metropole in order to analyze the experience of persons with disabilities in colonized settings (Meekosha, 2008). The supposition that the western narrative is the standard is also problematic because it contributes to the development of disability management where interventions to support and rehabilitate persons with disabilities in Asia and Africa have a tendency to be modeled on western concepts that do not resonate with their disability experience (Buckingham, 2011).

Globalization and Neo-Liberalization

Although the spread of colonization has declined significantly during the last century (Barnes & Sheldon, 2010), it has paved the way for globalization which, according to Meekosha (2008), allows disabling of people in the majority world. According to Barnes & Sheldon (2010), with the intensification of globalization since the mid-twentieth century, all countries of the world are economically, technologically and socially interdependent more than ever before. Due to this reason, the gap between the high and low income countries has significantly increased. Transnational corporations, international banks and governments of rich countries exploit the inexpensive labor available in poor countries by establishing factories and exploiting their raw materials to maximize profits with minimum government interference (Barnes & Sheldon, 2010). The lower prices of local labor and natural resources prohibit the countries of the majority world to develop economically. Consequently, these countries are left with no alternative but to borrow from international corporations and wealthy nations, resulting in a cycle of debt that ensures their continued economic dependency (Hout, 1993, as cited in Barnes & Sheldon, 2010). The International Monetary Fund (IMF) and the World Bank now dictate economic policymaking in much of the world, because of which the poorer countries are forced to follow policies that are unfavorable to the interests of its population (Sheldon, 2005). According to Sheldon (2005), the economic polarization that is taking place within and between nations has affected both persons with disabilities as well as people of the majority world more generally. For instance, in the export processing zones of South East Asia, the workers are made to work in extremely poor conditions and are paid significantly lower than their counterparts in the northern metropole. Another instance is the violence and war that the minority world countries provoke creates disabilities, either directly or indirectly, in the tussle over the control of minerals, oils and economic resources. As a result, civil wars and genocides have destroyed many countries in the post-colonial period, producing mutilation and impairments (Meekosha, 2008). Such incidents are rarely mentioned in disability studies literature emanating from the minority world, even though vast numbers of people have been impaired in the Global South due to the processes of colonialism, neo-colonialism and post-colonialism (Meekosha, 2008).

The permeation of western ideas into the majority world has brought about profound changes in the lives of people which are not only complex, but also contradictory (Stone, 2001). While some of these changes such as literacy, mobility aids, or community group organizations have benefitted persons with disabilities (Ibid), it has also led to the spread of individualization and medicalization of disability that accompanies capitalist development in wealthy nations (Barnes & Sheldon, 2010). These have led to the loss of varied responses to impairment that had existed in the past, undermining the social accommodation that has been in place, weakening the role of the extended family as the main source of social security, threatening local strategies and healing systems, and creating a class of 'disabled' people that did not exist prior to outsider involvement in rehabilitation surveys or research, that may eventually lead to their exclusion from communal life (Barnes, 2009; Barnes & Sheldon, 2010). According to a few disability scholars, disablement is a socially created problem which is exacerbated by the intensifying processes of globalization (Barnes, 2009). They have argued that the proposed solutions to the problems encountered by persons with disabilities in the majority world are unlikely to make any headway, unless there is a radical change in terms of ideology, policy and practice at both national and international levels (Ibid). As can be discerned from above, these scholars have given their viewpoints about disability in the majority world by keeping the social model of disability as their reference point. This has been critiqued by several other disability scholars, which we will come to in a later section.

Disability Politics and the Role played by the United Nations

The growing international interest in disability during the 1960s and 1970s is also evident in the United Nation's (UN) Declaration on the Rights of Mentally Retarded Persons (1971) followed by the Declaration of the Rights of Disabled Persons (1975). These were necessary because the previous conventions such as the Universal

Declaration of Human Rights (1948) that intended to include all sections of the community, had failed to take into consideration the interests of persons with disabilities (Barnes, 2012).

In 1980, the World Health Organization (WHO) made the first attempt to introduce a universally acceptable definition of disability known as the *International Classification of Impairments, Disability and Handicap* (ICIDH) (WHO, 1980). The primary aim of this scheme was to clarify concepts and terminology surrounding disability in order to enable accurate and comparable research and policy within and across countries (Bury, 1997, as cited in Barnes, 2012). This scheme separates impairment, disability and handicap as follows:

> […] impairment is any loss or abnormality of psychological, physiological or anatomical structure or function;
>
> […] disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being;
>
> […] handicap is a disadvantage for a given individual resulting from an impairment or disability that limits or prevents the fulfillment of a role (depending on age, sex, social and cultural factors) for the individual (cited in Barnes & Mercer, 2003: 13).

The ICIDH was introduced by a group of social scientists without any involvement of persons with disabilities (Barnes, 2012). It has been critiqued for a number of reasons by disabled activists. First, the ICIDH relies heavily on individualistic medical definitions and biophysical assumptions of ‘normality’, which disregards the role played by social criteria in forming judgments about physical conditions that may be seen as limitations (Barnes & Mercer, 2003). According to Jones (2001), impairment is determined culturally because what may be seen as impairment in one society may appear to be beneficial in another. He cites the example of a South American tribe in which *dyschromic spirochaetosis* which induces colored skin lesions almost universally and is considered to be highly desirable, such that those few members who escape the infection are unable to find marriage partners (Jones, 2001). Wendell (1989) has argued that the differences in social construction of disability across cultures are missed when one looks at some universal category of disability. Second, impairment is seen as contributing to both disability and handicap which, in fact, privileges medical interventions, legitimizing the dominating role played by health professionals in the lives of persons with disabilities. This is in contrast to what persons with disabilities have been arguing that disability is not a health issue, but a problem emanating from the attitudinal and infrastructural barriers (Barnes & Mercer, 2003). Third, the ICIDH represents the environment as neutral and ignores the extent to which disabling social, economic and cultural barriers are significant in the social exclusion of persons with impairments (Barnes & Mercer, 2003).

This growing interest in disability issues at the international level also led the UN to declare 1981 as the International Year of Disabled Persons and 1982-83 the Decade for Disabled Persons (Barnes, 2009; Barnes, 2012). This signified a formal recognition that national governments are responsible for securing equal rights for persons with disabilities. In 1982 the UN General Assembly adopted a World Programme of Action Concerning Disabled Persons and a global strategy on the prevention of disability (Barnes, 2012). These followed a series of similar initiatives like the first and second Asian and Pacific Decade of Disabled Persons (1993-2002 and 2003-2012), the European Year of People with Disabilities (2003), the African Decade of Disabled Persons (2000-2009) and the Arab Decade of Disabled Persons (2003-2012), largely at the behest of disabled activists and their organizations located in these regions (Barnes 2009; Barnes, 2012). Following this, local, national and international organizations have taken a more prominent role in promoting social change based on their interpretations of disability and disability rights (Barnes, 2009).

Additionally, in 1981, disabled activists formed the *Disabled Peoples' International* (DPI), an international umbrella for national organizations that is *controlled* and *run* by persons with disabilities (Barnes, 2009). It was established because *Rehabilitation International*[11] (RI) excluded persons with disabilities from its controlling body. The DPI had adopted a socio-political definition of disability and its stated policy revolves around the promotion of grassroots organizations and the development of public awareness of disability issues in the struggle for equality (Barnes, 2012). According to a few, due to this reason, the social model became significant for persons with disabilities not only in Europe but also in the majority world (Driedger, 1989, as cited in Barnes & Mercer, 2005).

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[11] RI was formed in 1922 as the International Society for Crippled Children and was composed of rehabilitation professionals (Barnes, 2012).

In the 1990s, social model thinking is also evident in the policy statements and documents of the UN such as the Standard Rules on the Equalization of Opportunity for Persons with Disabilities (UN, 1993). It comprises of 23 standard rules to facilitate full participation and equality including awareness raising, medical and support services, education, employment, leisure and cultural activities (Barnes, 2012). It has been instrumental in shifting attention away from the medicalization of disability to providing a political guideline for most national disability policies (Grech, 2009).

In the late 1990s, due to the widespread criticism from persons with disabilities, their organizations as well as mainstream medical researchers, the WHO revised its classificatory scheme, which ensued into the development of *International Classification of Functioning and Disability* (ICF) (WHO, 1999, as cited in Barnes & Mercer, 2003). This approach sought to incorporate the medical and social models into a new 'biopsychosocial' approach. This is a multipurpose classification system that retains the concept of impairment in body function and structure, but replaced 'disability' with activities and 'handicap' with participation (Barnes & Mercer, 2003). The basic idea of the ICF is that the difficulties faced by persons with disabilities are created by interactions between individual-specific factors, including health condition(s), as well as environment factors; these difficulties include activity limitations and participation restrictions (WHO, 2001). In this definition, 'impairments' refer to problems in the body function or structure, 'activity' is the execution of a task by an individual; and 'participation' is the lived experience of people in the actual context in which they live (Mitra & Sambamoorthi, 2006a). This scheme also assumes that all these three factors are influenced by a multitude of environmental factors (Barnes & Mercer, 2003). The aim of the ICF is to develop a common language for describing disability and functioning in order to improve communication between different users such as health workers, researchers, policy makers and the public, including persons with disabilities, and to permit comparison of data on disability across different countries, healthcare disciplines, services and time (WHO, 2001).

In December 2006, the UN General Assembly adopted the Convention on the Rights of Persons with Disabilities (UNCRPD), which is considered to be the most comprehensive document ever produced on the rights of persons with disabilities. It sets out the duty of nation states to protect the human rights of persons with disabilities. Once in force, it is legally binding on the countries that ratify it. The Convention came into force in April 2008 (Barnes, 2009).

Even though the efforts of the UN to make disability a global issue is considered to be noteworthy, the application of the rights discourse in non-western settings is seen to be problematic (Grech, 2009). Some have argued that even though the ideology of rights has much to offer to persons with disabilities worldwide, its goal is fairly limited as its main aim is to make sure that every disenfranchised group has the rights of white middle class males (Sheldon, 2005). It has also been argued that rights are western invention which is largely premised on western values and norms of individualism and autonomy that are difficult to enforce (Sheldon, 2005; Grech, 2009). Such concerns are far removed from cultures where community ties persist, individual rights most often are absent and where strong family and community connections determine the ability to be politically active (Grech, 2009). In such a context where survival of persons with disabilities is largely contingent upon their families and communities, the discourse of individual rights may pose serious threats to economic stability and social cohesion (Ibid).

Additionally, the onus to implement the guidelines of these policies falls squarely on individual countries. This is a huge problem for poorer countries where the governments have very limited resources to bring about any radical changes in the lives of persons with disabilities (Sheldon, 2005). Also because of their essentially reformist nature, the rights discourse does not directly attack the root causes of disability, but only its symptoms (Ibid).

Following the Americans with Disabilities Act, 1990 and the UN Standard Rules, many governments of the majority world have introduced disability legislations in the 1990s. The impact of these legislations, however, is often limited, especially in settings that are characterized by widespread poverty and inequitable access to resources (Grech, 2009). Since this period, there has also been a dramatic increase in the number of local, national and international organizations that are controlled by persons with disabilities. Persons with disabilities from the minority world countries have played a key role in this given their greater access to resources (Stone, 1999). In such a context, the issue of representation is of paramount importance, that is, whether the large urban based *Disabled Peoples' Organizations* (DPOs) are really in touch with the poor persons with disabilities who rarely get the opportunity to participate due to certain basic constraints such as the inability to afford transportation to attend meetings, power relationships within the organization and little, if any, contact with other persons with disabilities (Grech, 2009). Despite the fact that several disability organizations from the majority world have imbibed some of the slogans of the western disability movements, the flow of ideas still remain from the North to the South (Grech, 2009). This process is also sustained by the flow of money and resources which invariably make it necessary to adopt donor ideologies by the recipients from the South (Ibid). Due to all of these factors, there is a growing realization that the legal route to social change is fairly limited and that rights alone will not help in the eradication of disability on a global scale (Sheldon, 2005; Barnes, 2009).

The Vicious Cycle of Disability and Poverty and Disability Inclusive Development

It is now widely acknowledged that disability and poverty exist simultaneously in the majority world (Meekosha, 2008). This is because of two reasons: first, the root causes of impairment in the majority world are malnutrition, lack of services and landmines, and these are more likely to hit the poorest hardest (Stone, 1999); second, people with impairments are more likely to be poor worldwide due to the disabling barriers that prevent them from getting an education, employment, access to appropriate healthcare and other services (Ibid). While some of these barriers are embedded in local attitudes and responses to impairments, others are rooted in the broader structural processes of poverty and injustice that produce disability as well as impairment (Ibid). Due to this reason, Barnes & Sheldon (2010) have argued that the poverty that persons with disabilities experience in the majority world cannot be simply explained in terms of disabling attitudes and prejudice, but has to take into consideration structural inequalities and social processes (Ibid). Since resources are not equitably divided between and within states, in all countries certain segments of the population are more likely to be poor than others, one among whom are persons with disabilities (Barnes & Sheldon, 2010). They are more likely to be unemployed, underemployed and underpaid, but in spite of this, the majority world countries are unable to provided adequate safety nets to them due to the lack of resources (Ibid).

Meekosha (2008), in her paper, asks a few very significant questions as to why disability and poverty are so intricately connected in the Global South, who exactly is responsible for this, and who benefits from this. In her paper she has shown very eloquently how disability in the Global South is firmly connected with western imperialism, centuries of colonialism and globalization (Ibid). Other disability scholars have also located the roots of poverty in the majority world in colonialism, the global capitalist system and the inequitable distribution of wealth (Sheldon, 2005). The European colonial powers wiped out indigenous industry and left the colonies with little choice but to purchase their products. They also weakened the self-sufficiency of their colonies and used them to extract raw materials which were necessary for the industrial revolution to take place. It is even speculated whether industrial revolution would have taken place without this exploitation in the first place (Ibid). As a result, while Europe prospered, the European states generated the process of uneven development that continues to plague the majority world even today. Although the colonial powers have retreated from the colonies, they have left behind unstable states with artificial borders, which have led to innumerable border conflicts and secessionist troubles (Ibid). According to Meekosha (2008), in spite of such a history, there is a complete erasure in the disability studies literature about how the metropole had acted on the colonies and contributed to the production of persons with disabilities.

Following the declaration of 1981 as the International Year of Disabled Persons, several different initiatives have targeted persons with disabilities living in the majority world (Stone, 1999). Poverty also got a newfound focus with the UN Millennium Development Goals (MDGs) (UN 2000). It, however, did not explicitly include persons with disabilities. In spite of this, probably due to the UNCRPD, disability and poverty have since been included in the monitoring of MDG implementation (Ingstad & Eide, 2011). There is also now a global commitment to ensure equal access to social and economic opportunities to persons with disabilities which represent a political framework to break the linkage between disability and poverty (Ibid). Around the world there is now a growing realization among international development cooperation actors that the continued neglect of persons with disabilities is one of the biggest hindrances in the national and international poverty reduction efforts (Hulme, 2004, as cited in Karr et al, 2016). In fact, persons with disabilities have been underrepresented in development projects due to the misconception that disability is a health issue and not a cross-sectional human rights issue (Kettm 2009, as cited in Karr et al, 2016). Post 2015, the UN Sustainable Development Goals (SDGs) sought to rectify this issue by ensuring that no person, regardless of their race, gender, disability, ethnicity or geography, is denied universal human rights and basic economic opportunities (Karr et al, 2016). Disability inclusive development actively includes persons with disabilities and their families in development processes and programmes. This approach recognizes that including people with disabilities creates more accessible and inclusive communities and results in more successful and sustainable development for all (CBM, n.d.). The rights expressed in the SDGs provide a more holistic view that is better aligned with human rights provisions than the MDGs (Ibid).

According to Karr et al (2016), the World Bank is committed to end extreme poverty and is working towards this goal by providing financial and technical assistance to low and middle income countries. In 2013, the Bank made a public declaration that including persons with disabilities is at the core of its work (World Bank, 2016). Karr et al.'s study (2016) on the inclusion of persons with disabilities in the current development projects of the World Bank has shown that despite the Bank's commitment to inclusiveness, it has not translated into practice. One of the problems that have been identified by this paper is that the Bank subsumes persons with disabilities within the broad category of 'vulnerable groups' without specially identifying them as target beneficiaries of its projects (Ibid).

While this is one part of the story, another is the neo-liberal agenda that is espoused by the World Bank and the IMF and is imposed on the majority world nations through Structural Adjustment Programme (SAPs) as conditions for borrowing to salvage their debts. These measures have led to the cuts in public expenditure, removal of tariffs and subsidies, exchange rate devaluation, market liberalization and mass privatization of sectors. These have often resulted in conflicts, unemployment, increasing poverty and inequality in weak economies (Grech, 2009). According to Grech (2009), the neo-liberal agenda itself is contradictory to inclusive development. This is because the cost cutting that is advocated by is inconsistent with the resources that are required for the inclusion of persons with disabilities. Furthermore, development itself can also contribute to destitution and disablement that may lead to serious health problems, displacement, social and economic consequences (Grech, 2009). Grech (2009) further states that,

> …the all encompassing mode of lifting people out of poverty remains economic growth through an assumed 'tickle down' approach, and not the removal of disabling structural and social barriers, social justice and equity (p: 774).

Additionally, the demands of the disability organizations are often suppressed or ignored if they oppose the neoliberal priorities, which is a risk that governments that are desperate for financial aid are unwilling to take. All this ultimately excludes persons with disabilities from expressing their concerns in the majority world (Ibid).

Relevance of the Social Model in the Majority World

As has been discussed earlier in the chapter, the social model is the 'big idea' of the British disability movement (Hasler, 1993 as cited in Shakespeare & Watson, 2002). While a lot has been written about it, its applicability to the majority world has not been questioned until very recently. Even to this day minority world disability scholars are divided in their opinion about the relevance of this model in the majority world. Some like Stone (2001) and Sheldon (2005) have opined that the social model is as much relevant in the majority world as it is in the minority world, even though they have made slight distinctions in their understanding of the model. According to Stone (2001), the distinction between 'disability' and 'impairment' as espoused by the social model has to be the starting point and the fundamental principle for action on disability in the majority world. This is because it is a radically different way of thinking about persons with disabilities and the society. She, however, makes a distinction between using the social model as a framework of analysis, as opposed to using it as a blueprint. According to her, as a framework the social model allows the possibility that disability and social oppression may or not exist in a given context or it may exist differently across cultures and over time.

Sheldon (2005) also argues in favor of the social model. According to her, it is an important tool that enables us to understand the mechanisms and processes that disable persons with impairments and also the ways in which this disablement can be challenged and eradicated. She argues that over time there is now an increasing discussion about the social models of disability, which broadly fall between two positions – the materialist and the idealist. According to her, the *materialist* position understands disability to be an outcome of the capitalist model of production. This position contends that the fundamental relationships of capitalist society are responsible for the oppression of persons with disabilities, and due to this, the elimination of disablement would require a radical transformation of the society (Gleeson, 1997, as cited in Sheldon, 2005). She argued that putting this approach into practice is an ambitious project which has not yet been attempted by the disability movement. Sheldon (2005) also acknowledged that the materialist explanation of disablement is as yet largely confined to the minority world states. In her opinion, even if the social model may not change the world in the short run, the adoption of the materialist approach of the social model and the development of a global political economy would be a step in the right direction. On the other hand, the *idealist* approach recognizes the realities of the materialist model, but understands disability as *"the irrational product of deep-rooted cultural beliefs, attitudes and prejudices"* (Sheldon, 2005: 119). This approach, instead of making connections between disability and the global economy, focuses on religious ideas and traditional belief systems of non-western settings, because of which it can never go to the roots of understanding disablement. She also stated that such interpretations have clear appeal for western researchers reporting on disability in the majority world which has both ideological and practical implications. She argues that by separating groups of people from different cultures, this approach not only isolates persons with disabilities from one another, but also encourages separation from other oppressed groups (Ibid). Furthermore, certain disability scholars who follow this approach have emphasized the importance of understanding the traditional beliefs about disability prevalent in a particular culture in order to understand more deeply the experience of disablement. According to Sheldon (2005), such analyses encourage a racist understanding about the nature of disability in the majority world which reflects the colonial nature of association.

Others, however, have considered using the social model in the majority world to be problematic. Grech (2009) acknowledges that the social model has been inspirational for persons with disabilities, but argues that the exportation of this model to the majority world has very many problems: The first major problem of this model, in his opinion, is that *"it is grounded in and highlights the concerns of western, white, urban, educated disabled academics in industrial settings"* (Grech, 2009: 775). According to him, while attempting to understand disablement in a particular society, it is imperative to understand the broader socio-cultural, economic and political environment. All these factors, however, are easily forgotten when life is viewed from the lens of the industrialist, welfarist and individualistic viewpoint of the west. In a context of high levels of deprivation, the emancipatory paradigm becomes a highly dubious endeavor (Ibid). Grech (2009) argued that the applicability of the social model as developed by the first generation of disability theorists to non-industrialized settings, where livelihoods depend on household economies and where communal relations challenge the presumed western individualism, becomes debatable. According to him, the solution proposed by this model to change the world economic order to accommodate persons with disabilities is not realistic given the neo-liberal prescriptions imposed on developing countries by the World Bank and the IMF.

His second criticism of the social model is that *"it promotes a 'universal discourse', which, [...] runs the pervasive risk of being contextually and culturally inappropriate"* (Grech, 2009: 775). He argues that the sharp distinction between impairment and disability negates the importance of *"the phenomenological aspects of functional limitations and pain and [completely abandons] the theorization of impairment"* (Grech, 2009: 776). These issues, however, have rarely been discussed across cultures. He argues that in the countries of the majority world, impairment remains a fundamental concern because poor livelihoods and ultimately their survival depend on hard physical labor that makes healthy body an imperative. This becomes even more risky where health and social protection systems are either absent or segmented. He argues that engaging with the body in the majority world setting is crucial because responses towards persons with disabilities are often contingent on the type of impairment as different impairments engender different manifestations of disablism (Thomas & Corker, 2002, as cited in Grech, 2009). Furthermore, since the subject of impairment is directly related to medical issues, Grech (2009) also argues that

> [s]oftening the issue of medical needs, even if for the purpose of politicizing disability, can become extremely dangerous in developing countries agonizing over

> the most basic health care and where functional abilities influence life activities and often survival (Grech, 2009: 776-777).

Grech’s (2009) final criticism of the social model is that it makes a homogenizing assertion that all persons with disabilities are oppressed and excluded. Grech (2009) argued that different studies have shown that persons with disabilities experience both positive as well as negative attitudes along a continuum, even within countries. Moreover, persons with disabilities are not a homogeneous group and due to this their experiences are shaped by a myriad of factors such as the type of impairment, gender, religion, tribe, roles and rights and finally depends upon what is culturally, socially and ideologically valued. He cautions us that representing a person to be oppressed when he/she does not consider him/herself to be one may only serve to marginalize and stigmatize that person (Ibid). Ghai (2002a) has also argued that the concepts of impairment and disability ignore the harsh realities of persons with disabilities who are trapped in socio-economic marginalization, whereby learned helplessness becomes a life trait (Ghai, 2001). In the midst of their chaotic life situations, it is difficult to consider disability as a social issue (Ibid).

Others such as Miles (2011) have also questioned the universal applicability of the social model. He asks Flood (2005), what she means when she wrote that the social model is under attack not only in the academic sphere, but also from persons with disabilities all around the world who have questioned its relevance in their lives. According to Miles (2011), this is not possible because a vast majority of persons with disabilities in the world do not read English, and have never heard of the social model of disability. He also reiterated that even in the UK, which is the birth place of the social model, only a miniscule of the population are aware about the existence of the model.

Research has indicated that people in the majority world are primarily concerned with the cause of impairment. Mehrotra (2013) in her review has referred to several indigenous communities who believe that the cause of impairment is either cosmic factors or a result of *karma*. However, due to western influences, changes are now visible, especially among the younger generation, on how these communities view disability. Harknett (1996) had classified beliefs about the causes of disabilities into three categories: (1) *traditional animism*, which includes beliefs that disabilities are punishments for bad deeds or the result of witchcraft exercised by other people; (2)

Christian fatalism beliefs, which revolve around notions that disability results as an act of God's will; and (3) *medical determinist beliefs*, which accept the explanations of modern medicine as the cause of disabilities (as cited in Stone-MacDonald & Butera, 2014). Individuals, however, use multiple categories of beliefs about cause, perhaps in an effort to counteract negative beliefs about disability (Ingstad, 1995, as cited in Stone-MacDonald & Butera, 2014) and also as a coping strategy (Mehrotra, 2013). According to others, the solution for academic imperialism is not to do away with western concepts, but to adopt a more accurate understanding of western social science as reflecting particular geographic and historical contexts (Hettne, 1991, as cited in Mehrotra, 2013).

Disability studies as a discipline has only recently begun to make its mark in the southern context. Studies from this context are trying to explore the diverse ways communities conceptualize and manage disability and how this is changing in a globalized context. Research into indigenous concepts of and responses to disability is an important but often neglected part of researching disability in developing countries (Mehrotra, 2013). In the South Asian context, disability scholars have felt the need to situate the experience of disablement in terms of its history, culture and specificities. They argue for much more diverse and differentiated view of disability through the lens of local and indigenous categories. Studies from this context are trying to explore the diverse ways communities conceptualize and manage disability and how this is changing in a globalized context. Research into indigenous concepts of and responses to disability is vital but frequently neglected part of researching disability in developing countries (Mehrotra, 2013). Some disability scholars in the majority world have cited the significance of the *religious model* in articulating disability beliefs and practices in the South and South East Asian setting (Mehrotra, 2013).

Alternative Theoretical Approaches to Understand Disablement in the Majority World

As can be seen from above, a certain section of disability scholars consider the social model of disability to be inadequate to explain the experience of disablement in the majority world (Ghai, 2002b; Meekosha, 2008; Grech, 2009). Instead they have used the concepts of social suffering and structural violence to understand the linkages between disability and poverty in this context (Ingstad & Eide, 2011; Muderedzi & Ingstad, 2011; Ingstad, Baider & Grut, 2011). *Social suffering* refers to problems that are imposed on people by conditions that are outside of their own control (Ingstad & Eide, 2011). These conditions are not connected to the concept of personal tragedy that has been critiqued by disability scholars (Meekosha, 2008). Social suffering is *"the result of what political, economic and institutional power does to people, and in reciprocally, how these forms of power themselves influence responses to social problems"* (Muderedzi & Ingstad, 2011: 178). By considering the suffering that a person is undergoing as social, he/she is absolved from the blame and guilt of his/her condition (Ingstad & Eide, 2011). *Structural violence* refers to the violence of everyday lives that causes social suffering and other disasters that are outside the control of a person with disabilities and his/her family (Ingstad & Eide, 2011). It is the negative impact of social structures on individuals and groups that are beyond their own control (Muderedzi & Ingstad, 2011). According to Muderedzi & Ingstad (2011), these two concepts bring in a new perspective which takes politics down to the level of the individual and household.

These concepts were used by Muderedzi & Ingstad (2011) and Ingstad, Baider & Grut (2011) in their studies on persons with disabilities conducted in Zimbabwe and Yemen respectively. In the first study which was conducted among the Tonga, it is seen that the entire community has been victims of structural violence since the construction of the Kariba dam in 1957[12] and their forceful eviction from fertile land to unfertile areas. Furthermore, the division of their tribe into two countries, Zimbabwe and Zambia, has added to their suffering by dividing kinsfolk which made it difficult for them to perform their important traditional rituals. Added to this is the present-day politics of Zimbabwe which is not concerned about relieving the sufferings of the poorest of the poor, but has further aggravated their sufferings and created a situation where the Tonga are close to starvation (Mudredzi & Ingstad, 2011). In such a scenario, it is people with disabilities, especially, children with disabilities, who are the most vulnerable. This is because while on the one hand their impairments are a direct result of the failure of the government to secure healthcare

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[12] The Kariba Dam was constructed on the mighty Zambezi River by the then Rhodesian government. It now provides electricity to the independent countries of Zambia and Zimbabwe.

and proper nutrition for its citizens, on the other hand, persons with disabilities are the first ones to suffer the most and die first (Ibid).

While such an understanding of the social factors is important to understand that there are larger forces at work that prohibit persons with disabilities from achieving their full potential, it however, runs the risk of homogenizing the experiences of persons with disabilities in the majority world. For instance, in certain cultures and countries, apart from these larger structural factors, other factors such as culture, religion and gender also create problems that restrict their full participation in society. This was highlighted by Ingstad, Baider & Grut (2011) in their study on persons with disabilities in Yemen, which acknowledges that poverty plays a significant role in increasing the risk for developing impairments. Likewise, education, employment and social services are less accessible to persons with disabilities in the country in comparison to others who are not disabled. These situations highlight ‘the violence of everyday life’ leading to social suffering. These concepts are useful in that they show discrimination and lack of integration is not due to personal shortcomings or bad will, but a result of larger forces such as political, social and cultural constraints that are imposed on the suffering individual (Ibid). This, however, is not all, as in Yemen it is seen that cultural factors also play an important role in disadvantaging women and girls with disabilities in significant ways than men and boys with disabilities. The intersection of poverty with gender and disability makes the lives of women and girls with disabilities even more precarious (Ibid). Thus, while looking at the experiences of persons with disabilities in the majority world, along with the structural factors, it is also important to look at cultural fa1ctors, religion and gender relations to make the analysis more nuanced.

Another important concept to look at while trying to understand the lived experiences of persons with disabilities in the majority is the importance of *social capital*. It refers to the features of social life that enable participants to act together more effectively in order to pursue shared objectives (Putnam, 1995, as cited in Grech, 2009). These relationships play a pivotal role in the lives of poor people in enabling their access to resources and even survival in the absence of formal safety nets (Grech, 2009), which is the case in many majority world countries. Even though many studies have not used the term ‘social capital’ but the importance of informal social relationships in the lives of persons with disabilities has been acknowledged. Grut, Olenja & Ingstad’s (2011) study among persons with disabilities in Kenya has shown that the family plays the role of the social security system that tends to persons with disabilities. Apart from parents, brothers and sisters of persons with disabilities provide care to their disabled family member. Having a person with disability in the family affects all the members of the family as the resources at the disposal of the household will now have to be redistributed. Due to this reason, it is very rare for a person with disability to fare better than the other members of the family. This makes it important to include the concerns of a *'disabled household'* (Ingstad, 1990, as cited in Grut, Olenja & Ingstad, 2011) as a whole in policy initiatives and not only of an individual with a disability within that household (Grut, Olenja & Ingstad, 2011).

How the vicious cycle of disability and poverty ravages individuals with disabilities and their families up to the next generation is shown eloquently in the study by Taksdal (2011) in rural Cambodia. Cambodia is one of the countries that is contaminated with landmines and explosive remnants of war. These mines are not deployed in 'minefields' but have been placed there in different phases of the internal and external wars that the country had faced in the recent decades. After the wars, these mines have not been systematically removed as a result of which they have been overgrown by vegetation and immersed in water, which makes them even more dangerous. The majority of the people who live near these mines are poor subsistence farmers. Even though they are aware of these dangers, they have to face the threat of the mines in order to avoid starvation. Even after losing a leg, the poor person and his/ her family members would invariably have to go into debt in order to pay the medical expenses. In spite of this, after recovery the same individual and his/ her family members will have to enter the mined area again and again as they depend on farming, collecting wood and other natural resources to sustain the family (Ibid).

Other than the family, disability organizations also play a significant role in the lives of persons with disabilities. Muyinda & Whyte's (2011) study on the relation between poverty and physical mobility in conflict and non-conflict situations in northern Uganda has shown that many persons with mobility impairments in the camps for Internally Displaced Persons (IDPs) were not able to break the mobility-poverty trap. While on the one hand, they were not able to get the mobility devices due to chronic poverty, on the other hand, they were unable to engage in any livelihood activities to reduce their poverty due to immobility. The effects of poverty were most evident in the lives of those who were left out by the intervention agencies. These mostly included those whose impairments were not due to wars as they lacked contact with disability organizations, mobility equipment and were not provided with credit facilities to start income generating activities. Even though Uganda has tried to improve the condition of persons with disabilities through affirmative action to facilitate their participation in decision making at various levels, lack of resources in a situation of other overwhelming problems such as HIV/AIDS, conflicts and political instability, makes disability a low priority issue (Muyinda & Whyte, 2011).

This section was aimed at showing how disability scholars have critiqued the disability literature coming from the Western countries, as they often overlook the concerns of persons of disabilities in the majority world. Let us now look at the disability scenario in India with a special focus on the studies that have been conducted in the last two decades.

Section III

Disability in India: A Socio-Cultural Perspective

For the longest time, the issue of disability and the concerns of persons with disabilities were not considered to be important in the Indian context. According to Dalal (2002), Indians have an ambivalent attitude towards persons with disabilities. The religious beliefs about disability makes matters even more confusing (Ibid). The refrains that people generally use to explain all kinds of suffering, including disability, are *karma*, *kismet* and *bhag* (Mehrotra, 2013). The two predominantly used models to understand disability in the Indian context are the religious/ moral model and the personal tragedy/ charity/ pity model. Within the *religious/ moral model*, disability is regarded as the divine retribution for past sins committed either by the individual or by his/ her ancestors. In this model, the concept of *karma* governs the basic assumptions about disability and persons with disabilities are considered to be suffering from the wrath of God (Ghosh, 2012). The intersection of sin, punishment and disability conveys the strong message that disability is a consequence of evil acts committed either by the individual or his/ her ancestor. Due to this reason, persons with disabilities are feared or despised by the wider society (Ghosh, 2012). Another related notion within this model is that God inflicts suffering on good people in order to test their resilience and inner strength. The common factor in both these understandings is that disability is God's will, which must be respected (Dalal, 2002). Such beliefs have resulted in a ready acceptance of disability, and consequently less effort is put on alleviating the life conditions of persons with disabilities (Dalal, 2002; Mehrotra, 2013). Furthermore, the religious/ moral model considers persons with disabilities to be unfit to live in mainstream society, which justifies their lack of entitlement for right to education, social life or employment that are available to other members of the society. Additionally, this model also stigmatizes the family members of person with disabilities, due to which they are sometimes hidden by the family. In this model, neither the government nor the society considers it to be their responsibility to provide for persons with disabilities as disability is seen as an individual problem (Bhanushali, 2007). Such notions about disability have created barriers for persons with disabilities in asserting their rights of equal access to social opportunities (Dalal, 2002). Ghai (2001), however, has argued that even though *karma* is used as the explanation for disability, it does not necessarily mean passive resignation to one's fate as sometimes such beliefs provide agency to the people to fight against oppressive practices. This was found to be true in my study on women with locomotor disabilities in Delhi-NCR, where several research participants had internalized the religious model of disability and due to this they attributed the occurrence of their impairments to cosmic factors such as God or *kismet*. While a few of them, felt sorry about their bad fates, others used it as a coping mechanism to absolve themselves of the stigma of having an impairment (Sarma, 2014).

The *personal tragedy/ charity/ pity model* considers individuals who are diagnosed with a particular condition or impairment to be helpless dependents who need care and protection from others (Bhanushali, 2007; Ghosh, 2012). In this model, disability is considered as eternal childhood, where survival is contingent upon constant care and protection (Ghai, 2001). This model relies on charity and benevolence rather than justice and equality (Bhanushali, 2007). Labels like *Bechara* (poor thing) accentuate the victim status of persons with disabilities, at the root of which lies the cultural perception that views impairment to be a result of the wrath of fate and is, therefore, beyond redemption (Ghai, 2002a). In this case, destiny is considered to be the culprit while persons with disabilities are seen to be the victims (Ibid). This model accepts the exclusion of persons with disabilities from social arrangements and services in the public domain. It replaces entitlement rights by relief measures creating an army of powerless individuals who lack control and bargaining power, and need to depend on either the state allocated fund or benevolent individuals (Bhanushali, 2007). Hindu religious texts such as Manusmriti and Dharmashastra exhort the non-disabled community to show pity and compassion to all those people who are suffering, without any expectation of returns (Dalal, 2002). Even today a lot of people make charity to the homes of the disabled because it is considered to be their *dharma* and not out of an understanding that persons with disabilities require help to cope with the environment (Ghai, 2002).

Persons with disabilities in Indian mythology as well as history have been usually portrayed in a negative light. Some of the disabled women in Hindu mythology include, *Manthara,* a woman with locomotor disability, who was strategized the exile of Lord Rama and *Kubja*, a hunchback *gopi* in Braj, whom Lord Krishna addressed as *sundari* (beautiful), but was in turn teased for linking an impaired women. Another example was that of Goddess Lakshmi’s older sister, whom Lord Vishnu refused to marry because of facial disfigurement saying that there is no place for such women in heaven! Eventually she was married to a peepul tree, which was regarded to be another form of Lord Vishnu, so that he could marry her younger sister, Goddess Lakshmi (Bhambani, 2003). In contrast to such pitiable depiction of women with disabilities in Hindu mythology, men with disabilities were shown to occupy prominent position such as *Dhritarashtra*, who was deprived of his throne because of his visual impairment and his brother-in-law, *Shakuni*, who plotted against the *Pandavas*. Eventually both of them sided with the evil (Ibid). Such portrayal of persons with disabilities have had a detrimental effect on the minds of the people in India, who either perceive persons with disabilities as objects of pity or the personification of evil (Ibid).

According to Dalal (2002), the story of Ashtavarka (named so for having eight deforminities) which has been referred to in many ancient texts, including the Mahabharata, is the archetype of disability and faith in the Indian setting. This is because the story dwells on several themes that are still relevant in India like showing patronizing attitude towards persons with disabilities, who in turn need to overcompensate for their impairments, guilt of parents for giving birth to children with disabilities and hope of miraculous cure of the disability (Ibid).

Services for Persons with Disability in India

Research on the history of disability in ancient India is virtually non-existent (see Miles, 2001; Buckingham, 2011). According to Dalal (2002), prior to the advent of colonial rule in India, large and extended families provided succor to all its members, including persons with disabilities. Within such a setup, the responsibility of persons with disabilities was shared by all the family members who ensured their lifelong social and economic support. Class and caste status of the family along with the networks of the family members played a crucial role in their well-being. Within the hierarchical structure of the family, all major decisions about the lives of the family members were taken collectively, keeping the interest of the family unit in mind. Since society was agriculture based and occupations were caste based during this period, all the family members, including persons with disabilities, were involved in the production system and contributed to the family income. The place of work and the place of residence were mostly the same which allowed persons with disabilities to decide their own pace of work and someone was always by their side if they needed any help. Due to such reasons, according to Dalal (2002), social and occupational integration was not a problem during this period. Apart from the family, the local communities also established many social and religious charitable institutions which provided basic care to the needy such as orphans, the poor, the deserted and persons with disabilities. These institutions survived mostly on public funding, with occasional funding by kings and nobles (Dalal, 2002).

With the advent of colonial rule, a lot of changes occurred in the society that had an effect on the lives of persons with disabilities. During this period, Christian missionaries started charitable organizations for persons with disabilities in different parts of the country with official patronage. These institutions, however, completely ignored the indigenous culture and belief systems, and followed the same philosophy and practices like in the west (Dalal, 2002). Notwithstanding these efforts, the issues faced by persons with disabilities were not addressed in a comprehensive manner primarily because disability was not a serious concern for the colonial rulers (Ibid).

Urbanization and industrial growth during colonial rule also brought about significant changes in the lives of persons with disabilities. This is because the capitalist mode of production placed a great value on the productive capacity of an individual for economic contribution to the market. This was in direct conflict with the traditional ethos of the society and affected the status of persons with disabilities who were then perceived as non-productive members of society (Dalal, 2002).

This argument is similar to what Finkelstein's (1980) evolutionary model mentioned earlier. Oliver's (1990) critique of Finkelstein's framework is equally applicable here that even though colonization explains the decline of status of persons with disabilities in the Indian society, the explanation is an oversimplification of Indian society prior to colonial rule. Additionally, since very less work has been done on the historiography of disability in India, it would be wrong to make such sweeping generalizations.

After independence, India accepted social welfare of the weaker sections[13] of society as state responsibility. As a result of this, the welfare activities that were earlier the responsibility of the voluntary or religious organizations now became the responsibility of the state. The Directive Principles of State Policy and the Fundamental Rights of the Indian Constitution guaranteed all citizens equality before law and equal protection of law, and prohibited discrimination on the grounds of religion, race, caste, sex and place of birth (Ghosh, 2012). In spite of this, the orientation of the state towards persons with disabilities has largely been that of welfare. This is evident in Article 41, which stipulates, 'The state shall, within the limits of its economic capacity and development make effective provision for securing the right to work, to education, and to public assistance in cases of unemployment, old age, sickness and disablement' (Ghosh, 2012).

According to Ghosh (2012), the reluctance of the government to formulate and implement a coherent disability policy is due to the prevalence of a religio-moral-medical model of disability in the socio-cultural sphere, according to which impairment is considered to be the result of divine retribution for past or present sins, and persons with disabilities were looked at with pity. Due to this reason, while the

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[13] Weaker sections were defined as groups of individuals who are in need of special considerations. These groups include children, women, people from schedules castes and tribes and people with disabilities.

state has initiated policies and programmes for the upliftment of other marginalized sections of the society, the attitude towards persons with disabilities has largely been that of token inclusion and general neglect and apathy for their concerns (Ibid).

During the first three five year plan periods, there was negligible allocation of funds for the welfare of persons with disabilities. One of the reasons for this was that there was no data[14] available on the magnitude of disability in India. Much of the available funds were spent in a skewed manner, whereby medical rehabilitation received top priority (Ghosh, 2012). According to Ghosh (2012), this is because by this time the state had adopted the medical model of disability as the key paradigm for service delivery. This perspective was attuned with the welfare model of development and was much appreciated by the international funding agencies such as WHO and UNICEF. In the process, however, persons with disabilities were treated as passive recipients of welfare services which primarily focused on free distribution of aids and appliances to the needy and the poor (Dalal, 2002). Such practices only increased the level of dependency of persons with disabilities. However, due to limited funds, these schemes were only able to cover a fraction of the population of persons with disabilities, primarily in the urban areas (Dalal, 2002; Ghosh, 2012).

In the late 1970s and early 1980s, four national institutes for four types of disabilities, viz. blindness, locomotor impairment, hearing impairment and mental retardation, were established in different parts of the country. These institutes were intended to serve as apex bodies in the respective fields to provide medical and paramedical support services to persons with disabilities all over India. The government also set up 11 regional vocational training centers in different parts of the country (Dalal, 2002; Ghosh, 2012; Mehrotra, 2013). The government also set up the Rehabilitation Council of India (RCI) in 1986 as a registered society, based on the model of Medical Council of India (Dalal, 2002), to regulate and monitor services given to persons with disabilities, to standardize syllabi and to maintain a Central Rehabilitation Register of

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[14] During the colonial period, the British Indian government took up a very important initiative to collect census data for different categories of persons with disabilities in order to guide policy through appropriate information. This practice was continued from 1872 to 1932.

all qualified professionals and personnel working in the field of rehabilitation and special education[15].

All these initiatives, according to Ghosh (2012), further reinforced the medical model of disability. She further argued that the welfare state of India, with its charity outlook and strong emphasis on the medical rehabilitation, lacked the political will to encourage the empowerment of persons with disabilities (Ghosh, 2012). The state also gave scant attention to other important concerns such as integration, social attitudes and access, as the primary focus was on the individual and not to bring about changes at the social and political levels (Ibid).

In the 1980s, there was a paradigm shift in the policy framework from welfare to development. This also resulted in the change of outlook towards persons with disabilities from passive recipients of care to participants in the development process (Dalal, 2002; Mehrotra, 2011). The Decade of Disabled Persons (1983-92) was another noteworthy shift in the debate about disability rehabilitation that neither charity nor welfare models could succeed in a country like India (Ibid). Instead the WHO advised the developing countries to adopt its Community Based Rehabilitation (CBR) project as it was considered to be more economical to extend community centred rehabilitation with the help of existing services for persons with disabilities than to continue with the centralized and capital intensive institutional rehabilitation (Kalyanpur, 1996). The CBR project was focused on mobilizing local resources in order to sustain disability rehabilitation programmes (Dalal, 2002). The 80s also witnessed growing interest and participation of international NGOs and emergence of local NGOs in partnership with the government to work for persons with disabilities at the community level (Mehrotra, 2011). The government found it to be an easy way to work with the disability sector (Dalal, 2002). However, the drawback of these services is that western models and theories of disability rehabilitation became an essential part of the funding package, which ran counter to the realities of the people in India. The international agencies brought about a change in the service culture, ideology and way of functioning of governmental and voluntary organizations.

The indifference of the state towards this population is also evident from the fact that until recently there was no comprehensive law or policy for persons with disabilities.

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[15] www.rehabcouncil.nic.in

Although attempts were made, initially in 1970-71 and then in 1980, these were largely due to the pressure from international developments like the United Nations General Assembly's Declaration on the Rights of the Disabled Persons in 1975, and the declaration of 1981 as the International Year for Disabled Persons (Ghosh, 2012). As a result of the pressure from international bodies and disability activists in India, the state incorporated disability as a category of data collection in the Census of 1981 (Ibid). Around the same time, a draft legislation known as Disabled Persons (Security and Rehabilitation) Bill 1981 was prepared and later shelved. In 1987-88, a committee was set up that submitted its report in 1988 with various recommendations pertaining to various aspects of rehabilitation, such as, prevention, early intervention, education, employment and training. Even though these recommendations could not be enacted into a law, the Indian Government later enacted several laws to ameliorate the conditions of persons with disabilities (Ibid).

The *Mental Health Act* came into existence in 1987. It is an Act to consolidate and amend the law relating to the treatment and care of mentally ill persons. The *Rehabilitation Council of India Act*, 1992 provides for the constitution of the Rehabilitation Council of India for regulating the training of rehabilitation professionals (Mehrotra, 2013). The Act also prescribes punitive action against unqualified persons who are deliver services to persons with disabilities[16].The *National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act* was adopted in 1999. It has provisions for legal guardianship of the four categories of persons with disabilities and for the creation of an enabling environment for their independent living as much as possible (Mehrotra, 2013).

The most significant among all of these laws was the *Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act*, 1995 which came into force in 1996 (Mehrotra, 2013). This Act was passed due to international developments and the pressure from disability rights activists in India (Ghosh, 2012). The Act considers disability to be of 7 types, viz. blindness, persons with low vision, leprosy cured person, hearing impairment, locomotor disabilities, mental retardation and mental illness (Ghai, 2003). This Act provides fundamental rights to all persons

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[16] www.rehabcouncil.nic.in

with disabilities in the country for equal opportunity. It also provides for both preventive and promotional aspects of rehabilitation like education, employment, vocational training, research, human resource development, creation of barrier-free environment, reservation, rehabilitation of persons with disabilities and so on (Mehrotra, 2013). The definitions cited by this Act are extremely important for they decide whether a person is disabled or not. To be categorized as a person with disability, s/he needs to be certified 40 per cent impairment or more by medical boards constituted by the states. These certificates enable persons with disabilities to receive certain benefits from the state (Ghai, 2003).

Soon after the adoption of this Act, its limitations started to surface which rendered its efficacy. This law has been criticized for many reasons. First, it defines disability in strictly medical terms and ignores the social perceptions about disability (Ghai, 2003; Ghosh, 2012). Second, it leaves out several key conditions from its purview (like heart diseases, cancer, epilepsy, communicable diseases like tuberculosis, HIV/AIDS and disabilities like autism, hemophilia and dyslexia) (Mehrotra, 2013). Third, there are very few penal provisions for non-implementation of its measures (Ghosh, 2012). Fourth, it protects persons with disabilities against discrimination only in the public sector, and not in the private sector. Fifth, the Act has not addressed the punishment to be given to persons who practice discrimination with persons with disabilities (Mehrotra, 2013). As the recognition of a category of disability depends on its inclusion in the Act, people belonging to categories that have been overlooked are being sidelined and refused access to services. The stipulation that the persons with disabilities will receive benefits according to the degree of their disability totally ignores the impact of social, psychological or political factors on individual disability. As the provisions of the State depend on the medical certificate indicating the percentage of impairment issued by State Medical Boards, there have been reports of gross discrepancies in the awarding of disability certificates (Ibid).

Within three years of the notification of the Act, an Amendment Committee was appointed by the government. This Committee submitted its report to the Ministry of Social Justice and Empowerment in 1999. In spite of this, these recommendations did not receive much attention and the ministry proposed its own set of amendments of the Disability Act in 2006. These amendments, however, failed to take into account the problems that have been the root cause for this Act remaining ineffective

(Mehrotra, 2013). Over time a series of consultations were carried out with the state government representatives, NGOs, disabled peoples' organizations and experts from four separate regions. Based on the suggestions received, a draft of the amendment was prepared taking into consideration the provisions of the UNCRPD and the requirements to make the Act harmonize with the provisions of the National Trust Act, 1999. Later, however it was argued that instead of amending the already existing Act, it is advisable to come up with an entirely new law to overcome the redundancy of the Persons with Disabilities Act (Ibid).

In 2005, the Ministry of Social Justice and Empowerment developed a draft of National Policy for Persons with Disabilities, which came into effect in 2006. It emphasizes on physical rehabilitation, educational and vocational rehabilitation and economic rehabilitation (Mehrotra, 2013). It is considered to be a more forward looking document than the Persons with Disabilities Act because of the influence of the UNCRPD (Ghosh, 2012). The Policy

> …attempts to clarify the framework under which the state, civil society and private sector must operate in order to ensure a dignified life for persons with disabilities and support for their caregivers (Ghosh, 2012: 26)

Even though this policy recognizes persons with disabilities as valuable human resources of the country, it is only confined to repeating the provisions that are enlisted in the different laws for persons with disabilities in India (Ibid).

In 2016, after a series of discussions, the Rights of Persons with Disabilities Act (RDP Act) was passed by both the houses of the Parliament. The Act upholds the principles laid down by the UNCRPD for the empowerment of persons with disabilities (Gazette of India, 2016). These principles include:

(a) respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
(b) non-discrimination;
(c) full and effective participation and inclusion in society;
(d) respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
(e) equality of opportunity;
(f) accessibility;
(g) equality between men and women;
(h) respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (Gazette of India, 2016: 1-2).

The act defines ‘persons with disabilities’ as

> …a person with long term physical, mental, intellectual or sensory impairments which, in interaction with barriers, hinders his full and effective participation in society equally with others (Gazette of India, 2016: 3).

The above definition shows a paradigm shift in the thinking about disability in India from a welfare issue to a human rights issue (Narayan & John, 2017). The list of disabilities under this Act has been expanded from 7 to 21 conditions, and it includes *physical disabilities* such as locomotor disabilities (leprosy cured person, cerebral palsy, dwarfism, muscular dystrophy, acid attack victims), visual impairment (blindness and low vision), hearing impairment (deaf and hard of hearing) and speech and language disability; *intellectual disabilities* such as specific learning difficulties, autism spectrum disorders; mental behavior; disabilities caused due to *chronic neurological conditions* such as multiple sclerosis and Parkinson’s disease; *blood disorders* such as haemophilia, thalassemia and sickle cell anaemia; *multiple disabilities* and *any other* category notified by the Central Government (The Rights of Persons with Disabilities Act, 2016, Gazette of India). Further, the Act defines a ‘person with benchmark disability’ as

> …a person with not less than 40 percent of a specified disability where specified disability has not been defined in measureable terms and includes a person with disability where specified disability has been defined in measureable terms, as certified by the certifying authority[17] (p: 3).

Thus, while the Act has incorporated most of the criticisms of the PWD Act, 1995, it still relies on competent medical authority to designate that a person has benchmark disabilities in order to avail the special provisions within the Act. This suggests that the shadow of the medical model is still hovering over the disability services in the country.

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[17] Much like the PWD Act, the RPD Act also relies on the guidelines of the Central Government for the purpose of assessing the extent of specified disability in a person. For this purpose, the appropriate government designates persons with requisite qualifications and experience as certifying authorities, who shall be competent to issue the certificate of the disability (The Rights of Persons with Disabilities Act, 2016, Gazette of India).

Magnitude of Disability in India

India is considered to be the home of the largest population of persons with disabilities in the world (Karna, 2000, as cited in Klasing, 2007). The Census and the National Sample Survey (NSS) are the two main official data bases that have collected data on the incidence and prevalence rates of disability in the country (Mitra & Sambamoorthi, 2006). The NSS is conducted as and when the need arises for an in-depth analysis of an issue; while the Census is conducted in a decadal sequence and it draws its strength from its universal strength and freedom of sampling error (Chakravarty, 2002).

The NSS was first conducted to collect information on physically 'handicapped' persons in the 15th round (July 1959-June 1960). This study was confined to rural areas alone. But in the next round (July 1960- August 1961) the geographical coverage was extended to urban areas also. The NSS was again conducted on persons with disabilities in the 24th (July 1969-June 1970) and in the 28th round (October 1973-June 1974). The objective of these surveys was to provide the estimates of the number of persons with disabilities in the country who suffered from certain 'physical handicaps'. These surveys provided little information on the cause, specific nature and other details associated with persons with disabilities. With the declaration of UN International Year of Disabled Persons, the 36th round (July-December 1981) undertook an exclusive and comprehensive survey of persons with disabilities with the aim to provide a database regarding the incidence and prevalence of disability in the country. This survey was conducted only on persons having physical disabilities (locomotor, speech, hearing and visual). The 47th round (July-December 1991) also enumerated the number of persons with disabilities. Although the concepts, definitions and operational procedures of the 36th and the 47th round were the same, it is difficult to compare them because the results or findings of the two have been put under different headings (Chakravarty, 2002).

The most recent NSS on persons with disabilities was fielded in the 58th round (July-December 2002). In this survey, a person was considered to be disabled "*if* [s/he] *has restrictions or lack of abilities to perform an activity in the manner or within the range considered normal for a human being*". This round classified disability into the following types: locomotor, visual, speech, hearing and mental (Mitra &

Sambamoorthi, 2006a). According to NSS data, there are 12 million persons with disabilities in 1981 (1.8 per cent of the total population), 16.15 million in 1991 (1.9 per cent of total population) and 18.49 million in 2002 (1.9 per cent of total population) (Klasing, 2007).

The history of collection of data on disability can be traced back to 1872, when the British began conducting Censuses in the country in a decadal sequence. However, this practice was discontinued after 1931 as the Census Commissioners expressed grave doubts on the authenticity of such data (Mehrotra, 2013; Reddy & Shree, 2015). The first Census on persons with disabilities in Independent India was undertaken in the year 1981. The reason for this was the declaration of the International Year for Disabled Persons by the UN. According to this Census the number of persons with disabilities in the country is 0.12 million (0.16 of the total population) (extracted from http://mospi.nic.in/Mospi_New/upload/disablity_india _statistical_data_ 11mar2011/Chapter%204-Dimension_Disability.pdf on 11/09/2013). This data on disability is considered to be a gross underestimation of the total number of persons with disabilities in the country (Chakravarty, 2002). The 1981 data had several lacunae in it. Firstly, only three categories of persons with disabilities were considered namely, totally 'crippled', totally 'blind' and totally 'dumb'. Persons having mental illness and hearing impairment were excluded. Secondly, the use of the word 'totally' ignored those who are partially disabled, who also form a significant part of the disability sector. Thirdly, the use of words such as crippled and dumb reflects the kind of ignorance among the Census enumerators with respect to the issue of disability (Chakravarty, 2002). The question on disability was again dropped during the 1991 Census as doubts were raised about the reliability of data, definitions and methodology adopted in the enumeration process (Reddy & Sree, 2015). The enumeration of the disabled was again renewed in 2001 due to the requests made by the Ministry of Social Justice and Empowerment in the light of the enactment of the Persons with Disabilities Act, 1995 and the Ministry of Planning and Programme Implementation, and the sustained efforts by several disability organizations in the country and lobbying by disability rights activists (Ibid).

The 2001 Census collected information on five types of disability namely: visual, locomotor, speech, hearing and mental. According to this data, 21.9 million people are disabled in India (Mitra & Sambamoorthi, 2006). Visual impairment topped the list (48.5 percent), followed by in movement (27.79 percent), mental (10.3 percent) and speech (7.5 percent) and in hearing (5.8 percent) (Reddy & Sree, 2015). The female to male ratio of persons with disabilities, according to the 2001 Census, is 42:58 (Addlakha, 2010). The rural urban ratio is 75:25 which display the patterns of the general population, that is, more persons with disabilities live in rural areas than in urban areas because the Indian population is largely rural (Ibid). This data, however, is also considered to be an underestimation of the magnitude of the problem of disability because it does not include the estimates of leprosy and cerebral palsy (Klasing, 2007).

As a response to the criticisms of the 2001 Census and in the light of increased international disability activism supported by the Indian civil society, the 2011 Census was designed to cover different disabilities that are listed in the Persons with Disabilities Act, 1995 and the National Trust Act, 1999 (extracted from http://Censusindia.gov.in/ last accessed on 17/04/2014). It made considerable revisions in the process of data enumeration on persons with disabilities in the country. The disabilities covered include: in seeing, in hearing, speech, movement, mental retardation, mental illness, any other and multiple disabilities. The 2011 Census expanded the definitions under 'in seeing', 'in hearing', 'speech' and 'movement' disabilities, and bifurcated 'mental' disabilities into 'mental retardation' and 'mental illness' (see Reddy & Sree, 2015). Furthermore, a significant difference between Census 2001 and 2011 is the inclusion of two new categories, namely, 'any other' and 'multiple disabilities'. The category 'any other' was introduced in the 2011 Census to ensure full coverage so as to allow respondents to report those disabilities which are not listed in the questions. The category 'multiple disabilities' has been added to record the conditions of persons suffering from more than one disability. This is significant because in 2001 Census, a person having two or more disabilities was forced to be categorized under one of the five categories (Reddy & Sree, 2015).

According to Census 2011, the percentage of total persons with disabilities is 2.21 per cent, out of which 2.41 are males and 2.01 are females (extracted from http://Censusindia.gov.in/ last accessed on 17/04/2014). The percentage of persons in movement disability is the highest (20.28 per cent), followed by in hearing (18.91 percent), in seeing (18.77 percent) and any other (18.38 percent). However, the 'any other' category in this Census poses serious challenge as it is difficult to identify the exact type of disability of the informants under this category (Reddy & Sree, 2015). According to Reddy & Sree (2015), the significant number of persons with disabilities under this category reflects serious lacunae in the enumeration process. Similarly, in the 'multiple disabilities' category the total number of persons with disabilities is quite high (7.89 percent).

According to 2011 Census, 69.49 percent of persons with disabilities live in the rural areas of the country, while the rest live in the urban areas. This shows that there is a 5.32 percent decline in the number of persons with disabilities living in the rural areas (Reddy & Sree, 2015). According to Reddy & Sree (2015), this could due to the increasing trend of urbanization and the addition of new towns in the country. In terms of gender, the 2011 Census has recorded higher number of males (55.59 percent) than females (44.1 percent). The data also shows that the proportion of women suffering from seeing, hearing and multiple disabilities is higher than that of men (Ibid).

Despite measures taken by the government to ensure that all persons with disabilities are counted in the 2011 Census, experts believe that there has been a severe undercounting of the persons with disabilities in the rural areas. This undercounting could be a reason why the total number of persons with disabilities increased from a 2.13 per cent in 2001 to 2.21 per cent in 2011, while the neighboring countries like Bangladesh, China, Nepal and Sri Lanka account for about 4-6 per cent of the total population. This led Javed Abidi, convener of NCPEDP to conclude that perhaps the consciousness raising in the disability sector was limited to the urban areas, especially the metros and state capitals, and that there is a long way to go in order to reach out to the majority of persons with disabilities living in the rural areas. Persons with disabilities as well as local enumerators in rural areas would need more training under the enhanced definition, and the government will need to take the initiative in launching awareness programmes towards this end (extracted from http://timesofindia.indiatimes.com/india/Rural-disabled-undercounted-in-2011-Census/ articleshow/28025244.cms accessed on 04/06/2014)

As can be assumed from above, it is very difficult to estimate the total number of persons with disabilities from the results of these two data sets. This is because there is a huge difference in all the NSSs and Censuses conducted so far in the way the questions are framed and the way disability is defined (Mitra & Sambamoorthi, 2006a). Table 1.1 gives an overview of the number of persons with disabilities from the NSS and Censuses conducted in India from 1981 to 2011. This number, however, is still an underestimation of the total population of such persons in the country. According to a World Bank Report, estimate of persons with disabilities is between 5 to 8 per cent of the Indian population that would be roughly 55-90 million individuals (extracted from http://mospi.nic.in/Mospi_New/upload/disablity_india_statistical_data_11mar2011/Chapter%204-Dimension_Disability.pdf on 11/09/2018).

Table 1.1: Overview of persons with disabilities according to the NSS and Censuses conducted in India from 1981 to 2011.

Year	Census 1981	Census 2001	Census 2011	NSSO 1981	NSSO 1991	NSSO 2002
Total disabled population in million	1.1	21.9	26.8	13.67	16.36	18.49
% of disabled population to total population	0.16	2.1	2.21	1.8	1.9	1.9
% of visually impaired out of the total disabled	43	48.55	18.77	--	24.79	15.29
% of locomotor disabled out of the total disabled	32	27.87	20.28	--	55.33	57.51
% of hearing impaired out of the total disabled	--	5.76	18.91	--	20.06	16.56
% of speech impaired out of the total disabled	25	7.49	7.5	--	12.17	11.65
% of mentally impaired out of the total disabled	--	10.33	5.6[18] 2.7	--	NA	11.34

Source: Mitra & Sambamoorthi, 2006 (p: 4023); Reddy & Sree, 2015 (p: 64).

The above table gives an overview of persons with disabilities in the country from 1981-2011. It is apparent from the table that the number of cases of locomotor disability is either the highest or the second highest (NSS 2001) in this entire period. Let us now look at the magnitude of this type of disability more closely.

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[18] As mentioned earlier, in the 2011 census, the category of mentally impaired (as recorded in the previous censuses) has been bifurcated into mental retardation and mental illness. The percentage of mentally retarded persons according to the Census is 5.6 percent, and the percentage of mentally ill is 2.7 percent (Office of the Registrar General & Census Commissioner, India, 2013).

Magnitude of Locomotor Disability

Locomotor disability has been defined as *"a person's inability to execute distinctive activities associated with moving, both personally and objects, from place to place, and such disability resulting from the afflictions of musculoskeletal and, or nervous system"* (Kundu, 2000: 213). This type of disability can be classified as: congenital and acquired, the common causes of which can be classified as congenital and developmental. Examples of congenital include: cerebral palsy, Congenital Taliphes Equino Varus (CTEV), meningocele, meningomyelocele, phycomelias, congenital dislocation of hip and so on. Acquired disability can be clubbed under two headings: infective and traumatic. Infective ones include: tuberculosis of the spine or other joints, chronic osteomyelitis, septic arthritis, acute poliomyelitis, Guillian-Barre (G.B.) syndrome, leprosy, encephalitis, etc.; while the traumatic ones include: traffic accidents, domestic accidents, industrial accidents, agricultural accidents, fall from height, bullet injury, violence and so on. Other than this, acquired can also include vascular, neoplastic conditions, metabolism and so on (Kundu, 2000).

Locomotor disability is the most prevalent type of disability affecting the population of all ages in India. Although it is not life threatening, it greatly affects the quality of life led by persons with disabilities (Padhyegurjhar & Padhyegurjhar, 2012). According to the 2001 Census, the percentage of persons with locomotor disability is 27.87 (6.1 million), while according to the 58th round of NSS (2002) the percentage of persons with locomotor disability is 57.51 (10.6 million) (Mitra & Sambamoorthi, 2006). According to the 2011 Census, persons with locomotor disabilities constitute 20.28 percent of the total population (Reddy & Sree, 2015). The difference in the prevalence rates of locomotor disability according to these different data sets could be due to the variations of definition. The 2001 Census covers the absence of all toes, all fingers, deformity, the inability to move without aid, the inability to lift and carry small articles. The NSS 2002 has a much broader definition of locomotor disability that includes persons with paralysis, amputation, deformity, dysfunction of joints and dwarfism (Mitra & Sambamoorthi, 2006). The 2011 Census expanded the ambit further to include those who have acute and permanent problems of the joints/ muscles; those who crawl; have stiffness or tightness in movement; have loose; involuntary movements or tremors of the body; have fragile bones; have difficulty in balancing and coordinating body movement; have loss of sensation in the body due to paralysis or leprosy; have a deformity of the body like the hunch back or dwarfism (Reddy & Sree, 2015).

According to NSS 2002, the major cause of locomotor disability is poliomyelitis (30.9 percent), which is followed by burns and injuries (28.5 percent) and other illnesses and diseases (12.7 percent). It also shows that 2.8 percent cases of locomotor disabilities are due to 'old age' (58th Round of NSS, as cited in World Bank Report, 2007). It is important to note here that the survey does not point whether the cause of what is reflected as 'old age' is due to ageing related disabilities or ageing of the cohort of persons who had acquired their disabilities earlier in life. The 2001 Census collected data on ten age groups from below 4 years to above 80 years, while 2011 Census collected data on eleven age groups from below 4 years to above 90 years. While the 2011 data show a decline in the number of persons with disabilities in the age group of 5- 20 years and 50-59 years, there is a significant increase in the number of persons with disabilities in the age group of above 60 years (Reddy & Sree, 2015). Reddy & Sree (2015) have argued that old age related disabilities must be separated from congenital and other disabilities acquired at an early age in the enumeration process as the lived experiences of both the groups would be significantly different (Ibid).

In terms of gender, all the data sets from 1991 (including Censuses 2001 and 2011 and NSSO surveys 1991 and 2002) have shown that the incidence of locomotor disability is more common among males than among females (Das & Agnihotri, 1999; Addlakha, 2010, Office of the Registrar General & Census Commissioner, 2013). Table 1.3 gives an overview of the prevalence of different forms of disabilities recorded by Census 2011 in terms of gender.

Table 1.3: Proportion of Persons with Disabilities by Type of Disability and Gender in India

Sl. No.	**Type of Disability**	**Persons with Disabilities**	**Males with Disabilities**	**Females with Disabilities**
1.	In Seeing	18.8	17.6	20.2
2.	In Hearing	18.9	17.9	20.2
3.	In Speech	7.5	7.5	7.4
4.	In Movement	20.3	22.5	17.5
5.	Mental Retardation	5.6	5.8	5.4
6.	Mental Illness	2.7	2.8	2.6
7.	Any Other	18.4	18.2	18.6
8.	Multiple Disability	7.9	7.8	8.1
	Total	**100.0**	**100.0**	**100.0**

Source: Census of India, 2011 (Office of the Registrar General and Census Commissioner, 2013)

The above table shows that the greatest disparity for males and females by type of disability is for locomotor disability (22.5 per cent for males and 17.5 per cent for females). Addlakha (2010) has argued that the gender disparity in the prevalence rates of different types of disabilities is not necessarily only due to biological reasons, as the role of socio-cultural factors cannot be negated. Factors such as lack of adequate nutrition and healthcare for pregnant women, neglect of the female disabled infant, infanticide and selective abortion of the disabled fetus could all be responsible for the differential survival rates of the females and the prevalence of disabilities (Addlakha, 2010). Moreover, because of gender stereotypes that necessitate women to be more home-bound could also play a role in such prevalence rates because many disabling conditions could be normalized according to the societal norms (Addlakha, 2010; Wendell, 1989), thereby lessening the incidences of locomotor disability for women.

The aim of this section was to highlight the disability scenario in the country. It has been found that unlike in the West where disability is considered to be a form of oppression, in India, persons with disabilities generally internalize the negative attitudes about disability which make them look at cosmological factors for explanation about their conditions. Unfortunately the attitude of the state towards their issues is also that of apathy, due to which they do not have anyone else, but their families, to lean upon.

Section IV

This final section of the chapter reviews the literature that is significant from the point of view of the study.

Family Support for Persons with Disabilities:

Family is an intimate group that is constituted by members who are related to one another by bonds of love, sexual mating or legal ties. It is the group that provides succor to its members in times of need. Family plays an important role in taking care of the children, the sick, persons with disabilities and the elderly. The family, however, is a patriarchal institution that provides an impossible barrier to equality between the sexes (Jain & Banerjee, 2008). Within such a context, women are usually expected to care for children and adult family members. They are also expected to provide care in ‘extra-normal’ circumstances for the chronically dependent persons, that is, the disabled and the elderly (Dalley, 1988 as cited in Chakravarti, 2002). According to Dalley (1988), in capitalist societies, those who cannot work, either due to the nature of their impairments or due to crossing of the retirement age set by the society, inevitably become dependent on the state or the family. This dependency, however, is not intrinsic to their physical or medical condition, but instead is socially constructed because they are indiscriminately ruled out from actively participating in society. Due to this reason, the hardships that persons with disabilities experience depend upon the care and support they receive from their families, which has the capacity to either mitigate their issues through integration or to complicate them through marginalization and stigmatization (Dalley, 1988, as cited in Chakravarti, 2002). According to Dalley (1988), in societies which do not have formal care systems, the principle structure of kinship provides the basis for caring. In contrast, in societies where the state takes the responsibility of providing care, the form of care adopted has tended to replicate the family model (as cited in Chakravarti, 2002).

Since the 1960s, feminist researchers have pointed out that worldwide, women are the primary caregivers who rear children and tend to the needs of the sick, the disabled and the elderly (Tong, 2009). Care-focused feminists have argued that in different societies different values, virtues and traits are associated with men and women, and through their work they have developed different answers for explaining *why* this is so (Ibid). While some of these explanations have concentrated on the different biologies of men and women, others have focused on their diverging psychological paths, and still others have focused on the ways in which societies systematically shape men's and women's distinct identities and behaviors. Whatever the explanations they provide, the common thread amongst this strand of feminist researchers is that they regard women's capacities for care as a human strength rather than a human weakness. Care-focused feminists have also spent considerable energy in developing a *feminist ethics of care* as a complement of, or even a substitute for, a traditional ethics of justice (Ibid). According to Carol Gilligan (1982), men adhere to a morality of justice, whose primary values are fairness and equality, while women adhere to a morality of care, whose primary values are inclusion and protection from harm. According to her, it is because of this reason, that studies of moral development that adhere exclusively on traditional ethics of justice do not provide an appropriate standard for measuring female moral development (as cited in Fischer, 1987). Over the years, Gilligan's work has been criticized for its methodological flaws (see Tong, 2009), and for focusing too much on gender of women in her study at the expense of other markers of identity such as race and class. Other critics have argued that it is unwise to promote the view that women are essentially better carers than men, as it can have negative consequences for women as a collective in the long run (Ibid).

Other feminist researchers have attacked the family as the context in which women provide unpaid care to 'dependents'. In the late 1960s and early 1970s these dependents were largely children, but from the late 1970s onwards they widened their scope to include other 'dependents' such as persons with disabilities and the elderly

(Morris, 1991). Such research stressed that the unpaid care work that women perform for their children or for persons with disabilities and/ or elderly people is an important aspect of their experience of oppression. This research was done in the context of government policies in the UK during this period that were aimed at reducing the numbers of people living in residential institutions and to enable them to live in the 'ordinary' homes in the community. Feminist researchers have pointed out that it is actually women's unpaid work of caring for disabled and older family members which makes such an option plausible. They have argued that such work have a deleterious effect on women's life chances in terms of equality of opportunities with men (Baldwin & Twigg, 1991, as cited in Morris, 1995). Morris (1995) has critiqued such research due to its explicit focus on the 'burden of care' imposed on non-disabled women within the family, which have completely obliterated the subjective experiences of older people and persons with disabilities who have been constructed as 'dependent' individuals. According to her, such research has in effect upheld the prejudicial social attitudes about older people and persons with disabilities, but at the core of which is the failure to identify with such experiences (Morris, 1995). She is also critical of this body of work which is identified as 'women's issue' but has generally failed to consider the voices of elderly women and women with disabilities in the category of 'women'. As a result of this lack of empathy towards their predicament, Morris (1995) has argued that some feminists feel that the denial of a home and family life are apt policy reactions to the needs associated with growing old or experiencing impairments. She argued that,

> [o]ur rights to have a home of our own, to live with those we love and who love us, our rights to have children and to bring them up in the way that nondisabled women take for granted, are not even considered in the debate about sexual division of the labour of caring within heterosexual family household (Morris, 1995: 72).

According to Morris (1991), the failure to look at the point of view of those who receive 'care' means that research and analysis on the experience of caring is incomplete. She further stated that in certain situations, the caring roles are not clear-cut, but are blurred or shifting (Ibid). Begum (1992) has also argued that for women with disabilities there could be an unconscious assumption that their disabilities will prevent them ever taking up caring responsibilities. She said,

> [t]o many women, the absence of rigidly prescribed gender roles would be a source of great relief and a sense of liberation, but for those of us who have been constantly

> denied to what could be constructed as the ‘goals of womanhood’, the attainment of such goals can be a real sense of achievement (p: 74-75).

The independent living movement (ILM) in the UK and the USA has rejected the medical model of disability that has historically contributed to the incarceration of persons with disabilities outside of the society in special institutions. In the ILM, persons with disabilities demand for the right to have control over their own lives. This is important because, according to Brisenden (1986), society has deprived persons with disabilities to have control over their own lives, which has left them with very little chance of participation in society. According to him,

> [w]e are the victims of a viscous circle, for the control that is denied the disabled individual by the medical profession, social service, relatives, etc. conditions that individual to accept a dependent status in which their life only takes place by proxy, resulting in them being unable to visualize independent ways of living (p: 178).

Another demand of the ILM is the right of all individuals to live in the community, regardless of their impairments (Brisenden, 1986). He has also clarified the meaning of the term ‘independent’ to mean

> … [not] someone who can do everything for themself, but to indicate someone who has taken control of their life and is choosing how that life is led (p: 178).

The most important aspect of being independent is not the amount of physical tasks a person is able to perform, but the amount of control s/he has over their everyday routine, which is not determined by the degree of disability of the individual. Due to this reason, this term is not applicable to someone living in the institution as the life of such a person will be pre-determined by the needs of the professionals who are in charge of the institution (Brisenden, 1986). This clarification is important because in Western societies the term independent is usually associated with the ability to be self-sufficient and self-reliant. Due to this reason, when an individual is unable to do certain things for themselves due to their impairments, it is automatically assumed that s/he is ‘dependent’ on others. This is the reason why persons with disabilities are assumed that they are unable to control their own lives, and are subject to control of others (Morris, 1995).

Morris (1995) further stated that the concept of independent living is of particular relevance for women with disabilities. This is because the experience of oppression due to their gender may further limit their opportunities to seek independence. For instance, women with disabilities, who are economically dependent on others in the family and also require personal assistance, may face particular difficulties in asserting their autonomy. This aspect has been completely negated in feminist literature on the experiences of non-disabled women's dependency within the family (Ibid).

As elaborated earlier, the disability rights language is based on western concepts of individualization and autonomy, which are far removed from the reality across cultures where community ties persist (Grech, 2009). For instance, unlike in the West, individual welfare problems are not considered to be the responsibility of the Government or the society in South Asian cultures. Instead such matters are regarded as private concerns of the family. To expose such problems to outsiders is considered akin to losing face in front of the community (Miles, 1989). In such a context, survival is dependent on the support persons with disabilities receive from the family and community. Individual rights are almost non-existent, and in fact, may pose a threat to economic stability and social cohesion (Grech, 2009). Likewise, the social relationship between caregivers and care-recipients as depicted by western disability studies does not hold true in the context of Asian and other communitarian societies where much of the care is provided informally in the family and the community (Ghosh & Banerjee, 2017). Due to this reason, Ghosh & Banerjee (2017) have argued that it is imperative for disability studies to take better account of the informal care provided by the family. As a result of the absence of any form of care available within formal settings, the responsibility of caring for persons with disabilities falls squarely on the family, specially the mother. In such a context, caring and receiving care becomes a paradoxical experience that is further complicated by poverty and lack of access to resources (Ibid). In their paper on the lived experiences of girls with disabilities and their primary caregivers, their mothers, living in conditions of abject poverty and lack of resources, Ghosh & Banerjee (2017) have shown that in such a situation care entails contradictions where intimate interdependence signals culturally specific power relationships and constraints alongside prospects and opportunities. Further, the dichotomy between social constructs of care and neglect that is much seen in the western literature does not hold true for contexts such as India as intersecting strands of poverty, disability and restrictive gender norms make such straightforward differentiations difficult. According to them, the concept of 'cripping care'[19] offers a critique of perspectives that normalize violent and/ or dehumanizing care regimes. This approach takes into consideration the critique of the social model that it does not include individual experiences of pain and internalized oppression, by providing a way to include individual and bodily experiences which are then contextualized within the specific social settings in which it is applied (Ibid).

Empirical studies have shown that disability is intricately related with social class as disability is both a cause and consequence of poverty. Poor people are more likely to fall ill, and due to non-availability of resources, they are less likely to avail medical services and more likely to be disabled (Klasing, 2007). Disability also severely cuts down on the resources available to the family in more ways than one. Firstly, due to the lack of adequate facilities and the presence of structural and attitudinal barriers in the society, persons with disabilities are often unable to avail adequate educational qualification, which affects their employment prospects in the future. As a result, persons with disabilities often live as dependents on their family members, especially in the cases of severe disabilities. This reduces two working members for the family, the person with disabilities, and the care-giver (Ibid). Having a disabled person in the family also includes additional costs like visits to the health centre / hospital, visits to the physical rehabilitation centre and costs for buying aids and appliances. All this creates a huge economic burden on the family members (Ibid).

Chakravarti's study (2002, 2008) in urban India (Delhi & Chennai) on mothers of young adults (14-25 years) with cerebral palsy shows that the burden of care-giving is not only experienced by families of disabled persons who are poor, but also those who belong to affluent families. This is because even when they are able to hire help from outside, there is no guarantee on the quality of services that will be provided. Due to this, in most cases, the mothers of children with disabilities sacrifice their career ambitions to look after their children. However, the same study also shows that in cases where mothers are not able to leave their jobs due to the economic necessities, they are overly burdened with their care-giving responsibilities, household responsibilities, as well as the responsibility to earn for the family to supplement the family income (Ibid). In one of the case studies, Chakravarti (2002; 2012) elaborated

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[19] According to Ghosh & Banerjee (2017), crip theory functions as resistance to the norms of the society, and supports the choice of a person with impairment to call oneself crip and to experience pride, instead of hiding it or feeling ashamed.

that the mother of two sons with severe cerebral palsy was undergoing profound mental distress, due to which the doctor advised her to take at least an hour out in a day for herself, where she would go out of the house and meet other people. The mother followed the doctor's advice, and reported feeling better in the study (Ibid).

Several studies have also shown that parents are often overprotective about their children with disabilities, and do not allow them to do any task at home, out of the fear that this would harm them in some way (Klasing, 2007; Dhar, 2009; Ghosh & Banerjee, 2017). Such kind of overprotection, although showered out of love and concern, negatively impacts on the lives of persons with disabilities when they grow up. As a result, persons with disabilities do not have any life of their own outside of their parents. According to Chakravarti (2002), although parents indulge excessively with their children, one of the reasons for this could be that the social network is so negligent that the parents in their attempt to ensure some entertainment for their children themselves become their primary 'entertainers' as this need is not recognized by anyone else in the society.

At the other end of the spectrum, it is seen that certain families hurl abuses on the disabled members, and neglect them completely (Klasing, 2007; Daruwala et al, 2013). A number of studies have shown that the birth of a daughter with disabilities in the Indian context is considered to be a fate worse than death (Ghai, 2001; 2002; 2003; Mehrotra, 2004; 2013). In order to understand this, one has to understand the culture of son preference among certain communities in India, where the birth of even a non-disabled daughter goes uncelebrated in certain pockets. In extreme cases, female foeticide and infanticide are also practiced; such is the preference for sons in the country (Ibid). In such a scenario, it is not difficult to imagine that the birth of a daughter with disabilities would be a source of grief for the family. Whenever a non-disabled person in the family passes away, it is not infrequent when neighbors, relatives or other 'well-wishers' of the family to comment that the disabled child should have passed away (Chakravarti, 2002; 2008).

Gender of the person with disability determines the reaction of the family towards the person. The type of disability and social class are also an important factor in this regard. It is seen that persons with visual and locomotor impairments are considered to be a liability in poorer households in both rural and urban areas, due to their inability to contribute labor in the public domain and supplement the family income (Mehrotra, 2004; 2013). Persons with cognitive and hearing and speech impairments, on the other hand, are not excused from performing their household chores (Ibid). It has also been shown that family members in the urban middle class milieu are more accepting towards children who do not have cognitive impairments, while among poorer families in both rural and urban settings, parents prefer to have a child who does not have a disability that would restrict them from contributing their labor (Chakravarti, 2002; 2012). It has also been shown in a few studies that mild locomotor disabilities among women is not seen to be a problem in certain cases, as women's movement outside the private sphere is anyway restricted. It is unfortunate that not many studies have focused on the experience of disablement among men in general.

Health and Access to Healthcare of Persons with Disabilities

The social model of disability as mentioned earlier differentiates between impairment and disability, and focuses upon the environment which transforms impairment into disability. This is an attempt to move away from the medical definition of disability by focusing on the social barriers. Although it is empowering for many that the social and physical environment also creates obstacles for persons with impairments, this has often left the 'health' aspect behind. As Susan Wendell (2001) puts it, the disability rights movement and academia has only focused upon the healthy disabled and this has left many persons with disabilities who suffer from incessant pain and need frequent medicalization and hospitalization without a voice. This is because it is assumed that if persons with disabilities talk about this aspect of impairment then this would be to accede to the non-disabled world's view of living a life with disability (Oliver, 1996; Finkelstein, 2001).

Apart from these, other works, although not from a disability studies perspective have shown that persons with disabilities suffer from numerous health problems and need frequent hospitalization in comparison to their non-disabled counterparts (Horner-Johnson, 2013; Reichard et al, 2011), which may worsen their functional limitations and result in the development of co-morbid conditions or even premature death

(Reichard et al, 2011). In spite of this, studies have shown that the access to health care for persons with disabilities is poor (Pharr, 2013). Another study has shown that even though women with disabilities are more likely to have a usual place of care, they were more likely to delay healthcare because of several reasons like inability to get through on the telephone, inability to get an appointment soon enough, having to wait too long at the physician’s office, the office not being open at the time when they could get there or lack of transportation (Smith, 2008).

Access issues also arise when women with disabilities seek healthcare for childbirth or other gynecological issues. A study by Walsh-Gallagher et al (2013) conducted in Ireland tried to find out the professional barriers faced by women with disabilities in undergoing normal deliveries and how these barriers can be reduced. The study was aimed at having the perspective of the health professionals to negative experiences of birthing by women with disabilities. Many of the participants (midwives) were saddened by the fact that so many women with disabilities reported negative birthing experiences but justified themselves saying they tried their best to support these women. The second finding was that many of these professionals were not aware about disabilities and, therefore, often equated it with inadequacy, and their training was not meant for pregnant women with disabilities, and this was reflected in their behavior towards the women with disabilities undergoing childbirth.

Tighe’s study (2001) on seven women with physical disabilities also found that due to inaccessibility of healthcare services, a few women need to spend considerable amount of time finding a health facility where they can get their health needs met. In her study one of the participants who had called a health facility for gynecological examination beforehand to find if they will be able to help her given her condition (cerebral palsy and visual impairment, using a wheelchair), upon arrival found that they spent considerable amount of time trying to figure out how to lift her. After the examination, however, the participant was told never to come back to the clinic as one of the nurses had badly hurt her back while trying to lift the participant. The participant then wonders how it is her fault when she had already called the clinic to find out if they would be able to help her.

In India the health of persons with disabilities is a neglected issue despite the fact that they utilize health services more than their non-disabled peers. Persons with disabilities utilize health services not only at the time of onset of disability but also due to the development of secondary health conditions. In the developing world, disability, poverty and poor health are inter-related leading to a vicious cycle. Health services do not cater to the needs of persons with disability due to different reasons such as, inaccessible buildings and diagnostic equipment, negative or stereotypical attitudes of health personnel or their ignorance and lack of training to communicate with hearing / speech impaired or cognitive impaired individuals, inaccessible transport to reach the health centre or sheer expense of treatment or rehabilitation (DEOC, 2009).

Klasing's study (2007) shows that for a vast majority of persons with disabilities residing in the rural areas (about 75 per cent according to 2001 Census) medical care is beyond access, primarily because rehabilitative services are concentrated in the urban areas. The study also cites a number of barriers to medical access for persons with disabilities in rural areas, including, geographical distance to the next hospital facility, poor road conditions and unavailability of transportation facilities, which makes access beyond the reach of persons with disabilities due to their restricted mobility and their dependence on caregivers to take them to the health facilities; physical barriers denies access inside the health facility coupled with lack of toilets, benches and chairs; lack of awareness among persons with disabilities hinders them from availing medical help for their health problems; and economic constraints which includes both the direct cost of treatment as well as the indirect opportunity costs of foregoing wage labor are unaffordable for many. Even when medical care is provided free of cost, the patient incurs cost of transportation to and from the health facility as well as for the purchase of medications which is too expensive for many persons with disabilities.

Thus, the above review shows that in terms of health, persons with disabilities have a great risk of developing secondary health conditions, but despite this their access to healthcare is poor in comparison to the general population. Access issues are also there for women with disabilities when they seek healthcare for childbirth and other gynecological issues. In the Indian context, studies on health of persons with disabilities are limited in number. A few studies have shown that health access is beyond the reach for many which in itself can be a cause of disabilities.

Psycho-Emotional Dimensions of Living with Disabilities

From the explanation about the social model of disability in Section I it is clear that the model and its proponents are primarily concerned about the barriers that persons with disabilities face on the 'outside', but they remain completely silent about the experiences that they have ensure on the 'inside'. In order to fill the gap, Thomas (2004a; 2004b) had introduced the concept of *psycho-emotional dimensions of disabilities* to understand the experiences of the women along psychological and emotional pathways. In her work, she has shown her skepticism about the reservation that certain disabilities scholars have about openly discussing personal experiences of impairment. As a feminist she is interested in the intimate and experiential aspects of disability, and argues that those who relegate these experiences to the realm of the private life actually ignore key dimensions of the experience of disability (Ibid). According to her this is a form of *disablism* that works with and upon gendered realities, which frequently results in people with disabilities made to feel worthless, unless, of less value, unattractive or as a burden. According to Thomas, this form of disablism comes into the picture when persons with disabilities have to continuously manage negative and discriminatory social reactions and behaviors at an interpersonal level. This is further compounded by their encounters with layers of degrading images of themselves in the media, art and other social discourses. Even in their interactions with their parents, teachers, health professionals, social workers or complete strangers, persons with disabilities have to confront words and actions that dampen their self-esteem and personal confidence. Such interactions limit them from being what they want to be by shaping their inner worlds and social behaviors. This, along with societal barriers that they encounter, restricts them from what persons with disabilities can do in the public arena. These restrictions on *"what a person with disabilities* ***can be*** *and what they* ***can do*** *fuse together in a 'toxic disablist mix"* (Thomas, 2006: 182; emphasis in original). She further said that because persons with disabilities usually remain isolated from one another, it makes it all the more difficult for them to confront this toxic mix. But through the self-organization and collective struggle of persons with disabilities, resistance has now become possible (Thomas, 2006).

Although persons with disabilities attempt to resist such forms of disablism, they involve additional emotional costs. Along with this, their efforts are also contingent upon how visible their impairment are and whether or not it interacts with other aspects of their identity such as gender, ethnicity, class and age (Thomas, 1999, cited in Reeve, 2006). Reeve's (2006) case studies have shown that persons with disabilities have to perform the 'grateful disabled person role' simply to overcome the obstacles they face in their day-to-day lives, as a result of which they face considerable emotional distress. Her study also reflects that perhaps it is more difficult for men with disabilities to receive help than women with disabilities due to the conflict between the cultural representations of masculinity as strong and independent and disability as weak and dependent. Two of the sources of psycho-emotional dimensions used by Reeve (2006) are the interactions with the structural environment and social interactions with others. Internalized oppression can also leave some people with disabilities feeling devalued and disempowered. It is very important that psychologists understand these aspects of living with an impairment (Reeve, 2006).

Furthermore, Begum (1992) has argued that for many women, their self-image is influenced by their body image. This is a direct consequence of the fact that women are primarily defined by physical appearance. This dominant concept of femininity does not take into consideration the diverse and individual characteristics of women. Women with disabilities is one such sub-group of women who face the brunt due to this emphasis on feminine attractiveness and the ability to at least take care of one's own basic bodily functions. Through the myriad images of beauty that women with disabilities are bombarded with, they begin to internalize the implicit message that they must have a certain appearance to be appreciated and loved by men. As a result of all the negativity that surrounds them, Begum (1992) argues that it is not surprising if women with disabilities regard their bodies as an enemy.

Ageing and Disability

There are two facets to the problem of ageing and disability: one is that older people develop disabilities and need long term care; and secondly people who were disabled earlier in the life cycle grow old.

Disability among the Elderly: Disability is commonly associated with old age. An important factor that needs to be kept in mind while examining the association between old age and disability is that it is a heterogeneous group and the health status of this group may vary according to different factors. While extreme losses of physical, mental and social functions are common among the elderly, many also retain high levels of functionality. Some researchers believe that the increase in the lifespan of the elderly would also lengthen the period of chronic illness and disability in old age. However other researchers have brought to light that there may be a ‘compression of morbidity’ with lesser incidence of chronic illness and restriction of disability to a brief period preceding death consequently increasing the number of healthier people in the old-old age group (Prakash, 2003).

Ageing in Persons with Disabilities: The concern for persons with disabilities who live till old age is relatively new as only recently we can see an increase in this population. However, statistics about this group is not available. Survival of persons with childhood disabilities till old age poses newer challenges. The issues that persons who acquire disabilities earlier in life face are not just medical, but also involve architectural and attitudinal barriers. In addition to this, sometimes it is also difficult to pin point whether the difficulties that a person with disabilities is facing is due to ageing or due to the condition or disease. One classic example in this regard is that of post-polio syndrome (Prakash, 2003).

Ageing and Gender:

Statistics from all over the world shows that women typically live longer than men, and this has led to a process called ‘feminization of ageing’ or ‘feminization of later life’ (Raju, 2011). In the case of India, however, where the overall sex ratio is skewed in favor of men, the number of males outnumbers the number of females even in the older age group (Rajan, 2006). It is only in the old-old category (80 and above) that women outnumber men (Rajan, 2006). Despite greater chances of survival, elderly women are at a greater risk of ill-health in later life due to adversities faced earlier like child bearing, less nutrition, care giving roles to the young and the elderly and economic deprivation (Raju, 2011).

Feminist gerontologists have argued that ageing women face a double disadvantage because the society's standards of female beauty and physical appeal are almost exclusively youthful (Twigg, 2006; Hunt, 2005). Due to this reason, women are more aware about the ageing process than men as the physical signs of ageing produce graver social consequences for them (Hunt, 2005). In addition to this, women in countries like India are considered to be ageing five years or so earlier than men in spite of their greater life expectancy (Bonita, 1998). As a result, women consider themselves to be older at a much younger age than men (Prakash, 1999). There are also different markers to assign the commencement of old age among men and women. For men, the retirement age of 60 or 65 has traditionally been considered to usher in old age (Berk, 2004). In the case of women, retirement age has little value as most women remain out of the workforce (Ibid). Instead other factors like the onset of menopause or the birth of the first grandchild are associated with old age for women (Bonita, 1998).

Traditional gender roles can affect the social and economic status of elderly women due to which they are more likely to live in unfavorable conditions like low economic security, lower educational attainment, less labor force experience and more care-giving responsibilities in comparison to their male counterparts (Raju, 2011). In addition to this, since most elderly women outlive their male counterparts, they are more likely to take care of their husbands in later years, and this burden of care giving often leads to deteriorating health and mental stress among them (Raju, 2011). Vatuk (1995) also points towards the social advantages of older women over older men in Indian society. An older man can be socially marginalized or neglected because of his failure to contribute actively to the household and therefore might be seen as a burden. Older women, on the other hand, continue to actively contribute to household chores although perhaps with some decreased level of energy expenditure. Due to this reason, older women continue to remain at the centre of the household, while older men are relegated to the peripheries. However, older men are also not without their own share of advantages. Firstly, since men are likely to be married in old age, they continue to receive companionship and caring attention from their wives, which many women do not receive. Secondly, as men have control over property, they are able to command authority in the family. However a majority of older men do not own substantial amounts of property and therefore male property ownership and patrilineal inheritance is only notional to a large extent (Vatuk, 1995).

Widowhood for women also means economic deprivation as women’s access to resources depends upon their marital status. High morbidity and mortality rates are seen among women who are widows. This, however, depends upon the presence of an adult son and the position of the widow as household head. Studies have shown that women in south India are more likely to be widows than women in the north because of high life expectancy in the south for women (Chen & Dreze, 1995). Most of the studies on widowhood in the context of India have focused on widowhood under unfavorable circumstances, that is, widowhood at an early stage in the lifespan of the women or without a surviving male offspring which makes them more vulnerable (Chen & Dreze, 1995; Vatuk, 1995). However, with the raising age at marriage for women and reduced male mortality in early adulthood, women who are widowed at a younger age are continuously declining in the total widowed population. Despite this, studies on widowhood have not focused on the problems faced by widowed women in later stages of the life cycle (Vatuk, 1995).

Feminism as a school of thought has tried to bring to the fore the experiences of oppression and subordination that women face in patriarchal societies. However most of these accounts have focused on women in the younger age group (Morris, 1991). Feminism has been accused of being guilty of ageism (Twigg, 2006). Accounts of women in the older age group focus primarily on the experience of menopause. In the context of India, older women, have been portrayed as villains in the lives of younger women (Vatuk, 1995; Lamb, 2000). Barring a few studies, accounts of women’s life beyond their reproductive age group is missing is India. Vatuk (1995) finds this surprising especially in a context when there is a growing scholarly interest in gerontology, and yet there is an absence of discussion on the lives of older women.

Disability and Gender:

Women with Disabilities and their (A)sexuality: Persons with disabilities till very recently have been regarded as asexual. The nondisabled world has found it particularly difficult to grapple with the idea that disabled women could have sexual feelings. In many cases the mere thought that they may engage in sexual behavior is considered to be repulsive and comical at the same time (Begum, 1992). Begum (1992) has argued that a child's sexual development is significantly influenced by his/her body image and self-esteem. In cases where young girls with disabilities acquire a negative body image, they may feel ambivalent and confused about their own sexuality.

Several studies conducted on women with disabilities have focused on them being reduced to asexual beings as a result of their deviation from the myth of the beautiful body. Wong's study (2002) conducted on 11 women with physical disabilities in San Francisco shows the kind of problems that they face while accessing information on sexuality and reproductive health. One of the participants in the study mentions that while there are materials available on increasing desire, there are no studies that deal with the negative effect of medication on desire or about difficult sexual positions for persons with disabilities, thus reducing women with disabilities into asexual beings. Tighe's study in New York (2001) also shows how it is difficult for non-disabled persons to believe that persons with disabilities can have a healthy sexual life. One of the participants in her study while sitting for a doctor's appointment was asked by an elderly woman how 'it' happened (how she got pregnant) to which the participant replied that she was raped. Tighe later mentions that the woman was not raped, but she was enraged by the question posed to her and decided to respond to it with an equally ridiculous answer. The elderly woman's question and the participant's answer to the question, according to Tighe, shows how the society perceives women with disabilities to be recipients of forced sex and never having any agency on their sexual lives.

In the Indian context where sexuality is defined within the parameters of marriage, Ghai (2003) found that many women with disabilities that she interviewed were without words to describe their sexuality. Ghai (2002b) also discusses her own experience in her adolescence where she as a disabled girl was allowed to sleep with her male cousins, while her other female cousins were not allowed to do so. She was thus desexed because of her disability. Such 'asexual objectification' of women with disabilities also disregards the danger of sexual violation to which they are exposed, not only from outsiders (Chakravarti, 2002) but also from their own family members (Ghai, 2003). A study conducted in Mumbai (CREA, 2012) also showed how women with disabilities undergo sexual violence in their childhood, and the perpetrators can be brothers, neighbors or strangers. When parents are told about sexual misbehavior, they refuse to believe it and often put the blame on the girl, which one of the participants asserted as another form of violence.

Ghosh's study (2013) among women with locomotor disabilities in Bengal shows how girls with disabilities are socialized to be *bhalo meye* or the ideal woman in all aspects but are still excluded from gendered notions of sexuality. They are not expected to get married. In addition to denial of sexuality, the mothers of these women also consider them to be at a lesser risk of sexual abuse than their non-disabled daughters. While this was so, their mothers will however expect them to avoid male attention as the onus was on these women to protect their family honour. According to Ghosh (2013), these women have already lost their honour because of their impairments and on top of this, if they also show that they have sexual urges, they will be doubly dishonoured. These women, therefore, according to Ghosh, live at a liminal space of not being a *bhalo meye* and at the same time not being a *baje meye* (bad woman) either.

Even though parents and the wider society render women with disabilities as asexual, nevertheless parents especially mothers want their daughters with disabilities to develop 'normally' and to reach menarche at the right time. This point came out clearly in Addlakha's study (2007) when one of the participants did not reach menarche till late adolescence, and when she and her mother consulted a doctor he told them she will never be able to reach menarche due to her 'inborn defects'. This news was extremely distressful for the participant's mother for she desired her daughter to be having the assigned sexual identity even though marriage was not a possibility for her owing to her visual disability.

Women with Disabilities and Marriage: Relationships of love with the significant other are one of the highlights of adult life for most individuals across different cultures. However, how such relationships are formed and lived are determined by a number of cultural factors. Not much of the literature in the western context has focused on marriageability of women with disabilities. In the Indian context, however, this is a recurring theme. In India, where arranged marriage is the norm, relationships with the significant other is not just a union between two individuals, but also a union between two families, that are hierarchically related to one another. Because of high preference for sons and the prevalence of the dowry system, the family of the bride has extremely low bargaining power in forming such relationships. Some of the criteria that are kept in mind while considering a potential spouse for one's son include the reputation of the girl's family, their caste and social class, the looks of the girl and her character, the ability of the girl to match harmoniously with the boy's family, especially when they are expected to live in a joint family after marriage (Nanda, 1992). Considering this backdrop, it is not difficult to imagine the plight of women with disabilities who are at an extremely marginal position in the 'marriage market'.

According to Ghai (2003), the traditional feminine roles of marriage and motherhood are not available for women with disabilities. Ghai's (2003) case studies show how girls need to compensate for their disability by their earning ability or with adequate amount of dowry. The case studies also show that men with disabilities prefer non-disabled wives and this makes women with disabilities even more marginalized in the marriage market. The study also found class to be an important factor that was closely connected to the marriageability of women with disabilities. Parents from poor background prefer to have their daughters with disabilities institutionalized so that not many people come to know of her existence. But later if she is employed, many parents are not keen on getting her married as it implies losing out on her income (Ghai, 2003). Ghai says that since there is no external pressure from the society to get such women married, the family can play a great role in oppressing their daughters (Ibid).

Denial of marriage was also reiterated in Ghosh's study (2013) among women with locomotor disabilities in Bengal. This study found that when marriage proposals come for women with disabilities, it is at a much advanced stage and that too mainly from men with disabilities. Most women in this study, however, preferred to have a non-disabled husband and Ghosh feels that this is because of the internalization of social acceptability to such a match. When alliances came from non-disabled men, it was often with unacceptable clauses which made such alliances impossible. As opposed to this, Limaye's study (2008) with two hearing impaired adolescent girls who were in relationship with hearing impaired boys shows their aspiration of marrying them even against the will of their respective families. Both of them are aware that their parents, especially their mothers did not prefer hearing impaired boys for them but wanted somebody who could hear. Addlakha's study (2007) also shows that the women wanted to get married to someone like them because such persons would be better able to live with them, than a person without disability. One of them who was in a relationship with a visually impaired man from a different caste feels that *'...in the case of blind people there is no caste or religion. There is only the disability'* (Addlakha, 2007: 12). Another study has shown that while women with visual impairments wanted to marry men with the same problems as them due to reasons like having a better understanding with their husbands or fear of betrayal or abandonment, women with locomotor disabilities were found to be more keen on marrying someone who did not have the same problems as them as, *"[t]hat won't look good"* (Addlakha, 2013: 233).

The theme of marriage in rural settings is different from that of the urban settings mentioned above. Unlike the urban settings, women with disabilities in rural India are not denied traditional feminine roles. Mehrotra's study (2004) in rural Haryana among 46 women found that parents made an attempt to marry their disabled daughters through such strategies as marrying her into the same household with another non-disabled daughter, so that the major portion of the household work can be shared by the non-disabled sister. The study however showed that women often have to do backbreaking work in their marital home where no concessions are made on the basis of their disability, unlike their natal homes. Another study conducted in rural Rajasthan and Andhra Pradesh (Klasing, 2007) found that more women with disabilities are married in comparison to men with disabilities but the percentage of these women getting separated is also higher than that of men with disabilities. Klasing cited several possible reasons for this. Unlike in urban areas, parents of women with disabilities in rural areas are under constant pressure to get their daughters married, due to which these parents try very hard to find a secure match for their daughters. But the only people who are willing to marry women with disabilities are widowed men or those suffering from chronic illness, men living in acute poverty or who are looking for a second wife. In order to find non-disabled husbands for their daughters, parents often need to make compensations in terms of paying huge amounts of dowry. As opposed to this, there is not much stigma associated with unmarried men with disabilities, and due to this parents of men with disabilities do not have to bend over backwards in order to ensure that their sons are married.

Another recurring theme with that of denial of marriage and gender roles is that of domestic violence faced by women with disabilities. Mehrotra's study (2004) found disability to be a contributing factor to domestic violence, especially when the disability took place after marriage. Klasing's study (2007) also found that getting women with disabilities married at any cost made them more vulnerable to desertion and abuse. The study also found that men walk out of the marriage if their wives become disabled after marriage or if the disability is hidden at the time of marriage. Daruwalla et al.'s (2013) study in Mumbai also shows that women with disabilities are involved in violent relationships with their intimate partners and the key to these violent episodes include: spousal alcohol use, forced marriage, disputes with in-laws and suspicion of infidelity. This study also shows that the respondents are vulnerable to violence from their natal families if they chose to go against their family and marry across religion.

Some studies have also dealt with the perception of women with disabilities towards violence in intimate relationships. A study conducted in Mumbai (CREA, 2012) found that although all the women were unanimous in thinking that a husband had no right to beat his wife, but some of them believed that a husband could beat his wife if she disobeyed him or if she is suspected of adultery. The study also found that about 22 per cent of the women had experienced violence at the hands of an intimate partner for varied reasons like: their disability, poverty, their inability to work, stigma, dowry, remarriage of their partner or alcoholism of their partner. As a result of this violence, many of the women in this study experienced mental distress like: depression, of being fearful, contemplated suicide, attempted suicide (CREA, 2012).

Thus a review of literature on marriage of women with disabilities shows that in the urban context feminine roles are unavailable for them in comparison to those in rural areas. The reason for this is that parents in rural areas are more under pressure to look for a husband for their daughters than those in urban areas. It also shows that even when alliances come for women with disabilities it is usually from such persons as widowers, persons with chronic illnesses and poor men, or the woman's family has to adequately compensate it with enough dowry. After marriage, women with disabilities are also more vulnerable to violence and desertion.

Women with Disabilities and Motherhood: A lot of literature is also available on the problems faced by women in fulfilling their mothering responsibilities. Children of disabled parents are often referred to as 'little angels' who are forced to neglect their schoolwork and friends in order to take care of their parents (Morris, 1998). Morris (1998) writes that most of these disabled parents are actually single disabled mothers who are forced to ask help from their children due to such situations as poverty. Attitudes of health and social service professionals are also not very helpful who consider persons with disabilities as incapable parents for the latter to ask any help out of the fear that their children will be taken away (Ibid).

Carol Thomas's study (1997) with 17 women with different disabilities shows that most of these women had to face issues related with 'reproductive risk' either to themselves or to their babies. Most of the women believed that passing on the impairment to the child was irresponsible and unfair. Some of them, willingly or reluctantly, also ceded to the authority figures' demand of getting themselves sterilized. Women also suffer from guilt if the condition is passed on to their children. A second theme that was raised in the study was about being inadequate as a mother because of their disability. These women go to great length to prove to others that they themselves and their children are managing normally, which is at significant physical and psychological cost to themselves and their children. Another concern that was voiced by the women in this study was the kind of help that was received from health care professionals and social workers which was largely inappropriate for them.

In the Indian society, motherhood provides women with a purpose and an identity which nothing else can bring them (Kakar, 1978, as cited in Ghai, 2003). Motherhood, however, is only legitimized when the child is born within wedlock and not outside it. For women with disabilities since marriage is a remote possibility for many, motherhood is an aspiration that is difficult to achieve. Ghai's (2003) study has shown that even when non-disabled men marry women with disabilities, they do not want to have a baby with such a woman out of the fear that the disability may be passed on to the child, even when the disability is not genetic. The study further shows that when women with disabilities decide to adopt a child, even such an option is unavailable because looking at their disability they are deemed to be unfit for mothering responsibilities.

The above review shows that women with disabilities are considered to be unfit for motherhood responsibilities. Even before conception women with disabilities are warned about the risk of transferring their ‘faulty’ genes to their children. They are also considered inadequate to physically bring up a child. Due to such reasons women with disabilities often go to great length in order to fulfill their mothering responsibilities. In the Indian context where sexuality and marriage are interlinked, motherhood for women with disabilities is a distant dream. Those women who get married are also reminded about their disability when they express their desire to become a mother.

The theme of marriage in rural settings in India is different from that of the urban settings as mentioned above. Unlike the urban settings, women with disabilities in rural areas are not denied traditional feminine roles. Mehrotra’s study (2004) in rural Haryana among 46 women with disabilities found that parents made an attempt to marry their disabled daughters through different strategies such as marrying her into the same household with another non-disabled daughter, so that the major share of the household work can be shared by the non-disabled sister. The study also showed that women often have to do backbreaking work in their marital homes where no concessions are made on the basis of their disability, unlike their natal homes. Another study conducted in rural Rajasthan and Andhra Pradesh (Klasing, 2007) found that more women with disabilities are married in comparison to men with disabilities, but the percentage of these women getting separated is also much higher than that of men with disabilities. Klasing (2007) cited several possible reasons for this. Unlike in urban areas, parents of women with disabilities in rural areas are under constant pressure to get their daughters with disabilities married, due to which they try very hard to find a secure match for their daughters. But the only people who are willing to marry women with disabilities are widowed men, or those suffering from chronic illness, men living in acute poverty or those who are looking for a second wife. In order to find non-disabled husbands for their daughters, parents often need to make compensations in terms of paying huge amounts of dowry. As opposed to this, there is not much stigma associated with unmarried men with disabilities, and due to this reason their parents do not have to bend over backwards in order to ensure that their sons are married.

Another recurrent theme with that of denial of marriage and gender roles is that of domestic violence faced by women with disabilities. Mehrotra’s study (2004) found that disability was a contributing factor to domestic violence in her study, especially when the disability took place after marriage. Similar reason for domestic violence was also found in Sarma’s study (2014) in Delhi-NCR. Klasing’s study (2007) found that getting women with disabilities married at any cost made them more vulnerable to desertion and abuse. The study also found that men walk out of the marriage if their wives acquire their disabilities after marriage or if the disability is hidden at the time of marriage. Daruwalla et al’s study (2013) in Mumbai also shows that women with disabilities are involved in violent relationships with their intimate partners and the key to these violent episodes include, spousal alcohol use, forced marriage, disputes with in-laws, and suspicion of infidelity. The study also shows that the participants are vulnerable to violence from their natal families if they chose to go against their family and marry across religion. Sarma’s study (2014) in Delhi NCR found that one of the participants in her study agreed to marry an alcoholic man despite the opposition from her family members, because she felt that even if he beat her up after marriage, she would feel safe about being married to him than being unmarried at all, as there is more probability of harassment from the outside world. At the time of the interview, however, she regretted her decision to marry as she had frequent quarrels with her husband because of his alcoholism which left little money for the needs of the household and her children. Her husband also beats her up every night and called her names because of her disability.

Some studies have also dealt with the perception of women with disabilities towards violence in intimate relationships. A study conducted in Mumbai (CREA, 2012) found that although all the women were unanimous in thinking that a husband had no right to beat his wife, some of them believed that a husband could beat his wife if she disobeyed him or if she is suspected of adultery. The study also found that 22 per cent of the women had experienced violence at the hands of an intimate partner for varied reasons like, their disability, poverty, their inability to work, stigma, dowry, remarriage of their partners and alcoholism of their partners. As a result of this violence, many of the women in this study experienced mental distress like, depression, of being fearful, contemplated suicide and some have even attempted suicide (Ibid).

Conclusion

The aim of this chapter was to map out the existing literature on disability emerging from the western theorists, majority world theorists and to expand upon the Indian context. The existing literature clearly shows that the experiences of persons with disabilities cannot be homogenized as there are a myriad of factors that separate them. Keeping this into consideration, this study has been designed to understand the lived experiences of women with locomotor disabilities in the Kamrup Metropolitan District of Assam. The following chapter gives an overview of the research methodology used in the study.

Chapter 2

Methodology

Conceptualization of the Research Problem

There is no universally agreed upon definition of disability as it is a complex experience that needs to take into consideration the interconnected components of medical limitations and social prejudice (Addlakha, 2008). In addition to this, majority world theorists have argued that the experience of disablement varies greatly depending upon the geographical location of the person with disabilities (Barnes & Mercer, 2005). According to the World Report on Disability (2011), the global prevalence of disability among the adult population is estimated to be between 15.6 and 19.4 per cent. This figure is gradually increasing worldwide due to various factors such as wars, ethnic conflicts, HIV/AIDS, industrial injuries, road accidents, population growth, medical advancement and increasing life expectancy that make people more susceptible to old age related, chronic illness induced disabilities (United Nations Enable: Development and Human Rights for All, n.d.; Addlakha, 2010). Additionally, due to demographic transition, the number of persons with disabilities who are surviving till old age has also significantly increased over the last few decades, which can be attributed to advances in medicine, rehabilitation, public health and technology. It has been estimated that about 80 per cent of the world's total population of persons with disabilities lives in countries of the majority world (United Nations Enable, 2008), even though these countries report much lower prevalence rates than the countries of the minority world (World Report on Disability, 2011).

Notwithstanding these facts, the discipline of disability studies is dominated by western theorists, who largely focus on western industrialized settings. As a result of this, much of the theorizing that is produced by the discipline has focused on the deprivations faced by persons with disabilities in the minority world (Grech, 2009). In contrast, the issues faced by persons with disabilities in the majority world have either been ignored, or have been added in a superficial manner in the mainstream disability studies literature (Priestley, 2001; Barnes & Sheldon, 2005; Grech, 2009). This has resulted in the exportation/ importation of ideas and models from the minority world to the majority world along with the implications about the presumed situation of persons with disabilities in the majority world countries from the perspective of scholars from the minority world (Ibid). It has also been argued that disability studies literature emerging from the North assumes the South by not paying any attention to geography. It is only when the work is located outside of the northern metropole that disability scholars are expected to make their geopolitical position explicit (Meekosha, 2008). The heterogeneity of the social, political, historical, cultural and economic contexts in the majority world countries and the ways in which these factors influence the lives of persons with disabilities in these countries, largely remain unacknowledged (Grech, 2009). Additionally, majority world theorists have also called out minority world theorists for imposing a universal discourse on disability, while completely ignoring the specificity of the context of the majority world (Meekosha, 2008). For instance, history of colonization or the effects of globalization are often ignored while studying disability in the context of the majority world (Ibid). Disability scholars have also raised questions about the applicability of the social model of disability in the context of the majority world. While some studies such as Stone (2001) and Sheldon (2005) have argued that the social model is as much relevant in the majority world, as it is the minority world, others such as Grech (2009) and Meekosha (2008) have considered its usage in the majority world to be problematic. Grech's (2009) criticisms of the social model are particularly important for this study. According to Meekosha (2008), due to the difference in context, the western differentiation between disability, impairment and chronic illness are inadequate to successfully explain the lived experiences of persons with disabilities in the majority world. In fact, different set of methodologies and frameworks are required in order to analyze the experiences of persons with disabilities in colonized settings (Ibid).

India is estimated to have one of the highest numbers of persons with disabilities in the world (Karna, 2000, as cited in Klasing, 2007), even though the official statistics[20] shows a very low prevalence rate. One of the major causes of disability in the country is poverty (Ghai, 2001), which is something common with much of the majority

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[20] According to 2011 Census, persons with disabilities constitute 2.21 per cent (26.8 million) of the population, but according to the estimates of the World Bank Report (2007), about 5-8 per cent (55-90 million) of the population is disabled in India.

world. The two reasons why disability and poverty exist simultaneously in the poorer countries include (1) the root causes of impairment in the majority world are malnutrition, lack of services and landmines, which are likely to hit the poorest hardest; and (2) people with impairments are more likely to be poor worldwide due to the disabling barriers that prevent them from getting education, employment, access to appropriate healthcare and other services (Stone, 1999). While some of these barriers are embedded in local attitudes and responses to impairments, others are rooted in the broader structural processes of poverty and injustice that produce disability as well as impairment (Ibid). Due to this reason, Barnes & Sheldon (2010) have argued that the poverty that persons with disabilities experience in the majority world cannot be simply explained in terms of disabling attitudes and prejudice, but has to take into consideration structural inequalities and social processes (Ibid). Additionally, even though persons with disabilities in the majority world are more likely to be unemployed, underemployed and underpaid, their countries are unable to provided adequate safety nets to them due to the lack of resources (Barnes & Sheldon, 2010).

The current study is an attempt to understand the complex interplay of larger structural factors in the lived experiences of women ageing with locomotor disabilities acquired early in life (below 20 years) in the Kamrup Metropolitan district of Assam. The study understands the lived experiences of the women as embedded in the culture and structure of the society of Assam that makes their lives different from those of others located in other social contexts. Assam is located in the northeastern region of the country. Since independence, the state has experienced different kinds of conflicts based on language, ethnicity and identity, as a result of which it has remained one of the most backward regions of the country (the context would be elaborated in Chapter 3). Within such an identity-conscious state, almost nothing is known about the experience of disablement. Due to this reason it was found that studying the experiences of women with disabilities within this state would provide interesting insights.

The study critiques the homogenizing assertion that all persons with disabilities are oppressed and excluded, and instead argues that disability is not a single marker of identity for an individual, and like everyone else, they also live in the intersection of multiple social identities. Persons with disabilities are a heterogeneous group, and their experience of disablement is likely to differ on the basis of different axes such as the type of impairment, age of onset of the impairment, cause and nature of the impairment, present age, gender, class, caste, ethnic, religious and linguistic identities, geographical location, educational qualification, employment status, support from the family and the community. Furthermore, the responses towards persons with disabilities is often contingent upon the type of impairment, as different impairments produce different manifestations of disablism (Thomas & Corker, 2002, as cited in Grech, 2009). Due to these factors, persons with disabilities experience both positive as well as negative attitudes along a continuum, even within the same society. Therefore, depicting persons with disabilities to be oppressed while they do not consider themselves to be such may only perpetuate their marginalization and stigmatization (Ibid).

This study focuses on only one type of disability, that is, locomotor disability. According to Census (2011), locomotor disability is one of the largest causes of disability in the country. The largest cause of this kind of disability, poliomyelitis, has recently been eradicated from the country, which means that it is unlikely to have polio outbreaks in the future[21]. However, rehabilitation of polio survivors is a huge task and, therefore, needs serious attention from researchers and policy makers. This study focuses on locomotor disabilities acquired early in life as certain such disabilities creates new obstacles for the individual as s/he ages (for example, poliomyelitis). This study also tries to understand the progression of other kinds of early age locomotor disabilities and its effects on women as they age.

As discussed in the review, existing studies have shown that women with disabilities experience multiple disadvantages (Tighe, 2001; Ghai, 2003; Mehrotra, 2004; Daruwala et al, 2013; Ghosh, 2013). However, very few studies have particularly focused on the lived experiences of women ageing with disabilities acquired early in life through a life course perspective. Although in terms of statistics, locomotor disabilities are less prevalent among women than among men, yet the possibility of underreporting and the role of socio-cultural factors restricting the mobility of women cannot be negated (Addlakha, 2010), and therefore requires greater attention.

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[21] Even though cases of non-polio acute flaccid paralysis continue to rise (Yotsu et al, 2012).

In disability studies, the proponents of social model have made a distinction between impairment and disability, and have shifted the focus away from the physical limitations of the individual to the ability of the society to systematically oppress and discriminate against persons with disabilities from social functioning (Lang, 2001). Due to this, very few studies have elaborated on the impairment and health aspects of disablement (Wendell, 2001), even though several existing studies have shown that persons with disabilities develop secondary conditions and have a greater risk of developing chronic illnesses (Reichard et al, 2011; Horner-Johnson et al, 2013). In spite of this, persons with disabilities have poorer access to healthcare in comparison to nondisabled people (Pharr, 2013). These studies, however, were all conducted in the minority world context where people have more access to the recent technologies. According to Grech (2009), the universal imposition of the sharp distinction between impairment and disability is problematic because in many countries of the majority world, where people are struggling for basic healthcare services, and social protection systems are either absent or segmented, impairment is a fundamental concern. Due to this reason, engaging with the body in the majority world setting is of utmost importance (Ibid). In India, for instance, studies have shown that a vast majority of people do not even have access to primary levels of care which in itself can be the cause of disability (Klasing, 2007). Due to this reason, the cause of the impairment needs to be studied in greater detail. The current study makes an attempt to understand the cause of the impairment of the research participants. But instead of focusing on the medicalized understanding of health or impairment, the study tries to understand the perspectives of the women about their own health as well as to understand the broader context in which disabilities are created and sustained. Apart from this, the study also aims to understand if women with disabilities develop secondary conditions or chronic illnesses as they age and from where they seek healthcare for the same.

In addition to physical health, it is also important to study the *psycho-emotional dimensions of disability*, that is, the experiences that persons with disabilities have to endure along psychological and emotional pathways as a consequence of living with an impairment in a society that does not easily accommodate people who are different, or who have different needs (Ferrie & Watson, 2015). Embodiment is an important aspect of a person's lived experience. We are all embodied beings, and therefore, we experience the world through our bodies. In such a context having a body with a visible disability may have a severe impact on the mental well-being of the women across different stages of their lives. As has been shown in Chapter 2, disability studies literature through its emphasis on the social model of disability has largely focused on the 'public' experience of oppression but has avoided discussing the more 'personal' experience of oppression, that operate at the emotional level (Thomas, 1999, as cited in Reeve, 2006). Disability scholars have taken such a stance in order to avoid invoking the much prevalent personal tragedy theory (Reeve, 2006). Feminist disability scholars such as Morris (2004) and Thomas (2004a; 2004b), however, have critiqued such a viewpoint and have argued that it is very essential to understand the intimate and experiential aspects of disability. Existing studies have shown that young people with disabilities have poorer mental health in comparison to other young people because they face many years of living with disabilities, and this life stage is important for the development of identity, body image, independence and social inclusion (as cited in Kariuki et al, 2011). Other studies have reported that depression is not directly related to functional limitation among women with locomotor disabilities but other factors often play their part including younger age, less time with disability and more secondary health conditions (Froehlich-Grobe et al, 2013).

In a situation of scarcity of resources, dependent individuals such as persons with disabilities are often considered to be burdens on their families, as they are largely seen to be unproductive. It is one of the primary reasons why they face neglect and sometimes even abuse from the members of their families (Klasing, 2007; Daruwala et al, 2013). With the intensification of globalization, the dissemination of western ideas such as individualization and medicalization of disability has become very commonplace (Barnes & Sheldon, 2010). The negative effects of these include erosion of diverse responses to impairment, the risk of undermining the social accommodation that has been in place, weakening of the role of the extended family as the main source of social security, threatening local strategies and healing systems, and creating a class of 'disabled' people that may not have existed prior to the involvement of outsiders in rehabilitation surveys or research, which may eventually lead to their exclusion from communal life (Barnes, 2009; Barnes & Sheldon, 2010).

Given this backdrop, it is essential to understand the dynamics of interpersonal relationships within the family, and the factors influencing the same.

Additionally, in the absence of adequate support from the government, it is seen that from the 1990s onwards in many regions of the majority world there has been a proliferation of regional, national and international disability organizations that provide the necessary services to persons with disabilities. However, these organizations depend entirely on the funds they receive from donor agencies due to which they cannot entertain universal claims based upon social welfare rights. Ultimately, it is the state that is the only institution that is capable of creating and implementing the rights of persons with disabilities (Chakravarti, 2002). This study also tries to understand the kind of support that the women have received from their disability organizations and the kinds of expectations that they have from them.

The study would use the life course perspective to understand the lived experiences of women with disabilities across the life span. It focuses on the *lived experiences* of women ageing with locomotor disabilities because such experiences would enable us to understand the ways individuals make sense of their situations and actions (Moi, 1999: 63, as cited in Thapan, 2009: 3-footnote 5). The theoretical perspective used for the study is that of the life course perspective. This perspective looks at how chronological age, relationships, common life transitions and social change shape people's lives from birth to death (Hutchison, 2010). This perspective would enable us to better understand the lived experience of women with locomotor disabilities from birth till their present age. It is important to note here that the life course perspective is different from the life cycle perspective. The life cycle approach is a developmental model(s) which outline the social and psychological changes that a person encounters as s/he moves through the major 'stages' of life like childhood, adolescence, mid-life, old-age and finally death. This model reduces behavior and outlooks associated with these stages with the 'biological clock' in which ageing is perceived to be a biological process which also has psychological repercussions (Hunt, 2005). The life course perspective, on the other hand, takes into account both the social surroundings of the individual while also tracing the stories of the lives of people over time in an ever-changing society (Gielle & Elder, 1998, as cited in Hunt, 2005). This perspective, therefore, allows us to look at the individual life stories of the women while also locating these stories in the changing social and historical context.

The life course perspective has been considered to be important by different authors in the study of women's health and disability. Bonita (1998) considers this perspective to be appropriate in understanding women's health because the health of a woman in the earlier stages of the life course would help in determining her health in the later stages of her life. The theoretical frame of this perspective is also considered to be important in understanding disability from a social model perspective because it helps in understanding the life course through the individual biography and unique life experiences, while at the same time, allowing us to understand how shared cultural norms and structural boundaries define the life course for persons with disabilities in different generational locations (like childhood, adulthood and old age) (Priestley, 2003).

To sum up, this study aims to understand the lived experiences of women ageing with locomotor disabilities acquired early in life in the Kamrup Metropolitan District of Assam. The following are the research questions and objectives of the study.

Research Questions

The questions that guide this research are the following:

- What is the cause attributed to the occurrence of their disability (infection/ wrong treatment/ poverty/ black magic/ retribution for past sins/ God's will etc.)?
- What kind of support do women with locomotor disabilities receive from their families/ peer group/ community etc. through the life course?
- Do women with locomotor disabilities experience abuse in the family/ community because of their disabilities/ gender/ age?
- What are the corporeal experiences of women with locomotor disabilities with regard to different reproductive processes through the life course (menstruation/ sexuality/ pregnancy/ childbirth / nurturing/ forced sterilization/ menopause)?
- Do women with locomotor disabilities develop secondary and chronic health conditions as they age?

- Does the effect of the disability on the bodies and lives of these women aggravate as they age?
- What have been the significant events in the lives of women with locomotor disabilities (onset of their disabilities/ birth or death of a loved one or a caregiver/ marriage/ widowhood/ spinsterhood/ ageing/ education/ employment etc.)?
- How have these significant events impacted their mental wellbeing?
- What are the other significant intersections in the lives of women with disabilities (gender, disability, ageing, ethnicity, linguistic background, caste, class, religion, education and employment status, marital status and so on)?

Objectives

Broad Objectives

To understand the lived experiences of women ageing with locomotor disabilities acquired early in life (below 20 years) through the life course perspective in the Kamrup (Metropolitan) District of Assam.

Specific Objectives

- To understand the women’s subjective explanations of the occurrence of their disabilities.
- To understand the social support (or its lack) received by women with locomotor disabilities.
- To understand the corporeal experiences of living a life with disabilities, including body image, progression of disability, secondary conditions, chronic illnesses and reproductive processes.
- To understand the influence of significant life events on the mental wellbeing of women with locomotor disabilities.
- To understand the intersection of disability with other forms of identity in the lives of women with locomotor disabilities.

Research Design

Research design is defined as the plan or proposal to conduct research which involves an intersection of the philosophical worldview, research methodology and research methods used for data collection (Creswell, 2009). The *philosophical worldview* usually remains hidden in research, but they influence its practice, due to which it needs to be identified. This information helps in identifying why a particular research method is used over others (Ibid). The term 'worldview' is used to define 'a basic set of beliefs that guide action' (Guba, 1990, as cited in Creswell, 2009: 6). A *methodology* is a theory and analysis of how research should and does proceed and it includes accounts of how the general structure of theory finds its application in particular scientific disciplines. *Research method* involves the forms of data collection, analysis and interpretation that researchers propose for their studies (Creswell, 2009).

Philosophical Worldview: This research uses the principles of feminist research. This is because feminist imagination(s) is important in conducting research on women and health as it helps in challenging the widely held assumptions regarding women's physical and mental health to be necessarily poor (Doyal, 1995). Feminist research

> …challenges the basic structures and ideologies that oppress women […] by documenting women's lives, experiences and concerns, illuminating gender-based stereotypes and biases, and unearthing women's subjugated knowledge (Brooks & Hesse-Biber, 2007: 4)… [t]his approach incorporates interpretation, subjectivity, emotion and embodiment into the knowledge-building process, elements historically associated with women excluded from mainstream positivist research (Brooks & Hesse-Biber, 2007: 13).

Feminist research acknowledges that the lives of women and their experiences are situated within broader social, political and economic contexts, and it tries to unearth the multiple social relations that give structure to the lived realities of the women (Ironstone-Catterall et al, 1998). Feminist researchers emphasize that all researchers carry with them their particular worldviews, histories and biographies with them into their research projects, and these worldviews need not be seen as obstacles to achieving knowledge or truth but can offer each of us a unique way of seeing the world through which we may be able to see and / or understand phenomena in ways in which others cannot (Brooks & Hesse-Biber, 2007). It also emphasizes upon 'strong reflexivity' that requires the researcher to be cognizant and critically reflective about the different ways her positionality can serve both as a hindrance and a resource towards achieving knowledge throughout the research process (Ibid).

In the area of women's health, feminist researchers have linked the sources of health to the communities where the prerequisites of health may or may not be found. It places women at the centre of analysis and emphasizes the ways that gender and its associated social roles and rules affect the health of women. In this way, feminist analysis have been able to transform certain aspects of biomedicine, like demanding research on how gender affects etiology, the natural history and treatment of diseases and the subsequent inclusion of women in clinical trials. In spite of this, such forms of research have not been able to address health issues of women who live at the margins of society due to a variety of social characteristics, locations and identities. Women's health research faces the challenge of dealing with differences and the conceptual and practical problems the recognition of differences pose to research (Ironstone-Catterall et al, 1998). Hankivsky and colleagues (2008; 2009; 2010; 2011) have espoused the use of the intersectionality paradigm in women's health research in order to overcome this problem.

In the area of disability, feminist research has been critiqued for its inability to adequately explicate the experiences of women with disabilities. Morris (1998) has critiqued the focus of such research on women with disabilities on the 'double disadvantage' they experience, and which among the two, sexism or disablism, is 'worse', in terms of their life chances. She contends that such research is disempowering for women with disabilities and makes them feel like a passive victim of disadvantage. She further states that,

> [a]s disabled women, we have to find a way of making our experiences visible, sharing them with each other and with non-disabled people, in a way which – while drawing attention to the difficulties in our lives – yet does not undermine our wish to assert our self-worth (p: 5).

Through her research, Morris came to the realization that neither feminist perspective nor the disabled people's movement adequately represented the experiences of women with disabilities (Morris, 1998). From her own research, she gave the illustration where feminist research about circumstances where people have to depend on their families for assistance with daily living tasks divided women into 'carers and their dependents', and through this made the experiences of women who need support invisible. On the contrary, feminist researchers have argued that non-disabled women suffer economically as a result of the unpaid caring work they do within the family, and have suggested that women with disabilities and older women should be transferred to residential care (Morris, 1995; 1998). Morris (1991) argues that the failure to include the concerns of women with disabilities in research and analysis of policies can result in fundamental undermining of their human and civil rights. According to her, one of the reasons that the experience of disability has not been included into feminist theory is because of the premise of feminism, that the ‘personal is political’ (Morris, 1991). Persons with disabilities have little opportunity to share their experiences within the wider culture and society. As a result of this, the experiences of persons with disabilities are isolated and individualized, which makes it difficult for non-disabled feminists to incorporate their reality into their research theories, unless it is colored by the lens through which the non-disabled world see them (Ibid).

In her book, “*Pride against Prejudice: Transforming Attitudes to Disability*”, Morris (1991) asserted that feminist perspectives have great relevance to persons with disabilities and to the disability movement. Through her book, she tried to make the personal experience of disability political, something that has been overlooked by the disability movement and the development of theory of disability, both of which are dominated by men with disabilities, and have shown the tendency of avoiding the personal experience of disability (Morris, 1991). Morris and other feminist disability scholars like Liz Crow (1996), Susan Wendell (2001) and Carol Thomas (2004b) have been at the forefront in critiquing the sharp distinction between disability and impairment by stating that these experiences do not resonate with their experiences of their bodies. In their turn, they have been accused for ‘not dealing with the real world issues’, that is, not fighting against the barriers created by the society, and for feeding into the non-disabled world’s pity of persons with disabilities (Morris, 1998). The works of these feminist scholars have influenced several other disability scholars to move beyond the ‘rigid’ social model to embrace their experiences of their bodies (Shakespeare, 1997; Shakespeare & Watson, 2002).

In the 21st century, several feminist disability scholars have worked on the theme of gender and disability in the Indian context to illuminate the experiences of the research participants. Like in the West, the disability movements and the feminist movements have been critiqued for their apathy towards the issues and concerns of women with disabilities (Ghai, 2002; 2003). The issue, however, is complicated by poverty and the overwhelming preference for sons, where the birth of even a non-disabled girl is viewed with disdain (Ghai, 2002; 2003). Some of the studies that have tried to look at the experiences of women with disabilities include Addlakha (2008a; 2008b), Bhambani (2003), Chaturvedi (n.d.), Daruwalla et al (2013), Ghai (2002; 2003), Ghosh (2010; 2012; 2016), Limaye (2008) and Nayar (2002) among others. These studies have tried to bring to light the hitherto invisible and, hence, unheard voices of women with different disabilities. Some of these studies provide a general overview of the lives of women with disabilities like the neglect they face within the family, lack of access to healthcare and rehabilitation facilities, discrimination in education, lack of employment opportunities, asexual objectification and denial of traditional feminine roles such as marriage and motherhood (see Ghai, 2001; 2002; 2003; Bhambani, 2003). Other studies are located in the socio-cultural milieu of a particular Indian state and have adequately reflected on the assumptions regarding women with disabilities in that setting. These studies include Addlakha's study in Delhi (2007); Mehrotra's study in rural Haryana (2004) and Ghosh's study in Bengal (2010; 2013; 2016). These studies have reflected on how the intersection of gender, disability, poverty, rural-urban residence and socio-cultural assumptions shape the lives of women with disabilities in different settings.

Research Methodology: The methodology for the study is qualitative, which is defined as:

> …a means for exploring and understanding the meaning individuals or groups ascribe to social or human problems. The process of research involves emerging questions and procedures, data typically collected in the participant's setting, data analysis inductively building from particulars to general themes, and the researcher making interpretations of the meaning of the data. The final written report has a flexible structure. Those who engage in this form of inquiry support a way of looking at research that honors an inductive style, a focus on individual meaning, and the importance of rendering the complexity of a situation (Creswell, 2007, as cited in Creswell, 2009: 4).

Qualitative methods are extensively used in feminist research because of its ability to access several aspects of women's experiences that have been neglected by traditional social science research. Qualitative methods enable women to express themselves, to discuss their experiences and have their knowledge(s) legitimized, and to do so in their own terms (Ironstone-Catterall et al, 1998). This method is now increasingly used by healthcare practitioners and policy makers to enhance understanding of health, health behavior and health services (Green & Thorogood, 2013). Much of the research that has emerged from within the emancipatory research paradigm has been generally associated with qualitative rather than quantitative data collection strategies. This has been justified on the grounds that quantitative methods are inherently exploitative of research participants and they produce less authentic data, in comparison to the qualitative emphasis on inter-subjectivity and non-hierarchical relationships (Barnes, 2008). Several studies on gender and disability have used the qualitative methods for understanding the experiences of the research participants (such as Tighe, 2001; Thomas, 1997; Addlakha, 2007; 2008b; Daruwalla et al, 2013; Ghosh, 2010; 2012b; Limaye, 2008; Mehrotra, 2004 and Nayar, 2012).

Qualitative research includes different strategies or approaches (see Creswell, 2009). This study uses the strategy of narrative research, which is defined as:

> …a strategy of inquiry in which the researcher studies the lives of individuals and asks one or more individuals to provide stories about their lives. This information is then often retold or restoried by the researcher into a narrative chronology. In the end, the narrative combines views from the participants' life with those of the researcher's lives in a collaborative narrative (Clandinix & Connelly, 2000, as cited in Creswell, 2009).

Narrative research is a broad spectrum methodology which may be used in various forms like spoken, written or visual narratives and the study of people using these different forms will provide different insights into people's lives (Topp, 2004). For the purpose of this research, only spoken narratives were used. Narrative research method has been critiqued by many as it is seen to be unscientific as storytelling might infer untruth. Polkinghorne (1995) argues that *'building a collection of narratives bound by context… provides a pool of stories that may be compared and tested on specific dimensions in order to provide empirical evidence'* (as cited in Topp, 2004: 4-5).

Research Method: The research uses life history approach as the primary tool for data collection. This approach provides a framework which allows the stories of the research participants to emerge as well as to explore these stories within the social, political, historical, cultural, familial and psychological contexts within which they are embedded (Matiss, 2005). This approach involves collecting ‘life stories’ from the research participants (Kakuru & Paradza, 2007). Life story is a person’s story of his or her life, or what he or she thinks is a significant part of life (Titon, 1980). It is a story of personal experience that emerges from conversations between the storyteller and the listener. The storyteller trusts the listener and the listener respects the storyteller, not interrupting the train of thought until the story is finished (Ibid). The life stories that are elicited through the life history approach are

> …reconstructions of [a] person’s experiences, remembered and told at a particular point in their lives, to a particular researcher / audience and for a particular purpose: all of which will have a bearing on how the stories are told, which stories are told, and how they are represented or interpreted (Etherington, 2006: 234, as cited in Kakuru & Paradza, 2007: 288).

Individual stories are powerful because they lead us to new insights and allow us to understand experiences more comprehensively (Matiss, 2005). This approach involves collecting stories from the research participants over multiple settings on the assumption that this would provide more meaningful data as the relationship between the researchers and research participants develop over time (Kakuru & Paradza, 2007). The predominant characteristic of this method is that it focuses on the stories of the individual to understand his or her perspective in the broader historical and social contexts in which the individual is located (Matiss, 2005). This characteristic of the method sets it apart from other research methods (Ibid).

There are several advantages of this method which includes having the effect of ‘humanizing’ the research participant by enabling the researcher to know the research participant better and by revealing the history and culture as lived by the participants; enabling a ‘recuperative role’ for the participants in the study and for the societies in which they live; and by becoming a ‘moral act’ from which the narrator “*may benefit from the opportunity to talk about their life in their own words to the researcher, and may benefit from the empathy and the unique audience which the life story interaction provides”* (Kakuru & Paradza, 2007: 289). Life history approach also enables the researcher to arrive at the same emotional and social plane as the storyteller which helps in narrowing the power gap between them. Life stories are also helpful to the readers as it provides the insider’s view of society in a particular historical era by putting the experiences of the individual within a wider web of meanings (Ibid). The focus of this method is dual and it constantly moves between the changing biographical history of the individual and the social history of his or her lifespan (Matiss, 2005). This approach is considered to be especially helpful in generating new insights into the experiences of women and other vulnerable groups which are either ignored or silenced in other research techniques (Kakuru & Paradza, 2007).

In addition to life history approach, in-depth interviews were conducted with the family members of the women and members of the disability organizations, from which the women were recruited. Interviewing is a valuable research method to gain insight into the worlds of the research participants (Hesse-Biber, 2007). This method seeks to understand the 'lived experiences' of the individual and is used to explore a particular topic and to gain focused information on the issue from the participants. Researchers use this method in order to understand the 'subjective' understanding that individuals bring to a given situation or a set of circumstances (Ibid).

Apart from family members, health personnel (orthopedics, general medicine physician and physiotherapists) from the Guwahati Medical College and Hospital (GMCH) and a private hospital were also contacted in order to gain deeper insights about the health conditions of the research participants. One of these interviews was facilitated by one of my mother's relatives and the rest of them were approached through his contact.

Setting of the Study: An Overview of Kamrup Metropolitan District

The fieldwork for the study was conducted in the district of Kamrup Metropolitan in Assam. It is located in the northeastern part of India, which after partition in 1947, is connected with the rest of the country via a narrow stretch of land known as the Siliguri corridor. The state is divided into 33 districts with 80 sub-divisions, 219 Developmental Blocks and 2202 Gaon Panchayats (http://des.assam.gov.in/information-services/state-profile-of-assam). According to Census 2011, the total population of Assam is 312.05 lakh, out of which 159.39 lakh are males and 152.66 lakh are females. Out of the total population, 86 percent reside in rural areas while only 14 percent reside in urban areas. The sex ration of the state is 958 (Ibid).

Kamrup Metropolitan is one of the 33 districts in Assam. It was carved out in the year 2003 out of the erstwhile Kamrup district. In the predominantly rural state of Assam, this district is an exception as out of the total population of 1.2 million, an overwhelming majority of 1 million individuals reside in the urban areas of the district. The administrative headquarters of the district is located in the city of Guwahati. The geographical area under the district is 127.84 Sq. Km. According to 2011 Census, the district has a population of 12.06 lakh, out of which 6.55 lakhs are males and 6.04 are females. The sex ratio of the district is 922. The district is primarily urban with 10.37 lakh individuals living in urban areas and 2.16 living in rural areas (2011 Census). It is divided into 6 revenue circles, namely, Dispur, Guwahati, Sonapur, Azara, Chandrapur and North Guwahati. Additionally, the rural areas of the district have been divided into four Development Blocks with 22 Gaon Panchayats (GPs). These Blocks include Bezera Development Block (1 GP), Chandrapur Development Block (4 GPs), Dimoria Development Block (12 GPs) and Rani Development Blocks (5 GPs) (Official Website: Kamrup Metropolitan District Administration).

According to 2011 Census, the total number of persons with disabilities in Assam are 4.80 lakhs. The following table gives an overview of the number of persons with disabilities as per 2011 Census.

Table 2.1: Total number of persons with disabilities in Assam according to 2011 Census.

Sl. No.	Type of Disability	Number of Persons with Disabilities
1.	Seeing	80553
2.	Hearing	101577
3.	Speech	39750
4.	Movement	76007
5.	Mental Retardation	26374
6.	Mental Illness	18819
7.	Any Other	87461
8.	Multiple Disability	49524
	Total for Assam	480065

Source: Census – 2011, Government of India

In spite of a huge number of persons with disabilities in the state, research on disability is particularly limited (Deepak, 2016). The present study is aimed at filling this gap. As shown in Chapter 1, available statistics indicate that out of the total population of persons with disabilities in India, a vast majority reside in the rural areas under extremely poor conditions with little access to services (Klasing, 2007). It was felt that the rural-urban differentials of the Kamrup Metropolitan district would give a unique picture of the experience of disablement of women with disabilities. In addition to this, the presence of several established disability organizations made it easier to recruit the participants for the study.

Process of Data Collection and the Selection of Research Participants

In a context such as India, persons with disabilities and their family members live a highly stigmatized life. Due to this reason, researchers often find difficulty in finding such persons at the community level (Singal, 2010). Even though things have somewhat changed now after the implementation of the landmark Persons with Disabilities Act, 1995 which entitles persons with disabilities to certain benefits[22] (Ibid), for this study it was considered best to make an entry into the field with the help of organizations that are working in the field of disability in the district of Kamrup Metropolitan in order to recruit the participants for the study. This strategy has been used earlier by other researchers such as Ghosh (2012) and Nayar (2012).

For this study, the participants were recruited from four different disability organizations. The initial entry to the field, however, was more difficult than I had expected. For my M. Phil study in Delhi-NCR, the women with disabilities were recruited through disability organizations, which were contacted through emails that were mentioned in the websites http://www.udaan.org/parivaar/orgdelhi.html and http://punarbhava.in/index.php/resources-/institutions/ngosspecial-schools/new-delhi.html. In the case of Assam, when I went there to check the feasibility of my study in the spring-summer of 2015, it was realized that the list of organizations in the internet were very limited, and for those organizations which had a website, their

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[22] Even though the benefits that persons with disabilities are entitled to are far from adequate, in the recent years the law has brought about a definitive awareness about the benefits of having a certified disability (Singal, 2010).

email addresses for contact were not updated. This posed a problem in finding the disability organizations. Fortunately, one of the prominent and oldest disability organizations in the district, Sanjeeboni[23], was founded by a woman (Suchismita, a polio survivor) who happened to be a friend's aunt. In 2015, just before I went to the field, I came in contact with Dr. Nandini Ghosh, who was working with disability organizations in Assam for a project. She also gave me the contacts of a few organizations, one of which was Sanjeeboni. Through these contacts, Suchismita was approached for an interview, and she was more than happy to help me in my research (being a friend of her niece helped immensely). She was the first woman with disability I had interviewed for this study. This interview primarily focused on her organization, which was founded in 1997 in Joonaki Block[24]. The organization provides Community Based Rehabilitation (CBR) to persons with disabilities. In 2015, the organization started working in the Kushal Block[25] in the district of Kamrup Rural. Later when I approached her for another interview to talk exclusively about her life experiences as a polio survivor, she asked me to read a book written by a friend of hers about 12 extraordinary women of the Northeast, in which one of the chapters was written about her[26].

One of the other organizations, which also worked at the community level and provided CBR did not show much interest in the study, and eventually after one pre-pilot interview with a 18 year old polio survivor, the hope of contacting any more participants from this organization had to be abandoned. The feasibility of the study was ascertained through interviews with 12 women with different locomotor disabilities facilitated by Sanjeeboni. One of the CBR workers from the organization also took me to interview a young woman who lived within the jurisdiction of the other organization (mentioned above) to show the poor work of the CBR workers of that organization.

After finalizing my research topic and the inclusion criteria for the study, I approached Sanjeeboni again in the spring-summer of 2016 to recruit the participants for the study. During this period, the CBR workers and Disabled People's

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[23] The names of all the disability organizations and research participants are pseudonyms.

[24] For protecting the identity of the disability organization and the research participants, the actual name of the Block has been substituted by the pseudonym, Joonaki Block.

[25] Kushal Block is another pseudonym used for hiding the identity of the organization and the research participants.

[26] Due to this reason, her name has not been changed in the thesis.

Organization (DPO) members were busy in doing the fieldwork for a project. As a result of this, they were not able to accompany me to the houses of the women in the villages. Due to this reason, only the women who worked at the organization and were present at that time or who had visited the organization for some training were interviewed for the study. Most of these women had milder forms of disabilities. One day when I requested to interview women with comparatively severe disabilities (like those using some mobility aids, like crutches, calipers or wheelchairs), I was taken to interview a young 18 years old woman who lived very close to the organization by a CBR worker. In total, seven women were interviewed from this organization. The impairments of these women include cerebral palsy (3), congenital disability (2), medical negligence leading to lower limb inequality (1) and disability after a bout of fever (1). The ages of these women varied from 18-45 years. It is important to note here that not all of the women were aware about the causes of their disabilities and in certain cases did not agree about the cause of their disability as reported by the organization. During the same period, I also visited the other Block where the organization functioned and interviewed a woman (31) who worked as a CBR worked from the organization. The cause of her disability was dwarfism or short stature, which according to her was caused after an episode of ‘typhoid’ fever. Even though she did not belong to the district of Kamrup Metropolitan, I decided to include her for the study as her interview provided valuable insights about her experience of impairment. Additionally, her transition from a meek person to an articulate person within a short period of time after joining the organization seemed very interesting. During this period, I also insisted Suchismita for another interview with her focusing on her lived experiences. When she did not show much interest, I interviewed her mother who often visited the organization with Suchismita. Suchismita (57) was impaired at the age of one and half years and her disability is a result of post-polio residual paralysis.

Alongside these interviews, I tried to look out for other organizations that worked in Guwahati to understand the rural-urban differentials. I got in touch with Dr. Sunil Deepak, who was deputed to look at the functioning of Mobility India Northeast (MINE) which had started working in Guwahati from 2015. At that time, MINE did not have direct contact with persons with disabilities, but had a list of the organizations that were working for persons with disabilities in the entire

Northeastern Region. Dr. Deepak asked one of the Programme Coordinators of MINE to show me the list, and once I had selected the organizations, Dr. Deepak asked him to write a forwarding letter to the organizations introducing me and my research and asking for their cooperation. Out of a list of 66 organizations, I had selected eight based on the area in which the organization is located and the type of disability it dealt with. Some of these organizations wrote back to me stating that they do not work in the area of locomotor disabilities or do not have contact with women. Other organizations redirected me to the organization Senehi which I had initially overlooked as they mostly worked on rehabilitation of children with cerebral palsy and multiple disabilities (up to 18 years of age). Another organization asked me to visit their office, but upon visiting I came to know that it only provided prosthesis to amputees, most of whom were men, who had acquired their impairments later in life. In most cases they also do not follow up on the beneficiaries. Due to this reason I decided not to spend any time to find my study participants through this organization. In the meantime, the Secretary of Helen Keller Charitable Trust (HKCT) had sent me an email showing their eagerness to participate in the study. This organization also did not have direct contact with persons with disabilities and only provided financial assistance to them. Since I did not have much choice, I decided to approach Senehi and HKCT.

Senehi was one of the first organizations to work on children with cerebral palsy in Assam. It started functioning in the year 1987 in Guwahati. The organization works in the area of early intervention and rehabilitation, education, livelihoods, advocacy and awareness, and protection of rights and legal aid for children and persons with disabilities in the entire North East. The organization provides education to children with cerebral palsy and other disabilities such as autism, Down’s syndrome and ‘mental retardation’. In 2015, the organization had initiated a network for women with disabilities to provide a platform to empower them on the issues of economic, social, cultural, legal and political rights in both public and private spaces. Six women were interviewed from this network, four of whom had been students of the organization, one was a student at the time of the interview (but she lived at the backside of Suchismita’s residence, and the interview with this young woman was facilitated by her). One of the young women was referred to the network from the Vocational Rehabilitation Centre. The impairments of these women include: cerebral palsy (4), post-polio residual paralysis (1), and congenital disability (1). The ages of these women varied from 18-35 years of age. All but one interview was conducted in the organization.

HKCT is a charity organization that provides financial assistance to persons with physical and or / mental disabilities, and helps financially weak critically ill persons to avail costly treatment. The organization was founded in the year 2011 to cater to the needs of the defined population all over Assam. It has a trust that comprises of ‘distinguished’ persons who have retired from (mostly government) service, and wish to contribute something positive to the society. The organization does not have an office space. Suchismita introduced me to the President of this organization, and he asked me to visit his home for an interaction. During the interaction it became clear that the organization does not have direct contact with the beneficiaries, but he asked me to contact the General Secretary of the organization, who has all the application forms of the beneficiaries. After contacting him at his residence, the General Secretary gave me the freedom to find out what I want from the heap of files from 2011 when the organization started functioning to April 2016. The application forms of persons with different disabilities and of critically ill persons were not separated, due to which finding out the potential study participants was very difficult. I was able to find out the contact numbers and addresses of six women with different locomotor disabilities from Guwahati. Out of these, only four women could be interviewed. One of these women refused to be interviewed when I gave her a call, but was later interviewed when I met her at Moromi, where she worked. The phone number of another woman was not working. Out of the four women who were interviewed, their impairments include amputation due to puncture wound and medical negligence (1), head injury in childhood and burn injury in adolescence (1) (although she and her family emphasized more about her burns than her head injury), post-polio residual paralysis (1) (according to the file but the woman and her mother mentioned that it is a result of ‘typhoid’ and medical negligence), and short stature (1). The ages of these women varied from 25-51 years. Three of these interviews were conducted in the homes of the women where their family members contributed generously to the narrative, while the fourth one was conducted in the shop owned by the woman in the presence of her husband. He remained quiet throughout the interview and catered to the customers in the shop.

From two of the beneficiaries of HKCT, I was informed about Moromi, which works in Guwahati, and provides economic rehabilitation to persons with different disabilities. Although all the organizations that were contacted before knew about this organization, no one mentioned it in the interviews. This organization was also not mentioned in the list that was provided to me by MINE. One of the reasons for this could be that the founder of the organization had allegedly committed suicide in 2013, and since that time, it has not been able to overcome his loss. Three women were interviewed from this organization. Compared to all other interviews, the interviews in this organization had to be cut short because the supervisor interfered several times, citing that the women had to get back to work. The impairments of the women include short stature (1), amputation of right hand following an accident (1), delay in treatment seeking following a fracture of hand (1) and burns (1). The ages of these women varied from 30-35 years. All the four interviews were conducted in the organization in the presence of their coworkers.

Before entering the field, the inclusion criteria for the research participants were set in terms of the current age of women with locomotor disabilities (between 35-65 years) who had acquired their disabilities below 15 years of age. As has been illustrated above, I as a researcher did not have a say on whom I could interview for the study. In most of the cases I had to rely on the organizations for choosing the research participants for me. As a result I had to interview all the women that the organization chose for me. It was only after the interviews that I chose whom to include for the study, and it was based on the women's ability to talk and willingness to share their experiences extensively. I relaxed the age criteria for the study to include anyone above the age of 18, as I did not find many women in the age bracket I had chosen in the beginning of the study. The age criterion was also complicated by the fact that many of the women were either not aware about their actual ages or were not ready to reveal their actual ages. I had faced a similar problem in my previous study in Delhi-NCR (Sarma, 2014). In total 22 interviews have been conducted with women with different locomotor disabilities. Out of these, 18 women were included in the final study, who were interviewed multiple times. The women have different levels of education: one was still in school at the time of the interview (Class 9); two were pursuing graduation (through distance education); two were considered unable to study from their school (Senehi) due to the nature of their impairments (cerebral palsy) but engaged in other activities in the school till the age of 18; five had left their studies incomplete due to many reasons (below class 10); four failed in their matriculation and thereafter left studies; and two had passed high school and did not study further; one passed her Higher Secondary Examination and was not able to study further; and one was a graduate. Among these women, one is the founder of Sanjeeboni, three are working as Community Based Rehabilitation Workers with Sanjeeboni, two are working as weavers at Sanjeeboni, two are working with Moromi, two are self-employed (have opened their own shops), one is working as a coordinator for a network on women with disabilities with Senehi. Out of these 18 women, five were married at the time of the interview, and one was widowed. Majority of them belong to very poor socio-economic background, and in the case of a few women, their families depended on their income for sustenance. In terms of ethnicities of these women, 13 were caste Hindu Assamese, 2 were Bengali Hindus, 1 was Bengali Muslim, 1 was Nepali and 1 was Karbi. During the course of the study it was found that ethnicity did not play a significant role in their lives. Two of the study participants were in fact married to men who belonged to different ethnicities. Although their marriages had problems, ethnicity was not one of the reasons for this problem.

Table 2.2: Summary Information of the Research Participants in an alphabetical order

Sl. No.	**Name**	**Age**	**Impairment**	**Age of Onset**	**Place of Residence**	**Education**	**Employment**	**Marital Status**
1	Anamika[27]	38	Limb inequality due to a surgical intervention	22 days after birth	Rural	Failed in 10th board exams	Works at a disability organization.	Unmarried
2	Ananya	22	Cerebral palsy	A few months old (does not know the exact age)	Urban	Could not study because of the nature of her disability but was admitted in a special school till the age of 18	Unemployed	Unmarried

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[27] All the names of the research participants are pseudonyms in order to protect their identities.

3	Bandana	30+	Short Stature	Congenital disability	Urban	10th pass	Rents a shop with her husband	Married
4	Chitra	30+	Cerebral Palsy	Childhood (does not know the exact age)	Rural	Third grade	Homemaker (since the birth of her son)	Married (with an 11 month old child)
5	Dolly	34	Amputation of right hand after an accident at her workplace	14 years	Urban	Fifth grade	Works at a disability organization	Unmarried
6	Gargi	18	Cerebral Palsy (uses a wheelchair)	Congenital disability	Rural	Studied in the 9th grade at the time of the interview	NA	Unmarried
7	Hema	34	Puncture wound that lead to amputation of her right leg (uses crutches for mobility)	16 years at the time of the ailment- 22 years at the time of the amputation	Urban	Could not write her 10th boards exams because of her ailment	With the help of her mother runs a small shop from her home	Unmarried
8	Jeuti	25	'Typhoid' fever (poliomyelitis)	Less than a year old	Urban	Discontinued education after 8th grade due to familial circumstances	Works at a disability organization	Married to a non-disabled man
9	Korobi	51	Head injury and later severe burns (uses walker for mobility)	4 years old (head injury) and 18 years old (burns)	Urban	Pursuing her BA in History through distance education from IGNOU	Unemployed	Married to a non-disabled man (with a 17 years old son)
10	Lata[28]	32	Short Stature	Congenital disability	Rural	12th pass	Works at a disability organization	Unmarried

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[28] Lata works as a CBR worker at Sanjeeboni, Kushal Block, Kamrup Rural. She was interviewed twice between 2015 and 2016. Her life story is very interesting and shows a clear transition in her persona after she began to work for the organization. Due to this reason I am adding her in this study even though she is =-not from the district of Kamrup (Metropolitan).

11	Minakkhi	42	Syndactyly	Congenital disability	Rural	Failed in 10th board exams	Weaver at a disability organization	Unmarried
12	Nayana	30+	Poliomyelitis	3 years	Urban	Failed in 10th board exams	Coordinator of a network of women with disabilities	Unmarried
13	Pronoti	26	Mysterious fever	11 years	Urban at the time of onset of disability, but moved to rural after the death of her father	Discontinued education after 9th grade due to familial circumstances	Weaver at a disability organization	Unmarried
14	Risha	35	Cerebral Palsy	Congenital disability	Urban	10th pass	Quit her job after an accident that aggravated her physical difficulties	Unmarried
15	Sobiha	18	Cerebral Palsy	Congenital disability	Urban	Could not study due to the nature of her impairment, but was studying at a special school	NA	Unmarried
16	Suchismita	57	Poliomyelitis	Around one and half years old	Urban	Graduate	Founder of a Sanjeeboni	Widowed (with a son and a daughter)
17	Surabhi	30+	Mysterious fever/ fall in infancy	6 years	Rural	Pursuing her BA through distance education from KKHSOU	Works at a disability organization	Unmarried
18	Uma	34	Weakness in the left lower limb	Congenital disability	Rural	10th fail	Homemaker	Married (with a seven years old son)

Apart from these women, one member each from all the four organizations was interviewed in order to understand the basic ideology of the organizations and the kind of support they provide. to persons with disabilities. Except in the case of Moromi, all the other organization members talked extensively. In the case of Moromi, the supervisor was approached for an interview, but he refused to have a face-to-face interview citing his busy schedule. A short telephone interview was conducted with him, but he did not answer several of the questions. Since the founder of the organization is no more, some of the answers to my questions are perhaps gone with him. A sense of gloom hovered in the organization space, as all of the participants and other workers missed their 'Sir' terribly, who was like a fatherly figure to them. At the insistence of the founder's sister, his aged mother was interviewed, and the same sense of gloom screamed out of every part of the room where she lived. As can be expected, she did not know much about the organization's functioning, but talked about her son's large-heartedness which compelled him to quit his well-paying job at the tea gardens, and to establish an organization for, in her words, *"the upliftment of the downtrodden and the most neglected in the society"*.

Interviews with family members of the women have been conducted in a few cases with the permission of the research participants. In most of the cases, the women's mothers have been interviewed, as the fathers of most of the women had passed away. In a few cases, the sisters of the women were interviewed. Several women, however, seemed reluctant to take me to their homes. One of the reasons I could identify was that they were very poor and did not want me to come to their homes because of this reason. In certain cases I felt that the women and their families took so much strain when I visited their homes (by making tea and other kinds of snacks, sometimes they also provided me with lunch) that I felt very guilty about visiting them, and thought it best not to probe further if some of them were not comfortable to take me to their homes. For the purpose of interviewing the family members, I did not find it necessary to ask the disability organizations for permission (even though this suggestion was made at Senehi), as I considered these women capable enough to give consent on their own, and not be forced by anyone in authority.

In the initial stages I had also planned to interview health personnel from the Guwahati Medical College and Hospital (hereafter GMCH) in order to understand their perspectives about persons with disabilities. Owing to the busy schedules of the doctors from this hospital, I also interviewed 1 doctor and 1 physiotherapist from a nearby, and now very famous, private hospital. In total, 3 orthopedics and 2 physiotherapists were interviewed for the study. Due to some confusion about the nature of fevers that led to locomotor disabilities, the Head of the Department, Medicine, GMCH, was contacted for the clarification of my doubts. Most of these interviews were very short and lasted between 15 to 30 minutes, and were conducted in the hospital premises generally over two or three sessions because of their busy schedules. Only one of these interviews (of a post graduate orthopedic student) was recorded. In one of the interviews, the doctor was not comfortable in a verbal interview, but preferred to write down his responses in the interview guide itself. After completing the list of questions, he read out his responses, and clarified my doubts during this period. In another interview, the physiotherapist insisted that I write down his responses in a piece of paper that he brought out. In the other three interviews / interactions I did not ask them if I could use my recorder and preferred to take notes instead, as I realized that this was non-threatening for them.

Constraints faced in the Field

Terminology used in data collection: In feminist and disability literature, it is imperative to use politically correct language (Ghai, 2003). The tussle with terminologies is a common theme in much of the disability studies literature. This is because the diagnostic categories that are used in disability discourse imply ‘implicit hierarchies’ which have the potential of reducing persons both in status and to labels themselves (Ghai, 2003). Over the ages, persons with disabilities have been referred to by several derogatory terms such as ‘crippled’, ‘handicapped’, ‘confined to the wheelchair’, ‘invalid’, ‘lame’, ‘deaf’, ‘blind’, ‘idiot’ and ‘mentally retarded’. In order to defy such terms, an alternative vocabulary has been envisaged which is a source of endless debate (Morris, 2001; Barnes & Mercer, 2003; Ghai 2003). The term *‘disabled person’* is used more commonly in the UK and it assumes an identity category by stating that it is the society that disables a person. This term is used when disability is referred to as a form of social oppression meted out on people with impairments and manifested in discriminatory practices (Ghai, 2003). Such a view is substantiated by the UPIAS understanding of the term ‘disability’. On the other hand, the term *'persons with disabilities'* has its origin in the USA which is used to convey that a person with a disability is a person first and the disability is incidental to it. This is a way of fighting against the stigma of disability and re-emphasizing on the humanity, wholeness and normalcy of that person (Ghai, 2003). Another term that is often used to refer to persons with disabilities is *'differently abled'*. This term is used to suggest that to be disabled in one aspect is not akin to being disabled in all aspects of life. It can also be used to suggest that a person with disabilities may have abilities by virtue of their disabilities which the able-bodied lack (Wendell, 1989). But Wendell (1989) contends that to call someone 'differently abled' is analogous to calling someone 'differently colored' or 'differently gendered', because it reinforces the fact that this person is not the paradigm of humanity and enforce their 'otherness' more starkly. To use such a term is also to disregard the special difficulties and struggles that certain persons with disabilities face due to both the architectural barriers as well as their physical and cognitive limitations (Ibid).

In India, in the official discourse the term 'person with disabilities' has been used more commonly, which is often abbreviated to PWDs. For instance, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 is often abbreviated to the PWD Act. An entire population of persons with disabilities, therefore, is reduced to a mere abbreviation, with an 's' added at the end to denote their plurality (Deepa, 2007). Few persons with disabilities have rejected such connotations, and instead prefer to be called by their impairments (like blind or Deaf) (Ibid).

More generally persons with disabilities are referred to by different derogatory terms in the regional languages. For instance, in Haryana, persons with different disabilities are called by different names such as *surdas* for the visually disabled, *langdi / langda* for the physically disabled and *bawali* / *bawala* for the mentally challenged, all of which have negative connotations (Mehrotra, 2004). In order to counter this, recently Prime Minister Narendra Modi forwarded the Hindi word *Divyang* to refer to persons with disabilities as having divine body parts or being imbued with divinity as compensation for their physical impairments. In the words of Ghosh (2017),

> [this word] intends to change social attitudes towards disabled people but ends up reinforcing the negative attitudes that construct disabled people as evil and monstrous in the religio-cultural ideologies. The word is a repository of disgust towards disabled

> people with its religious connotations of sin and punishment, thereby reinforcing the charity / sympathy prism and is suggestive of a fatalistic acceptance of the gift from god.

This word also denies the political struggles that persons with disabilities have engaged in for their socio-economic and political rights, non-discrimination, respect and dignity. Further, using such words absolves the state and the wider society from any responsibility of removing the barriers that are restricting persons with disabilities from participating fully in the activities of the society (Ghosh, 2017). Disability activists see this term as analogous to the term *harijan* used by Gandhi to describe people of the so-called lowest castes. Both the words, according to Ghosh (2017), are imposed by an apparently benevolent outsider, but are seen as patronizing to those whom these words describe.

It is with the awareness of the above mentioned debates that the term ‘persons with disabilities’ is used for the written material in this study. Most Indians with disabilities are still struggling for the bare minimum like food, education, employment, fighting stigma and disdain, unlike other contexts where such persons have recognized the environment as disabling. According to Singal (2010), the person first language is extremely important in the context of persons with disabilities in the majority world because of the way disability is stigmatized in these societies. In the same vein, the terms ‘women with disabilities’ and ‘men with disabilities’ are used instead of disabled women or disabled men.

While the choice of terminology did not cause much dilemma in writing, it was absolutely perplexing to choose the appropriate word(s) to refer to disability or persons with disabilities in Assamese during the interviews. The most commonly used word for women with locomotor disabilities in Assamese is *lengeri* (*lengera* for men). Most of the women who were interviewed were referred to as *lengeri* by the wider community, but this was considered to be derogatory by most of them. The more refined words were *okhyom*[29] (disabled), *xariririk bhabe okhyom* (physically disabled), *bixex bhabe xokhyom* (specially abled) and *bikolango* (physically disabled). I found these words also carried negative connotations among the participants and refrained from using them. Similar problems are also noted in other studies conducted

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[29] Most of these words refer to physical disability and not to other types of disabilities (like learning difficulties, visual impairments, hearing and speech impairments). Due to this, it can pose problems for researchers specifically researching on disabilities other than physical disabilities.

in Hindi in other regions of the country (Singal, 2010). This has also been observed in other studies conducted in other cultures of the majority world. In a study conducted in Kenya, the word *'wasiojiweza'* in Kiswahili is used to refer to persons with different types of disabilities. The word, however, means that an individual is incapable of gainful employment (Ndurumo, 2003, as cited in Singal, 2010).

Due to this reason, I started thinking about other words which would not be derogative but would also describe their condition adequately. During her fieldwork in Kolkata, West Bengal, among the mothers of children with mild to severe 'mental retardation', Rao (2001) had found that the mothers often used the Bengali word '*asubidhe'* (inconvenience) to refer to their situations where one did not have the required amenities to easily negotiate a particular situation (like lack of appropriate public transport). Influenced by her, I also tried to use the Assamese word *oxubidha* (inconvenience) to refer to their physical difficulties during my interviews, but soon realized that most could not associate it with themselves, that is, their disabilities were milder [in comparison to the study participants in Rao's (2011) study] and as such did not experience much inconvenience. After a few interviews, it was found that the English words 'disability' and 'disabled *luk xokol*' (persons with disabilities) were more objective for the participants as it was devoid of any derogatory connotations for them. While some of them understood the meaning of the term 'disability', most did not. Instead, they used another English word 'handicap' to refer to themselves and their disabilities. This term was used by the ICIDH to refer to *'a disadvantage for a given individual resulting from an impairment or a disability or prevents the fulfillment of a role (depending on age, sex, social and cultural factors) for that individual'* (WHO, 1996). Over time, this word has been replaced by the word 'disability' as it was found to be emphasizing on the medical and limiting aspects of a person, and is devoid of any connection with the physical and social environment in which the individual is embedded (Devlieger, 2009). Hence, even though the word 'handicap' is considered to be politically incorrect and is seldom used nowadays, I had to use it during some of my interviews with the women. This made me realize that more than political correctness, or using a word explaining the context where persons with disabilities live (Addlakha, 2008), it was more important to use a word which is understood by the women, and which does not hurt their sentiments. In the interviews with the family members of the women, especially their mothers, they usually used the term '*bikolango*' to refer to their daughters' conditions, or in certain cases, they talked without using any specific term for the condition. In the case of the organizations and the health personnel, the term 'handicap' was more commonly used.

Positioning the Researcher: Who should be engaged in studying disability issues, is an unrelenting question in disability research. Some like Morris (2001) have critiqued non-disabled researchers studying disability issues by stating that such research does not illuminate the lives of persons actually living with disabilities. According to her, as long as non-disabled people have the power to represent the realities of persons with disabilities, impairment will always be defined as something that, at best, needs to be cured, and at worst, makes life not worth living (Ibid). Others have also argued that traditional disability research conducted by non-disabled researchers has maintained, if not perpetuated, the alienation, objectification and exclusion of persons with disabilities (Barton, 2005, as cited in Petersen, 2011). According to Oliver (1992),

> disability research should not be seen as technical, objective procedures carried out by experts, but part of the struggle by disabled people to challenge the oppression they currently experience in their daily lives (p: 102).

There are, however, others like Barnes (2003), who has insisted that having a disability does not necessarily give someone an affinity with other persons with disabilities or an inclination to do disability research. According to him, doing emancipatory research is not about biology, but about the commitment that researchers will put their knowledge and skills at the disposal of persons with disabilities and their organizations (Ibid). Stone & Priestley (1996) have also written that during the initial phases of their respective doctoral research, they were very concerned whether they should conduct disability research at all. Over time, they have been able to overcome such fears because of the encouragement they have received from disabled people and their organizations and also because they have realized that disabled status alone does not guarantee emancipatory research. As Ghai (2008) argues that to ask a person who embodies difference to share his or her experiences may serve to reinforce the otherness that the person characterizes, rather than challenge it. According to Stone and Priestley (1996), non-disabled researchers who are interested in understanding disablement must make themselves more accountable to persons with disabilities by opening up the rationale of their research and thereby, their vulnerability to the widest possible scrutiny. This is important because "*the inherent power relationship between researcher and researched is accentuated by the unequal power relationship which exists between disabled people and non-disabled people in the wider world* (Stone & Priestley: 700).

Such kind of skepticism over who should conduct disability research usually emanates from the context of the minority world (Mehrotra, 2012). According to Mehrotra (2012), due to the smallness of community of scholars in the Indian context, which includes both disabled and non-disabled people, the efforts of non-disabled people to study the experiences of persons with disabilities is usually seen as a matter of solidarity.

Most of us, by virtue of being humans, are aware that we are all temporarily able bodied and disability touches all our lives, whether temporarily or permanently, directly or indirectly, through family members, friends and relatives (Wendell, 2001; Ghai, 2003). In my case, I have seen and heard about several persons with locomotor disabilities in my family, and this has increased my interest in understanding the lived experiences of such people. My mother would often tell stories about her life as a caregiver for both her disabled parents in her youth and for my father during the last three years of his life. These stories enabled me to understand the unique physical and emotional difficulties that persons with disabilities and their caregivers undergo from an insider's perspective, and this helped me quite a lot in understanding the experiences of my research participants. However, all of the persons that I have known were either hemiplegic or paraplegic, as a result of which, my knowledge was limited to the difficulties that such persons face. I was completely ignorant about the difficulties that persons with other kinds of locomotor disabilities might face. My research participants opened the window for me to understand the experiences of persons with other type of disabilities, and thereby the diversity of disabilities within locomotor disabilities. I feel that even though my personal background in several ways facilitated my research, I was still an outsider when it came to understanding the experiences of my research participants.

But being non-disabled was not the only aspect that made me an outsider for my research participants, and the power dynamics that played out in our relationships. My life and my experiences were far removed from the experiences of my research participants. As someone who was born into an upper caste[30] middle class family in Guwahati, that gave enormous emphasis on the education of their daughters, I had almost nothing in common to share with my research participants. I had moved out of home to pursue my higher studies about a decade ago and had not stayed at home for more than one or two months at a stretch during this period. On the other hand, some of my participants are so dependent on their families that they have never gone out of their homes alone. Their mobility was not only limited by the physical difficulties of having an impairment, but also from financial dependence on their families. It is perhaps because of the differences between us that usually my participants did not ask many questions about me. Another reason for this could be that they were asked by the organizations to participate in the study, and due to a sense of obligation they have towards the organization, they were not able to refuse.

The Drawbacks of Working with Gatekeepers: As cited above, research on persons with disabilities often necessitates the help from gatekeepers such as disability organizations in order to locate the research participants. Nind's (2008) review paper on the methodological challenges of conducting qualitative research with people with learning, communication and other disabilities shows that one of the prime ways that researchers have gained access to research participants in order to collect their data was through gatekeepers or facilitators. This approach necessitates providing the gatekeepers with information about the study and asking them to either suggest or contact potential volunteers to participate (Ibid). Since many of the disability organizations have been working with the people for a number of years, it increases the credibility of the researcher and makes it easier to approach and build rapport with the potential research participants. Her paper has also shown that gatekeepers can both facilitate and hinder access to potential research participants (Nind, 2008).

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[30] The focus on caste is very limited in this research. This is because none of the research participants talked about it as something that hindered or facilitated their lives in any way. However, during the interviews, the family members of the women would often ask me about my surname to identify which caste group I came from. After hearing my surname, they gave a meaningful nod, which seemed to me that they were satisfied. I do not know if their reactions would have been different if I had a different surname. None of my research participants were Brahmins. In fact, I do not know about the castes of many of my research participants. When I asked them about their *jati*, they usually responded in terms of their ethnicities that they are Assamese, Karbi, Bengali Muslims, Bengali (Hindus) or Nepali.

For my research also I had to rely upon the organizations to select my participants. In spite of the advantages, there are also a number of disadvantages associated with involving organizations. For example, these organizations have only a fraction of the population of persons with disabilities within their jurisdiction which limit the possibility of engaging with other participants who are probably relatively less 'privileged' than the ones associated with the organizations. Secondly, very often the research participants are not able to refuse the interview, even when they are not interested in sharing their experiences, and this can perpetuate the power dynamics that already exists in the relationship between the researcher and the researched. During the interviews, I tried my best to minimize the power dynamics as much as possible by letting them shape the interview session in their own way. Additionally, when I realized the power that the organizations exerted on the women, I decided not to seek their intervention for interviewing their family members, as many of them seemed to be reluctant about these interviews. I decided to take the consent for these from the women directly.

Another problem that was faced was that when the organizations were approached, one of the first questions that they asked me was the number of women that I wanted to interview. This often reduced my flexibility as it was quite difficult to give a clear number at the outset as not all women were equally vocal about their experiences. Since the method being used for the research gave primacy to the women's ability and willingness to talk, it was very difficult to give a number at the outset. What mattered was the quality of the interviews not the number of interviews, but it was difficult to get this point conveyed to the organizations. After three or four interviews, they often asked *"How many more do you want to interview? You have already interviewed the given number."*

Another observation was that when the organizations are approached, they give primacy to interviewing those who are present at the scene at the moment (like the CBR Workers). This reduced the possibility of reaching out to women with disabilities who are not directly involved with the organization, but avail services from the organization, and whose experiences are likely to differ from the CBR Workers'.

Some of the organizations also seemed to be very enthusiastic about the number of persons with disabilities that they have contact with, and often got baffled when I explained the inclusion criteria of my study: of interviewing only women, with locomotor disabilities, acquired below 18 years of age, and are now preferably above the age of 25. According to one of the organization members, this made my search very narrow and he advised me to expand it to include all types of disabilities and to include both men and women. Some organizations also did not remember the age criteria, and selected women for me who were as young as 18 years old, and perhaps had not given much thought about their embodiment. Due to this reason, the interviews with the younger women were comparatively shorter. In two cases, in fact, it was the mothers who did most of the talking.

To sum up, the support from the organizations was invaluable as without their support it would have been almost impossible to locate the participants. Some of the organizations, in fact, had gone out of the way to help me with my interviews. But the basic idea that I am trying to convey is that some of these organizations are not aware about the heterogeneity of the disability experience and often considered anyone to be good enough to be interviewed.

Going through the organizations posed other problems as well. I was often mistaken to be a representative of the organization, and was asked about providing financial assistance for the upkeep of the women. This was primarily because most of the women belonged to extremely poor socioeconomic background and the family members wanted some relief. Many of them were not aware about disability pension (which is a meager Rs. 3000 per year) and unemployment allowance (Rs. 6000 per year). I gathered information about how to apply for these schemes and gave them the relevant information. I also gave them information about applying for financial aid from HKCT. If they expected more from me, they did not let me know. Disability scholars in the minority world have critiqued researchers to be the only beneficiaries from the research projects on persons with disabilities, and for not doing enough to facilitate the empowerment of the subjects of their research (Oliver, 1997). Such questions are raised less frequently in the countries of the majority world, although they are equally pertinent.

The type of the organization also played a big role in molding the personalities of the women. For example it was found that the women who worked as CBR workers or were a part of the women with disabilities network were more forthcoming with their experiences, than the women who were not directly involved with the organizations (especially those from HKCT). Contact with the organization enabled these women to meet other persons with disabilities and made them feel that they are not alone in their experiences of isolation and stigmatization. In comparison to them, the other women were found to consider themselves as victims of personal tragedy.

The Shadow of the Medical Model: Challenges faced by a Researcher from Non-Medical Background: Not being from medical background posed a huge challenge as I could not be prepared enough for the disabilities I encountered in the field. As mentioned in Chapter 1, locomotor disability can be due to a number of causes. In the study area, it was found that a lot of variation existed in the causation of disabilities. Sometimes the participants themselves were very vague about the cause of their disabilities, especially when it was followed by a bout of fever. What made matters more complicated was the difference of opinion between the participants of the study and the organizations regarding the causation of disability. For example, in the case of an 18 year old woman with paraplegia, when asked about the cause of her disability, she said that it was caused by polio, her mother said that it was congenital, while the organization said that it is due to cerebral palsy. Another challenge faced was that the term ‘typhoid’ was used to refer to all kinds of fevers, and many disabilities were referred to as a result of typhoid infection, even when their medical records mentioned post-polio residual paralysis. All this created a lot of confusion for me, a researcher who has no medical background.

Some of the interviews were conducted in the presence of their family members. These people often asked about the causes of certain secondary conditions among the participants. In one interview, a woman who had suffered from a head injury in her childhood and was later burnt while attempting to light *dhuna* developed excessive phobia about staying alone in the room, even for a short duration. This has resulted in a lot of problems for the family members who cannot go about their work because of this problem, and one or the other person always had to stay by her side. Her husband, who is her primary caregiver and a freelance writer, finds it especially difficult to concentrate on his work because of her phobia. On my visit, one of the first questions that he asked me was, *"She has excessive fear. Why is it so?"* At that point I had not begun my interview and I had no idea how to respond. Later, when her mother who lives upstairs joined us during the interview, she asked me why she has this problem. I told her that I am not a psychiatrist or a psychologist and I can only presume that she had developed her phobia after the burn injury. Her mother asked me if phobia is more severe than mania (a term which is colloquially used to refer to obsession). This again was problematic to answer.

This kind of interactions have led me to understand that even though the medical model has been challenged enormously by the proponents of the social model of disability in the minority world, the medical explanations about disability still plays an important role in the lives of persons with disabilities and their family members, and thereby must not be negated.

Setting of the Interview: Out of the 18 interviews, only five of them were conducted in the homes of the women, and one was conducted in a shop owned by the woman. The rest of the interviews were conducted in the organizations. Even though I had planned to interview all the women in their homes, eventually I had to change my plan as I realized that most of the women worked throughout the week from Monday to Saturday, and were only free on Sundays, when they obviously had plans with friends and family members. As a result, the interviews were conducted in the organizations where they either worked or came for vocational training. After a few interviews it was realized that interruption from others was a normal part of the interviews. Someone or the other was always within earshot, and this sometimes made it difficult to ask intimate questions. Sometimes, out of curiosity, others members of the organization would come and stand near us to hear the interview. This, however, did not deter the participants from sharing their life stories with me. The contact with the organization which enabled them to meet other similarly placed persons with disabilities increased their level of confidence and they were very informative with their answers.

Interviewing the participants in their homes was a completely different experience. In some of the interviews it was found that the parents would not allow their daughters to speak, and would often answer the questions on their behalf. Presence of the other person again made it difficult to probe more deeply. For example, during two interviews it was found that the participants had a lot of problems with their family members, and they often talked about those problems in front of the person they had problems with. The presence of the other individual made it difficult to ask more deeply about the reasons behind the rift with him/her.

Similar problems of conducting one-to-one interviews with young people with disabilities were also highlighted by Singal (2010) in her paper on the methodological concerns that emerged in the Disability, Education and Poverty Project (DEPP), the central aim of which was to understand the role that education played in the lives of young people with disabilities living in poverty. The fieldwork for the study was conducted in the rural and urban sites of Dewas district in Madhya Pradesh. In her paper, Singal noted that the notion of ‘private’ space was unheard of in the community and the people lived their lives that were known to others. This was exacerbated by their poverty and the lack of physical space that they could claim to be their own (Ibid).

<u>Interviewing the Members of the Disability Organization:</u> Three members from the disability organizations: Sanjeeboni, Senehi and HKCT were interviewed in order to understand their individual understanding about disability issues as well as the ideology of their organization and the type of support they provide to persons with disabilities. From Sanjeeboni, I interviewed Suchismita Mazumdar, who is the founder of the organization and a polio survivor herself and Lalit, who had worked as a CBR worker earlier and is now working as the programme officer of a different project. In the case of Suchismita, her own experience of living with disability provided her with the motivation to work in the field of disability rehabilitation. She had earlier worked at Senehi for a few years as a special educator and had received in-service training from there. She also has the license as a Rehabilitation Personnel from the Rehabilitation Council of India (RCI), New Delhi. She founded Sanjeeboni in the year 1997 when she realized the kind of adversities persons with disabilities living in rural areas of Assam face that motivated her to work for them. Lalit Talukdar had joined the organization as a CBR worker in the year 2010. He has been associated with the organization ever since. During the interview, Lalit said that he likes working for the organization as it is a *mohaan onubhob* (great experience) which involves

serving humanity. He also said that persons with disabilities are often neglected by the society, which is why it is a matter of 'great luck' that he got the opportunity to work for them. His only sorrow in this line of work is that the pay is very less.

From Senehi, Rekha Chaudhury, a special educator, was interviewed. She had joined the organization in 1996, when she got bored of sitting idle at home after her children grew up and started going to school. Senehi, a special school for children with cerebral palsy was located very close to her natal home at that time. When she saw the children of the school, she was very curious to know about the kind of education that was imparted to them and one day she decided to go in and see it for herself. After talking to a special educator there, Rekha felt motivated to get employed at Senehi. The prime factors that facilitated her decision was that the job did not require any special qualification at that time, and the timing of the school matched with the school timing of her children, which meant that she did not have to make any comprises. At the time of the interview, Rekha had worked for the organization for almost two decades.

From HKCT, the president of the organization, Palash Mahanta, was interviewed at his residence. He is an IPS officer who retired from the post of Director General of Assam Police in the year 1992. He and a few like-minded men started the organization in the year 2011 in order to serve persons with disabilities and critically ill persons.

From Moromi, as mentioned earlier, I tried to interview the supervisor, but he did not show much interest. A telephone interview was conducted with him but it did not yield much information.

Interviewing the Health Personnel: The interviews with the health personnel were not as smooth as the other interviews, due to their busy schedules. I found the hospital space to be particularly intimidating, especially GMCH, where hundreds of patients and their attendants were moving around in the corridors to find the particular health department they were looking for. I could clearly see that the doctors were overburdened with patients. I actually felt guilty in a few occasions about 'wasting their valuable time' talking to me when they could have instead consulted a few patients. The power hierarchy in the institution was appalling where post-graduate students could not even talk openly in front of their professors. I had to stop an interview due to this reason. Since the senior doctors had very limited time in their hands, I had to make sure that I ask the right questions. This made me overly conscious about what I asked. In these interactions I could sense that the power relationship had reversed. Their age, their profession and their experience made them superior to me in many respects. It was only with the post-graduate student that I felt comfortable.

At the private hospital, on the other hand, the interviews with the health personnel were much relaxed. Even though they also had a lot of patients in their hands, they could still take out time for me, with minor distractions.

Data Analysis

Except for the interviews with the health personnel, all the other interviews have been recorded with the permission of the research participants. The interviews were translated and transcribed on the very same day or a day later in order to remember and write about particular nuances of the interviews. Along with this, I also maintained a diary where I wrote down my impressions about the interactions I had in the field. Both the processes helped me immensely in developing the themes for my study. All along I was also aware that the accounts of the research participants about their experiences

> …do not give us direct, or unmediated, access to their lived experiences. Narratives are representations, involving interpretation and selection in their construction (the telling), in their consumption (my reading), in their reproduction (my representation), and in their future interpretation (your reading) (Riessman, 1993, cited in Thomas, 2001: 251).

In spite of the drawbacks of using narratives, it is important to note that the accounts of the women provide many rich and intricate details about their lived experiences. It is also important to note here that their experiences are extremely heterogeneous, due to which it was impossible to draw clear-cut patterns. Although they do have many similarities with one another, their differences were also stark. In order to keep these similarities and differences of their life stories intact, I have used many long narratives in the chapters (either verbatim[31] or in my words) to demonstrate the (few) triumphs and (countless) tribulations in their lives. While the findings of the study cannot be generalized to other social contexts, their importance lies in the sense that the participants make of their lived experiences and the way they articulate it. The details about their lives would surely resonate with women with disabilities elsewhere, which is why more and more such studies are necessary.

Ethical Consideration

The study has been approved by the Institutional Ethics Review Board (IERB), Jawaharlal Nehru University. Before starting the interview, the research participants were explained about the nature of the study, the nature of participation in the study as well as the kind of questions that they would be asked. They were told that participation in the research was voluntary and they have the right to withdraw from the study at any point. The participants were also requested to sign the informed consent form and were assured that confidentiality regarding their identities would be maintained. The names used in the study are all pseudonyms, including the names of the organizations.

While getting formal consent from the participants was easy due to the help from the disability organizations, it was more difficult to comprehend whether they understood the purpose of the interaction. In many cases it was found that the women did not have anyone to talk to about their problems and so were simply happy that someone was interested in listening to them. Many of them even wept while narrating their stories of struggles and humiliation that they had faced throughout their lives. I tried my best to console them during such moments, by only listening and nodding to what they said, and refrained from probing more. The emotional bond that some of the research participants had formed with me made it somewhat difficult to exit from the field, and we remained in contact for many months following the interviews. During this period I could only listen to their problems, as it was not possible for me to do anything to resolve their problems that very much rooted in the structure and culture of the society of Assam. In a situation of utter hopelessness in which some of these

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[31] By verbatim I mean my translation of what they had said during the interviews in Assamese language.

women lived, the principles of the *emancipatory research paradigm* (noted in Chapter 1) which I had initially thought of applying in my study, made no sense.

This chapter, therefore gave a detailed outline of how the study was conducted, who were interviewed, how they were contacted, how the data was collected and analyzed and the constraints and ethical issues I had faced in the process. In the next chapter, I elaborate on the historical and socio-political context of Assam and women’s position in it, in order to situate the lives of the study participants.

Chapter 3

Contextualizing the Lives of Women with Disabilities in Assam

Introduction

Assam is located in the northeastern region of India. It comprises of districts in the Brahmaputra Valley and districts in the Barak Valley, along with the three hill districts of Karbi-Anglong, West Karbi-Anglong and Dima Hasao that separates the two valleys from one another. Assam shares its borders with seven states viz. Arunachal Pradesh, Manipur, Meghalaya, Mizoram, Nagaland, Tripura and West Bengal and two neighboring countries viz. Bangladesh and Bhutan. After the partition of India in 1947, Assam and the other northeastern states are geographically connected to the mainland of India through a 22 km narrow stretch of land in West Bengal known as the Siliguri Corridor or "Chicken's Neck" (Baishya, 2016). Assam comprises of people belonging to different national, ethnic, religious and linguistic groups and some of them have been living together for centuries (Srikanth, 2000). Due to this reason, sometimes Assam is called the 'melting-pot' of diverse cultural streams, the Indo-Aryan and Austro-Mongoloid being the central ones (U. Misra, 1999). Historically Assam has never been politically integrated with any north Indian empires prior to the advent of the British rule (K. M. Sharma, 1980). Since independence, Assam has been severely plagued by insurgency, economic underdevelopment, continuous ethnic movements, resurgent sub-national movements and unchecked foreign infiltrations. As a result of this, today it is one of the most underdeveloped and destabilized states of the country (J. K. Das, 2005). This chapter provides a historical overview of the state of Assam and contextualizes the status of women within this state. This understanding is important in order to comprehend the lived experiences of the research participants of this study.

Pre-colonial History of Assam

The present-day demography of Assam shows that several peoples from the Indian subcontinent and countries lying to the east made this region their home in prehistoric times. According to some, the Bodos are the original settlers in the present-day territory of Assam (Hussain, 1987; P. K. Nath, 2014), while others state the same about the Karbis (Srikanth, 2000). Some of the other tribes that inhabit this region include Garos, Rabhas, Deuries, Mishings, Morans, Chutias, Dimasas, Koches (Rajbongshis), Lalungs and Hajongs (Ibid). Aryans started migrating to this region from central and north India in large numbers from the beginning of the second millennium. They started the process of *hinduizing* the tribal inhabitants who had been practicing different forms of animism (P. K. Nath, 2014). The formation of the kingdom of *Kamrupa*[32] in the 4th century AD, paved the way for Brahminism, caste system and the system of settled agriculture (J. G. Nath, 2012). The Brahmins created different myths and stories through which they tried to link the tribal people to the classical Hindu mythology in order to bring them within the Hindu fold. In spite of their efforts, the Brahmanic model of Sanskritization did not hold much appeal to the people beyond the socio-geographical limits of the Kamrupa kingdom which was confined to only some parts of present day Lower Assam, besides some parts of present day Bangladesh and north Bengal. Due to this reason, much of the Brahmaputra valley, especially Upper Assam, could not be entirely proselytized to the Hindu fold during this period (J. G. Nath, 2012; P. K. Nath, 2014).

The *Ahoms*, an offshoot of the Tai or Shan race, migrated to the Brahmaputra Valley from upper Burma across the Patkai[33] hills, in the 13th century and ruled over it for almost 600 years (1228-1818) (U. Misra, 1999; J. G. Nath, 2012). Although initially they faced stiff resistance from the many autochthon tribes, the Ahoms successfully conquered them over time and emerged as the ruler of the defeated tribes. Gradually they entered into marital relations with the women from the indigenous communities and embraced local customs and language (C. K. Sharma, 1996). After the Ahoms spread their rule over the greater part of the Brahmaputra Valley, the region came to be known as *Axom* (Assam), a derivative from the word Ahom (U. Misra, 1999). During the 600 years of their rule, the Ahoms brought about several changes in the

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[32] Prior to the advent of the Ahoms, the western part of present-day Assam (referred to as Lower Assam by the British) was known as *Kamrupa* with *Pragjyotispur* (present-day Guwahati) as its capital. The eastern part (referred to as Upper Assam by the British) consisted of several tribal kingdoms and principalities. During the early period of Ahom rule, Upper Assam was known as Ahom country, while Lower Assam was known as the land of the '*Dhekeris*' (Baruah, 1972, as cited in U. Misra, 1999).

[33] The Patkai are the hills on the northeastern border of India with Myanmar (Burma).

administrative and social structure of the society of Assam (P. K. Nath, 2014). According to U. Misra (1999), the idea of a composite '*Axomiya jati*' (Assamese nationality) has its roots in the process of Aryanization and rise and consolidation of Ahom rule in the Brahmaputra Valley. This process began during Muslim invasion from Bengal in the 16th century, followed by Mughal invasion and encroachment on Ahom territory in the 17th century leading to the defeat of the Mughal army in the *Battle of Saraighat* in 1671. During this period, the people of the Valley were brought under an Ahom or Assamese banner against the common enemy (Ibid).

In the course of the expansion of the Ahom kingdom towards Lower Assam, the rulers had to compromise their own customs in favor of the brahminical systems that were predominant in this region. From the 14th century onwards, the Ahom royalty came under Brahminical influence. However, it was only under the rule of *King Suhungmung* (1497-1539) who assumed the title of *Swarganarayan*, adopted Assamese as the court language and introduced the *Saka era* in all official purposes that replaced the Ahom era of *Lakni*, that had long lasting impact upon the kingdom (J. G. Nath, 2012). Thereafter, the Brahmins created a myth for him that legitimized his royal authority. Ahom King, Pratap Singha (1603-1641) built and patronized Hindu temples and provided land-grants to maintain them. He also brahminized most branches of his civil administration by recruiting officers from among the Brahmans and imposed brahmanical codes on the marriage systems of the Hinduized section of people (Ibid).

Religion, particularly the *Neo-Vaisnavite cult* of Hinduism, also contributed tremendously in consolidating the composite *Axomiya* identity. In ancient and medieval period, worship of Siva[34] and Shakti[35] was found to be prominent in the

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[34] Saivism or the worship of Siva was possibly the earliest form of institutionalized religion in Assam. Different tribal communities such as the Bodos and the Kacharis worshipped a tribal deity called the *Sivraj Bathau* and *Ghar Bura* respectively, which had similar characteristics as that of Siva. Several ancient and medieval kings of different dynasties of Assam have also worshipped Siva. He was mainly worshipped in his phallic emblem (Linga). According to Yogini Tantra, the number of Lingas in Kamrupa exceeds a million, which clearly indicates the prominence of Saivism during this period (B. Borah, 1993).

[35] From the medieval period, Shaktism or the worship of female deities gained prominence. The Shakti cult was considered to have its centre in Kamrupa with its chief temple at Kamakhya (B. Borah, 1993). This cult was most powerful in the 12th century in Kamrupa. The two Sanskrit texts Kalika Purana (12th century) and Yogini Tantra (16th century) were composed in Assam and have dealt with Saktism. The two texts talk about blood sacrifices of various esoteric rites. The ritual consists of partaking of the Tantra of five elements, namely, madya (wine), mamsa (meat), matsya (fish), mudra (parched grain) and mithuna (sexual union). These five elements form the principal features of Saktism (Behal, 1986).

Brahmaputra Valley (B. Borah, 1993). In the medieval period particularly several tribal communities, including the Ahom and Koch[36] rulers, were adherents of the Shakti cult, sometimes bordering on extreme *Tantricism* (B. Borah, 1993; T. Das, 2015). This had a profound impact on the social and political life of the people of this region. It is also said that certain esoteric rites such as animal and even human sacrifices were rampant during this period, and usually people from the 'backward' classes, castes, and tribes fell victim to such practices (Bhuyan, n.d.). In such a scenario, the *Neo-Vaishnavite movement* emerged as a major religion of Assam through the efforts of *Srimanta Sankardeb*[37] (1449-1568) and his disciples in the 16th and 17th centuries. Even though Vishnu and his incarnations have been worshipped from the early times, Neo-Vaishnavism or the worship of Vishnu as propagated by Sankardeb was different in form (B. Borah, 1993). The movement did not differ much from the Bhakti Movement[38] that was prevalent in the rest of the Indian subcontinent during this period. Sankardeb initiated the tribal population of Assam into *Vaishnava* faith which was more popularly known as the *Eka-Sarana-Naam-Dharma* (religion of the surrender to the One). Through his teachings, Sankardeb challenged Brahmanical priesthood[39] by criticizing the complicated rituals and the authority of the priest (Behal, 1986). The four fundamental principles of Neo-Vaishnavism, according to him, are: (1) God; (2) Guru (the religious preceptor); (3) the fraternity of *Bhakats* (devotees); and (4) *naam* (chanting the name of God) (Bhuyan, n.d.). He relegated Vedic *samskaras* to a secondary position and emphasized on the congregational

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[36] The Koch Kingdom was established in 1515 and was located between the Karatoya River in the west in present-day Bangladesh and Baranadi in the West in Lower Assam. It was a mighty kingdom that reached its zenith under the rule of Naranarayana (1533-1587). This kingdom was the principle rivals of the *Ahoms* in Lower Assam (D. Dutta, 2015; Talukdar, 1992).

[37] Sankardeb was born in 1449 in a respectable Bara Bhuyan (descended from the *Kayasthas* of Kannauj) family in Borduwa, Nagaon. He became a widower after four years of marriage at the age of 23 years. When he turned 34 years, he decided to go on a pilgrimage to all the holy sites of Hinduism. During the 12 years that he lived in these places he got introduced to the Bhakti Movement and decided to propagate it in the Brahmaputra Valley which was going through a very rough time during this period (Chatterji, 1978; Borah, n.d.).

[38] Bhakti Movement emerged as an all-inclusive spiritual movement in the medieval period. The movement represents a form of rebellion against the traditional authority of Brahmin priests and other high castes. Most of the Bhakti saints used the *Bhagavata Purana* to develop Vaishnava sects. Its importance lies in the emphasis given to Bhakti (devotion) to Vishnu and his various incarnations (Behal, 1986).

[39] As a result of his anti-Brahmin stance, Sankardeb was initially not able to propagate his views in the Ahom territory, as the Brahmins enjoyed patronage from the Ahom rulers. He had to eventually shift from his native place, Bordowa in the present-day Nagaon district in Central Assam to seek asylum under the Koch King Naranarayana in Barpeta in Lower Assam to set up the headquarters of his new faith (Behal, 1986; T. Das, 2015).

singing of the *naam*. He also made the Sanskrit scriptures such as *Bhagavata Purana* that were earlier the monopoly of Brahmins, accessible to all by reinterpreting them into simple Assamese hymns and verses so that the non-literate population could easily understand and recite them (Behal, 1986). In his popular work, *Kirtan-Ghoxa*, Sankardeb emphasized that there is no sense of caste difference in *bhakti* (devotion). The movement, therefore, initiated several avenues for a more inclusive society through its flexible and tolerant ideology[40] (P. K. Nath, 2014). Another noteworthy contribution of this movement is that the Neo-Vaishnavite texts adopted a standardized language which later became the foundation of a modern Assamese language by replacing all other dialects (P. K. Nath, 2014).

The distinguishing feature of the Neo-Vaishnavite movement initiated by Sankardeb is seen in the two unique institutions, the *Xatra*[41] (Vaishnava monastery) and the *Naamghar*[42] (prayer hall). Both of these institutions are intimately connected with the social, cultural and religious life of the Assamese society (Bhuyan, n.d). During Sankardeb's lifetime, the Neo-Vaishnavite Movement largely remained confined to Lower Assam (Ibid). After his demise, his disciples propagated the faith across the Brahmaputra Valley by establishing hundreds of *Xatras*. This spearheaded the process of Hinduization and Sanskritization of the plain tribal communities[43] from the 17th to 20th centuries which brought about significant changes[44] in the social and cultural realms of the Valley (Nath, 2014). Yet, ideological differences among the different disciples of Sankardeb led to the fragmentation of the movement, which resulted in

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[40] Sankardeb made the attempt to bring all the castes, classes and tribes into the fold of Vaishnavism by accepting devotees from different communities such as Garos, Miris (Mishings), Ahoms, Nagas, Bhutiyas, Muslims and even Brahmins (Bhuyan, n.d).

[41] The institution of *Xatra* was introduced by Sankardeb to create an atmosphere where single minded devotion to God with fellow *Bhakats* (devotees) under the guidance of a Guru (teacher) could be achieved (Bhuyan, n.d). A definite shape to its organizational setup was given by his principal disciple, Madhavdeb (Behal, 1986).

[42] The *Naamghar* evolved as an offshoot of *Xatra*. It is a community prayer hall with no idol at the altar, but only the *Bhagavata Purana* symbolizing the supreme God. Over time the *Naamghar* came to serve as a forum which not only held religious discourses and devotional recitations but also socio-cultural activities of the community (A. Dutta, 2017).

[43] Under Neo-Vaishnavism, newly converted tribals were accommodated into the lowest strata of the caste hierarchy. Sometimes new caste groups were also created to accommodate them. It also enabled them to attain the highest status in the caste hierarchy by emulating the practices of the latter, something which was not possible in the Brahminic model of sanskritization (P.K. Nath, 2014).

[44] Some of the changes brought about by Neo-Vaishnavism include changes in agricultural practices of the tribal communities such as the move from shifting cultivation to settled cultivation, from wet rice to dry rice cultivation and the use of bullocks instead of hoe; as well as changes in food habits from non-vegetarianism and alcoholism to vegetarianism and teetotalism and the practice of cremating the dead instead of burying them (P. K. Nath, 2014).

the emergence of four different orders or *Samhitis* of *Xatras* which include (1) *Purusha*[45] (2) *Nika*[46] (3) *Kala*[47] and (4) *Brahma*[48]. Consequently, the Neo-Vaishnavite movement no longer remained monolithic (Bhuyan, n.d,).

In the initial period of the Neo-Vaishnavite movement, the Ahoms, who followed the Shakti cult, did not support the Vaishnavite saints and *Xatras*. The growing popularity of this faith among the common people, however, compelled them to recognize this faith towards the middle of the 17th century. This enabled the *Xatras* to receive royal patronage (Bhuyan, n.d,; Nath, 2014). King Jayadhvaj Singha (1648-1663) established four *Xatras* of brahminical sectarian order of Vaishnavism, and he himself became the disciple of the *gossains*[49] of two of these *Xatras*. The growth of Brahmanical Vaishnavism and the patronage it received from the Ahom rulers led to the sharpening of caste rules and caste distinctions in the society. Additionally, kings like Jayadhvaj Singha also imposed harsh punishments on those who attempted caste transgressions as a lesson for others (J. G. Nath, 2012).

Since the latter half of the 17th century, the Ahom rulers became more concerned about maintaining the social hierarchy. King Rudra Singha (1696-1714) adopted a policy whereby he encouraged the conformist *Xatras*, while at the same time, discouraged the non-conformist Xatras, maintained generally by Sudra *mahantas*. His successor, King Siva Singha (1714-44), took initiation in the Sakta cult from Krishnaram Nyayvagish of Bengal who was an upholder of the *navya-smriti* of Raghunandan[50] (J. G. Nath, 2012). All these developments further accelerated the process of assimilation of many tribes into the Hindu fold and the idea of a composite

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[45] The Purusha Samhiti derives its origin from Sankardeb's eldest grandson, Purushottam Thakur and it lays emphasis on Naam or Prayer (Bhuyan, n.d.).

[46] The Nika Samhiti Xatras strictly conforms to the rules and regulations prescribed by Madhavdeb, Sankardev's chief disciple. In this Samhiti, Madhavdeb is given more importance than Sankardeb, who is only revered as the Guru of their Guru (Bhuyan, n.d.).

[47] The Kala Samhiti gave Sankardeb a supreme position. The Satradhikars of these Xatras mainly preached among the tribal and other 'backward communities'. It was more egalitarian and had a liberal outlook towards matters of caste in comparison to the other Samhatis (Bhuyan, n.d.).

[48] The Brahma Samhati consisted of the sub-sects of Damodardeb and Harideb, two Brahmin disciples of Sankardeb. Most of the Xatras affiliated to this samahti are headed by Brahmin preceptors. It permits Vedic rites and devotional practices alongside Naam, and lays highest importance on God, in comparison to the other three fundamental aspects of the Ek-Sarana-Naam-Dharma, that is, Guru, Bhakat and Naam (Bhuyan, n.d.).

[49] Gossain is a title given to the leaders of Vaishnava order.

[50] Raghunandan Bhattacharya was a 16th century Brahmin from Nadiya in Bengal. He had redefined the codes of behavior related to demarcation of castes, and rules of marriage and child-birth (J. G. Nath, 2012)

Assamese identity comprising of caste Hindus, the plain tribals[51] and the small section of *Axomiya Mussalmans*[52] began to emerge. From this period, up until the advent of the British, which brought about significant changes in the region, the perception about the Assamese nationality was limited almost exclusively to only those people who lived in the Brahmaputra Valley (U. Misra, 1999).

Over time the *Xatras* became very powerful and began to receive massive land endowments, *paiks* and other precious gifts from the ruling class. With time many of these institutions lost their previous progressive outlook and took a religious stance that was approved by the ruling class that upheld the Vedic rituals and the caste system. Several Neo-Vaishnavite preachers, however, did not conform to this order, some among whom (including some Brahmins) were even executed under royal orders. The people from the *Moamora*[53] *Xatra* under the *Kala Samhiti* were particularly attracted to the non-conformist stance and as a result of this they invited severe royal sanctions (C. K. Sharma, 1996).

In the 18th century, the Ahom state faced severe labor crisis as many well-off *paiks* freed themselves from the obligatory duties by paying commutation money. This in turn threatened the entire production system of the kingdom, which was primarily based on the *paik* system[54]. In order to overcome this, in the reign of Rajeshwar Singha (1751-69), each *got* of *paiks* came to be organized with three *paiks* instead of

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[51] In the 17th and 18th centuries, large sections of Bodo-Kacharis and other tribal groups embraced Hinduism (U. Misra, 1999).

[52] The Ahom territory was invaded by the Muslim from the 13th and 14th centuries onwards. After the failure of these expeditions, a sizeable section of the Muslims stayed behind in the Brahmaputra Valley as prisoners of war. Over time, this section assimilated with the emerging Assamese nationality as *Axomiya Mussalmans.* The Ahom rulers gave positions of power and eminence to the Assamese Muslims and the latter took active part in resisting successive attempts by the Mughals to overrun the region (U. Misra, 1999).

[53] Aniruddhadev (1553-1626), one of the Neo-Vaishnavite preachers who established the Kala Samhati, initially preached his doctrines among the members of a fisher community who caught *Moa* fish for a living. Due to this reason, his sect was called the *Moamara* (to kill the *Moa* fish) sect by the non-believers in a derogatory way (B. Gogoi, 2015). The followers of this sect were known as the *Moamarias* (C. K. Sharma, 1996).

[54] The *paik* system was one of the primary organizing bases of the Ahom state. It was a state organized system of compulsory labor exploitation. All active people of the state in the age group of 16-50 years came under the purview of this system. Each individual was called a *paik* and four paiks formed a *got,* which was the primary unit of the production system. Each *paik* had to render compulsory physical service to the state without any wages for three months in a year. Apart from this, the *paiks* also had to go to the battlefront as soldiers in times of war as the Ahom did not have a regular army. During their service period, the *paiks* had no individual liberties and had to do whatever they were asked to do. They did not have any rights over the goods produced by them. They were not provided with any food during their service period, but were given only 2.66 acres of wet rice land the yield from which only enabled them to live at a subsistence level. Periodic censuses of the *paiks* were conducted and anyone who was found to be evading this system was subjected to ruthless punishment (C. K. Sharma, 1996).

four. This further led to the repression of the *paiks* as now they had to render services for four months instead of three. During this period, many *paiks* joined the *Xatras*[55] or served as bonded servants (*bandha*) under aristocratic families in order to avoid such extreme exploitation (C. K. Sharma, 1996). Furthermore, the ruling class also imposed heavy taxes on the items of daily use of the *paiks* in order to compensate for the dwindling state revenue. All these forms of exploitation aroused intense antagonism among the *paiks* against their rulers. This exploitative system was particularly challenged by the *Moamarias* as a result of which several of their preachers were even executed on the orders of the Ahom royalty. This eventually led to the three *Moamaria* rebellions in the years 1769-70, 1782 and 1786-94 (see C. K. Sharma, 1996). These rebellions shook the very foundation of the Ahom dynasty and paved the way for the Burmese incursions in 1817, 1819 and 1821 (Talukdar, 1992). As a result of the brutality of the Burmese, large section of the people of Brahmaputra Valley fled to the hills and there was a general depopulation of the entire region. The Ahom rulers were hardly in a position to protect the kingdom, which made the Burmese de-facto rulers of the Brahmaputra Valley (Sandhya Barua, 1978).

Colonial History of Assam

The East India Company came into contact with the northeastern region with the acquisition of Diwani of Bengal (in present-day Bangladesh) in 1765. The region, however, did not attract the British at that time as it did not have enough economic worth or surplus revenue. The Burmese invasions between 1817-1824 in Assam and Manipur compelled the East Indian Company to change its policies as the security of neighboring Cachar and Sylhet areas of Bengal came under threat (P. K. Nath, 2014). When the Ahoms sought help from the Company to free their territory from the Burmese, they declared war against them. The Anglo-Burmese wars took place during 1824-1826. After the defeat of the Burmese, the Treaty of Yandabo was signed in 1826 which led to the annexation of Assam within the colonial empire of the British (Ibid). Even though the Ahoms revolted several times in the succeeding years to

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[55] The *paiks* who joined the *Xatras*, were exempted from the compulsory *paik* system (C. K. Sharma, 1996).

regain their lost power and prestige, they met with utter failure (D. Gogoi, 2013), and were subsequently excluded from the state machinery (K. M. Sharma, 1980).

The period from 1826 marks the beginning of the modern era in the history of Assam. Once the Company took over, they brought about significant changes in the structure of the society of Assam, with the primary aim to monetize its economy to effectively serve its imperial interests (K. Boruah, 1980; Goswami, 2001). The accidental discovery of tea plants[56] in a wild state in the foothills of Upper Assam by the British in 1823 also decided the fate of Assam. The British, however, found that even though Assam had enough land, there was insufficient labor[57] to work in the large tea plantations (P. K. Nath, 2014). Due to this reason, the British had to import labourers[58] to work in the tea gardens from Chota Nagpur and other adjoining areas with surplus population (Baishya, 2016). The growing tea industry also compelled the British government to build the basic infrastructure like transportation and communication systems in Assam to export tea to England via Calcutta (P. K. Nath, 2014).

From 1826-1873, Assam was administered as part of Bengal Presidency (Sandhya Barua, 1978). This era saw the introduction of taxation, bureaucracy and modern education which became the channels of colonial modernity (Gohain, 1973). In the initial years, however, the colonial administration did not strive to introduce English system of education in Assam. For achieving higher education, the youths had to travel to Calcutta, due to which a majority of the Assamese could not avail the opportunity of government jobs. In spite of this, throughout the nineteenth century, government services were handled by competent Assamese youth of aristocratic

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[56] By the 19th century, tea was already a popular beverage in Europe. At that time tea was exported from China as it was the only tea producing region. The British, however, did not have any control over China because of which they had to pay a huge sum of money to the Chinese. The colonial government was very enthusiastic about having large scale tea planatations in Assam in order to break the monopoly of China (P. K. Nath, 2014).

[57] As mentioned earlier, this was because the population of Assam was reduced by the civil wars and the Burmese incursions. It was also found that major chunk of the people were opium addicts and were reluctant to work in the tea gardens (Nath, 2014). According to 1901 Census data, as many as 5.91 lakh people were brought to Assam during the preceding decade to work in the tea industry (Goswami, 2001).

[58] Many of these tea garden laborers came to Assam with the intention of going back to their homes after a few years. Many '*sardars*' who were responsible for bringing these laborers from other parts of the country in fact resorted to false tactics and false promises to get them to work in the tea gardens (Baishya, 2016). But once they were in Assam, they were made to live in slave-like conditions and were not allowed to freely travel outside the plantations to which they were assigned. This eventually hindered their assimilation with the native population (K. M. Sharma, 1980).

families, without taking into account any academic qualifications (K. Baruah, 1980). These new avenues of employment and trade were cornered majorly by the caste Hindus who had earlier served the Ahom rulers as clerks and bureaucrats. This emerging native middle class, in fact, was grateful to the British for returning law and order in the society and for the benefits of British rule. Even the peasantry initially offered hearty support to the British as they refused to submit to serf exploitation and forced labor in the fields (Gohain, 1973).

After introducing western administrative systems, the British sponsored the migration of educated Bengali Hindus mostly from Sylhet to the Brahmaputra Valley to run the administrative services as they were already familiar with these changes from much before. This led to a lot of resentment among the newly emerging educated middle class Assamese elites, who also competed for the same government jobs within the colonial administration (K. M. Sharma, 1980; P. K. Nath, 2014). Moreover, for these jobs English education was necessary, as a result of which the uneducated youths who were earlier employed were being eliminated. This inevitably resulted in greater numerical strength of the Bengalis, in comparison to the Assamese (K. Boruah, 1980). However, according to K. Boruah (1980), this was due to limited scope of English education in Assam, and even when there was scope, the aversion of the Assamese to English education[59]. Apart from the Bengali migrants, the British also encouraged the immigration of Marwari traders and Nepalese servicemen to Assam during this period (Sandhya Barua, 1978; Goswami, 2001; M. Devi, 2007).

In 1836, Assamese language[60] was replaced by Bengali[61] in the schools and administrative offices of Assam. This replacement of the native language by a foreign one led to a lot of dissatisfaction among the common people, especially the Assamese elites. After a prolonged struggle, in 1873 the British government acknowledged the distinctiveness of Assamese and Bengali languages and decided to replace the latter with the former in the schools and offices of Assam (P. K. Nath, 2014). Furthermore,

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[59] At a point of time people who dared to avail English education had to face dire consequences of even being socially ostracized (K. Boruah, 1980).

[60] This was because Assamese was the *lingua-franca* among the different communities of Assam, and as mentioned earlier, it achieved its written form through the works of Sankardeb (P. K. Nath, 2014).

[61] According to several scholars, the immigrant Bengali clerks considered the people of Assam to be inferior to them. Some have even accused them of influencing the British to replace Assamese with Bengali language as the medium of instruction in the schools of Assam (Gohain, 1985; M. Deka, 2013).

in 1874, Assam was made a Chief Commissioner's province, which covered the Brahmaputra Valley and the areas ruled by the former Kachari Kings towards the south of the Valley, along with the adjoining hills inhabited by the Nagas, Kukis Mizos, Garos, Jaintias and Khasis. Additionally, for financial viability a major portion of the Bengali speaking areas of Cachar, Sylhet and Goalpara from East Bengal also came under the provincial administration of Assam, which created many problems for both the Assamese and the Bengalis later (Sandhya Barua, 1978; Srikanth, 2000). In 1905, a new reorganization took place. The densely populated province of Bengal was partitioned into a predominantly Hindu West Bengal, and a predominantly Muslim East Bengal that also incorporated Assam. In 1912, after widespread protests, the partition was annulled and Assam was again re-established as a Chief Commissioner's province that included the predominantly Bengali Muslim district of Sylhet and the predominantly Bengali Hindu district of Cachar. These boundaries remained intact till the partition of India in 1947 (Sandhya Barua, 1978).

In much of the 19th century, the Assamese elites, even the most radical amongst them, considered the British as their saviors or at least as their friends in their struggle against the 'other' Indians. They were completely indifferent to the plight of the peasants who revolted against the exorbitant land revenue that was imposed on them despite the slow and insignificant circulation of money in the society. In *Orunudoi*[62] these elites wrote a number of articles where they painted the peasants as ignorant and reckless, while praised the British for their valor and might (Gohain, 1973). Regardless of what they thought of the British, the latter carried through several policies which were detrimental for the people of Assam (K. M. Sharma, 1980).

One of these policies was the decision to encourage large-scale immigration of (mostly Muslim) peasants from the Mymensingh district of East Bengal from the beginning of the 20th century (Sandhya Barua, 1978; Srikanth, 2000) to settle down and cultivate jute[63] in the riverine tracts. This inflow of the immigrants continued

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[62] Orunodoi (1846-1882) was the first Assamese newspaper and it was published by the American Baptist Mission Press from Sivasagar in Upper Assam. Although the primary objective of the missionaries was to spread the Christian faith among the people, it led to an unintended consequence, which is that it led to the emergence of a standardized form of Assamese language.

[63] The immigration of *Mymensinghia* Muslim peasants from East Bengal is connected with the growth of the jute industry in and around Calcutta. With the expansion of this trade, its expansion also became a necessity (K. Boruah, 1980). The agrarian revenue and turnover in Assam, on the other hand, was very small. Since the area under jute cultivation could no longer be extended in Bengal, the British decided to expand it in Assam with the immigration of expert jute cultivators into Assam (K. M.

from 1901-1947 to such an extent that the indigenous population of the Brahmaputra Valley went down considerably towards the middle of the 20th century. Even though these immigrants contributed enormously to the economy of Assam, they also adversely affected the socio-cultural life of the state (Sandhya Barua, 1978). This was a huge cause of concern for the tribal and non-tribal peasants who were increasingly facing land alienation. Even though the Assamese elites acknowledged this problem, they were more concerned about regaining the status of the Assamese language (U. Misra, 1999). Some British officials also showed their concern about this issue, but they did not do anything to redress it (P. K. Nath, 2014). The British, in fact, thrived upon the disunity among the toiling masses in the name of language, nationality and religion. Many Assamese elites were also complicit in the influx of outsiders[64] into Assam as they provided cheap labor in their fields and homesteads (see K. Boruah, 1980). In the early decades of the 20th century, the tribal and non-tribal peasants fought together for the land question. As a consequence of this, the colonial government introduced the Line System[65] in 1920 to protect the land from the immigrants (P. K. Nath, 2014). However, the system was largely ineffective as the authorities did not strictly observe the divisions. Furthermore, the intention of the British was not to stop the influx of the immigrants, but to put effective administrative control on the settlement areas in order to derive more revenue benefits. In this way, the British created animosity between the immigrants and the indigenous population (Goswami, 2001).

By 1921, the Muslims from Bengal had completely outnumbered the Assamese Hindus. In order to retain the majority status of Hindus in Assam, Rajendra Prasad, during his visit to Assam in 1926, suggested the immigration of Bihari Hindus from overpopulated areas of Bihar into Assam (see K. Boruah, 1980). This suggestion also received support from the Assamese middle class (Ibid). In this way, another

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Sharma, 1980). The British realized that if these people are encouraged to settle down in Assam, it would increase the income of the Raj significantly (Ibid). The immigration also helped in defeating the growing peasant mobilization against the *zamindari* oppression and exploitation in Bengal (K. Boruah, 1980).

[64] While some Assamese elites encouraged the immigration of Bengali Muslims for cheap labor, others who were more conservative encouraged the immigration of Nepali Hindus instead. As a result of this, many Nepali Hindus got access to the forest lands and *char* areas of the Brahmaputra Valley (K. Boruah, 1980).

[65] As per the Line System, the villages were divided into three categories: (1) Open Villages, (2) Closed Villages and (3) Mixed Villages. In the open villages, immigrants could settle down freely. In the closed villages, they were not allowed to settle, and in mixed villages, a line was drawn where immigrants could settle down on one side of the line (Das, 1986, as cited in P. K. Nath, 2014).

community from another region of India migrated to Assam to work during the colonial period.

When the Muslim League came to power before the Second World War, they allowed and even encouraged immigration of Muslims from East Bengal. In fact, they also brought out a resolution in 1937 to abolish the Line System which was strongly opposed by the Tribal League[66]. After several debates and discussions a committee was formed to review the Line System. This committee came up with a report in 1938 where a middle path was suggested as an alternative to the Line System. However, the implementation of this report was set aside due to the political turmoil of the War and the Quit India Movement. In 1942 when the Bordoloi Ministry of Assam Congress resigned for the Quit India Movement, the Saadullah Ministry of the Muslim League came into power which not only encouraged migration but also allotted land on the payment of a meager sum of money. The recommendations of the review committee of the Line System for creating tribal blocks and belts were implemented only in 1949 after the Bordoloi Ministry again came back to power in independent India. By this time, however, the tribal belts and blocks were considerably occupied by the non-tribals (P. K. Nath, 2014).

The years 1919-1920 proved to be very crucial in the history of India as the struggle against colonization intensified, under the leadership of M. K. Gandhi. In 1919, Gandhi launched the *Satyagraha* Movement against the imposition of the Rowlett Act. In 1920, Gandhi called for the Non-Cooperation Movement for the attainment of *Swaraj*. Assam was also drawn to the national mainstream in 1921 with the formation of the Assam Provincial Congress Committee (APCC) (M. Phukan, 2011; Puzari & Mazane, 2001; L. Baruah, 2015). After an initial hesitation, Assam also plunged into the movement, and it got further momentum with Gandhi’s visit to Assam in 1921 for 12 days. A noteworthy feature of the Non-Cooperation Movement in Assam was the large-scale participation of students and women. From that period up until India’s independence in 1947, men and women from Assam had significantly contributed to the freedom struggle against colonial domination (Ibid).

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[66] Tribal League was established in 1933 as a tribal conglomerate organization, in which the tribal elites and illustrious leaders raised their voices for their respective communities and areas (P. K. Nath, 2014).

At the eve of independence, Assam had to face another significant historical event that is the Grouping System as suggested by the Cabinet Mission Plan[67] in 1946. The Grouping System planned to divide the country into three Groups[68], in which Assam and Bengal were clubbed together in Group C. This Plan created a lot of uneasiness among the leaders of Assam (expect the Muslim League) as they feared that it would negate the prospects of provincial status of Assam. It had also become clear at that time that the groupings would be in religious lines, which induced the fear in the minds of people of Assam that the province might get tagged with the Muslim dominated Bengal. Due to these reasons, the people of Assam under the leadership of Gopinath Bordoloi vehemently opposed this plan. The strong opposition from various quarters finally resulted in the collapse of the Cabinet Mission (J. K. Das, 1994). After the collapse of this plan, the British government had to look for another alternative. This is when Lord Mountbatten, the new Viceroy of India, was given the task of quickly dividing the Indian subcontinent into two countries, India and Pakistan. In Assam, the Muslim majority district of Sylhet made the decision in 1947 to be a part of East Pakistan (Ibid). In addition to the Brahmaputra Valley, the predominantly Bengali speaking region of Cachar towards the southern part of Assam, the other hill areas (Garo, Jaintia, Khasi, Naga and Lushai hills) barring North-Eastern Frontier Agency (NEFA)[69], formed the state of Assam at the eve of independence (J. K. Das, 2005).

Post-Colonial History of Assam

In the post-colonial period, Assam, including all the hill districts, had to suffer greatly from the partition as this entire region was cut-off from well-established rail and road connectivity with the rest of the country. Although the new rail link via North Bengal mitigated the difficulties faced by the people in the Brahmaputra Valley, the problem

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[67] The main purpose of the Cabinet Mission Plan was to arrange the framing of the Constitution, setting up of a constitutional-making body and the transfer of power from the British government to the Indian leadership, with the aim of preserving the country’s unity and granting it independence (Society and Politics of Post-Colonial India).

[68] Group A comprised of United Provinces (Uttar Pradesh), Bihar, Orissa, Central Provinces (Madhya Pradesh), Bombay and Madras Presidencies and Group B comprised of Punjab, North West Frontier Province, Baluchistan and the Province of Sindh (Society and Politics of Post-Colonial India).

[69] North East Frontier Agency (NEFA) was one of the political divisions in British India and later the Republic of India until 1972, when it became the Union Territory of Arunachal Pradesh. It received statehood in 1987.

faced by the people in the hills was very difficult to deal with (Mukerjee, 1969). Additionally, the entire region had flourishing trade links with East Bengal, which had to be abandoned as it was no longer possible to maintain such trades after partition (Ibid). In spite of the trauma that this region had to endure, the Assamese leaders considered Partition to be a blessing in disguise, as it enabled them to emerge as the dominant nationality in the state (Srikanth, 1980), while made the Bengali Hindus, their prime enemies since the time of the British, particularly vulnerable (Goswami, 2001).

In the post-colonial period, Assam has experienced several movements, both peaceful as well as violent, as a result of which the state has been reorganized several times, leading to a drastic reduction of its size (Hussain, 1987; Goswami, 2001). The peripheral location of Assam and the other northeastern states, the resultant underdevelopment and distorted political response to underdevelopment have made the society of Assam perpetually vulnerable to various kinds of violence, conflict and displacement (Hussain, 2000). The question of reorganization was first raised by the hill-tribal leaders soon after independence. However, the Bordoloi Ministry that came to power after independence was opposed to this idea and instead assured them that they would also get the benefits of independent India (Hussain, 1987). As described earlier, historically, the hill-tribes of northeastern India were neither a part of India nor Assam prior to the advent of the British rule. They lived isolated from the plainspeople mostly because of their geographical location and this enabled them to maintain their distinct culture, traditions, taboos and social systems, which are very different from the people of the Valley (Hussain, 1987). Even under British rule, the hill-tribes remained separate from the plainspeople of Assam. Under the Government of India Act, 1935, the hill areas of undivided Assam were separated into two categories, where the Lushai (Mizo) and North Cachar hills were classified as ‘excluded areas’[70] and United Khasi and Jaintia hills (with the exception of Shillong that was the capital of Assam at that time), the Garo hills, Naga hills and Mikir (Karbi) hills were classified as ‘partially excluded areas’. After independence, the

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[70] The government of Assam had no jurisdiction over the excluded areas, which were administered under the special power of the governor (Hussain, 1987). The accessibility to these areas was restricted even for the British subjects by the introduction of the Inner Line Regulation. The British government was not interested in allowing extension of trade activities in these areas as it found it extremely difficult to collect taxes from there. Additionally, by restricting the entry of their subjects, the government reduced the risks to their lives from the attacks by the tribals (N. Kumar, 2005).

constitution of India also accepted the spirit of this Act by providing each hill district an Autonomous District Council with fairly large autonomous powers under the Sixth Schedule (Hussain, 1987). Some educated tribals[71] from the hills realized that autonomy stipulated in the Indian constitution was not sufficient for their development. Some of them also felt that India should consider them as a sovereign power in their internal matters within their own territories. It is due to this feeling that insurgency started in the Naga Hills district in the early 1950s, which eventually led to the formation of a separate state of Nagaland[72] that was carved out of Assam in 1963. In 1960, the Assam government declared 'Assamese' as the official language[73] of Assam on the basis of a thin majority (Goswami, 2001). Although the major motive of this was to prevent Bengali domination[74] over cultural and employment spheres of Assam, it resulted in alienating all the tribal peoples of the state (Ibid). This hegemonic imposition of Assamese language was opposed by all the tribal groups, particularly the hill tribals and the Bengali Hindus of Barak Valley (Hussain, 2000). This policy along with the creation of Nagaland with only five lakh population hardened the attitudes of the other tribals and inspired them to fight more determinately for a separate hill state for the tribal people.

As a result of these protests, the government of India was forced to change its policies against the northeast (see Hussain, 1987). In 1969, the Indira Gandhi government declared Garo Hills district and United Khasi and Jaintia districts as an autonomous state (Meghalaya) within the state of Assam (see Mukerjee, 1969; Hussain, 1987).

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[71] By the time of India's independence, a small but distinguishable group of educated tribals had emerged mainly from among the Nagas, Mizos and the Khasis as a result of modern education, mainly at the initiative of the Christian missionaries. These leaders were conscious about their distinct identities and were apprehensive about the motives of the plainspeople (Hussain, 1987).

[72] Insurgency in Nagaland continues till today. The major demand of the insurgent group NSCN-IM is secession from India and the demand for Greater Nagaland or Nagalim comprising of Naga-inhabited areas of neighboring states of Assam, Manipur, Arunachal Pradesh and some portions of Myanmar.

[73] Due to the history of the fear of being dominated by the Bengalis, the Assam government led by the middle class elites completely ignored the multi-lingual and multi-ethnic character of the state, and made efforts to impose Assamese as the official language in 1960. In this way it attempted to Assamize all the linguistic minorities of the state (Srikanth, 2000). This undemocratic language policy not only led to riots in Bengali dominated Barak Valley, but also spitefully injured the emerging identity consciousness among all the tribals and its resultant sentiment (Hussain, 1987). The problem was again rekindled by AASU in 1972 when Assamese along with English was made the sole medium of instruction in schools and colleges of Assam (J. K. Das, 2005; A. Devi, 2017).

[74] After With the growth of Assamese nationalism in every sphere of political activity, Bengali middle class organizations began to demand that Bengali language also be given similar status as it would mean equality in opportunity in employment and political and social status (Goswami, 2001). This, however, was not acceptable to the Assamese elites, who thereafter declared Assamese as the official language of Assam (Ibid).

The United Mikir Hills and North Cachar Hills refused[75] to join the autonomous state of Meghalaya under the Assam Reorganization Act of 1969 and decided to stay with Assam (Hussain, 1987). In the year 1970, the district was bifurcated into two separate districts: Mikir Hills District (later renamed as Karbi-Anglong district) and North Cachar Hills (later renamed as Dima Hasao district). These two districts have their own district councils under the provisions of the Sixth Schedule of the Indian constitution which has provided the hills with some autonomy in managing their tribal society (Hussain, 1992). After the formation of Bangladesh in 1971, the Indian government gave full statehood to Manipur, Tripura and Meghalaya in 1972. In the same year, Mizo hills district[76] (renamed as Mizoram) and NEFA (renamed as Arunachal Pradesh) were elevated to the status of union territories and were given full statehood in the year 1987.

In contrast to the hill-tribes, the plain tribes have lived in close proximity with the Assamese population for generations. Due to this reason, while the hills tribes were seen as completely different from the non-tribes in the plains, the plains tribes were seen as yet another sub-nationality of the Assamese (Hussain, 1992). In fact, several plains tribes of Upper Assam such as Deuris, Tiwas, Sonowal Kacharies and Mech Kacharies, got *Assamized* due to different historical reasons (U. Misra, 1999; Srikanth, 2000). It was assumed that the other plains tribes would also eventually assimilate with the Assamese population (Goswami, 2001). As a result of this, beginning with the Government of India Act, 1935, through all the later policies, the plains tribes were not given any special consideration (Ibid). According to Goswami (2001), while different policies helped the hill tribes in protecting their distinct identity and culture, a similar provision[77] for the plains tribes could have averted much of the turmoil that plagued Assam in the last quarter of the 20th century.

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[75] In contrast to the other hill-tribes who are dominated by Christianized tribes, the Karbis and Dimasa Kacharis are Hinduized non-caste tribals. Due to this reason, the United Mikir and North Cachar Hills did not actively participate in the hill state movement as there was always an apprehension of domination by the Christians (Mukerjee, 1969; Hussain, 1987; Choudhury, 2014).

[76] Insurgency in broke out in the Mizo Hills in February 1966 because of which it was not allowed to be a part of Meghalaya autonomous state (Mukerjee, 1969).

[77] During the passage of the Assam Act, 1947, the provisions under the Sixth Schedule were not extended to the plains tribals. According to Goswami (2001), at that time there was ground for hope as there were some well-demarcated areas that were inhabited by the non-tribals. However, over the years, due to encroachment by the non-tribals, there is no contiguous area that could be considered as inhabited predominantly by the plains tribals (Ibid).

As noted earlier, during the colonial period, as a result of the large-scale migration of *Mymensinghia* Muslims, the plains tribals began to fear that they would be outnumbered and dispossessed of their own lands. However, the Assamese middle class leadership did little to assuage their fears (U. Misra, 1999). Besides, little effort was made to psychologically accommodate the plain tribals into the Assamese fold, even though the leaders occasionally made emotive appeals about the unity of tribals and non-tribals within the broader fabric of the Assamese society. As a result of this, the small number of middle class tribals began to resent the *Assamization* process (Ibid). In spite of this, during the Congress-led struggle against the British, the divide between the tribals and the non-tribals remained partially submerged because of the fight against the common enemy (U. Misra, 1999). The Cabinet Mission Plan also brought all the indigenous peoples of undivided Assam together. During this period certain tribal leaders seemed to have visualized a broader fraternity made up of all the peoples of undivided Assam, where the hills peoples would enjoy enough autonomy to develop according to their own means. However, the Assamese middle class did not share such an idea of a broader fraternity of the peoples of the northeastern region. In fact, their perception of Assam in the post-colonial period was limited to the Assamese speaking people of the Brahmaputra Valley. Even though the Congress leaders often claimed to speak for all the people of undivided Assam, in reality the leaders hardly gave any space to the other nationalities (U. Misra, 1999).

After independence, the Tribal League was disappointed by Bordoloi for not giving due importance to the demands of the plains tribals (Goswami, 2001). But unlike his colleagues, Bordoloi at least had the vision of a composite Assam where Assamese and the different tribal communities would have a friendly working relationship with one another. After his death in 1950, the succeeding leadership not only failed to incorporate the hill tribals, but also the plain tribals within the Assamese community (U. Misra, 1999). The insistence of the Assamese middle class on a dominantly Assamese linguistic identity[78] for the state, which was supported by the ruling Congress Party, also alienated the plains tribals (Ibid). The tribal leaders were dissatisfied that this policy put the tribal language speakers at a severely disadvantageous position (Goswami, 2001). Being insecure of their own fate within

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[78] Apart from making Assamese the official language of Assam, in 1972, AASU also launched a movement for making Assamese language the medium of instruction up to graduate level in addition to the existing English language (Hussain, 2000).

the larger fabric of the Assamese society, different plains tribal organizations started growing that demanded for political power and social justice (U. Misra, 1999). The Bodos, the largest plains tribals of the Brahmaputra Valley, for instance, began to assert their ethnic and cultural identity when the two organizations, the Plains Tribal Council of India (PTCA) and All Bodo Students' Union (ABSU) were established in the year 1967. It was also at this period that the Bodos demanded for a separate state '*Udayachal*' for the plains tribals (Goswami, 2001). The Assamese leadership, however, was antagonistic to their demands and continued to assert that the plain tribals are an integral part of Assamese society (Ibid). According to U. Misra (1999), one of the main reasons for tribal disenchantment was the lack of development[79] of their areas which remained as backward as before (U. Misra, 1999). In spite of their differences, when the *All Assam Students' Union* (AASU) and the *All Assam Gana Sangram Parishad* (AAGSP) launched the anti-foreigners agitation against Bangladeshi immigrants (popularly known as the *Assam Movement*) in 1979, they received unprecedented mass support from all the tribal and non-tribal peoples of the state (U. Misra, 1999; Basumatary, 2014). However, the fissures that had developed between the tribals and the non-tribals got further accentuated during the course of this movement which would be discussed later in the chapter.

The problem of immigration that had begun in the colonial period, continued unabated during the post-colonial period. After partition, the Bengali Hindus who were rendered homeless in East Pakistan started pouring in large numbers into Assam, West Bengal and Tripura (H. K. Hazarika, 1989). On the other hand, more than hundred thousand Muslims living in lower Assam involuntarily migrated to East Pakistan during the communal riots in the wake of partition of India in 1947 (Hussain, 2000). After the Nehru-Liaquat Ali Pact of 1950 that assured their safe return as well as rehabilitation, many Muslims returned back to their homes within two years. In the

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[79] It is important to note that all the problems of underdevelopment of areas inhabited by the plain tribals cannot be attributed to the state government as the central funds always came in a trickle. Moreover, the national leadership of the Congress refused to consider Bordoloi's plea for treating Assam as a special case as the colonization had completely drained the region of its natural resources without any ploughback of capital. Additionally, partition had also severely affected the state's economy by virtually cutting off the entire region from the rest of the country and putting an end to the centuries-old trade with former East Bengal. Assam also had to face the increase in population due to the immigration of a large number of Bengali Hindus from Pakistan after the newly-created state of East Pakistan came into being. In spite of all these factors, whatever little development was taking place under the Assam government was largely being concentrated in the non-tribal areas (U. Misra, 1999).

1960s, after the Indo-China war, again there were demands to detect and deport 'Pakistani infiltrators' from Assam. Following this, instead of sealing off the border with East Pakistan or preventing infiltration at the border, the government of Assam introduced the Prevention of Infiltration from Pakistan (PIP) scheme to detect and deport Pakistani infiltrators. This scheme virtually terrorized the defenseless rural Muslim peasantry, particularly the *Na-Axomiya* Muslims throughout the Brahmaputra Valley between 1961 and 67, even though this community had migrated from East Bengal (not East Pakistan), and were *Assamized* and identified themselves with the *Axomiya* nationality after independence (Hussain, 2000). During the Indo-Pakistan war in 1965 and the Bangladesh Liberation War in 1971, many Bengali Hindus were forced to leave East Pakistan. But they were also accompanied by many Bengali Muslims, who apparently never left Assam after that. This is in spite of the fact that the government of India had passed the Immigrants (Expulsion from India) Act, 1950, according to which any immigrant person except displaced persons who entered Assam due to civil disturbance or fear of civil disturbance was liable to be deported (H. K. Hazarika, 1989). It is said that as long as East Bengal was a part of Pakistan, due to the hostile relationship between the two countries, the border was properly guarded by the military and paramilitary forces that kept a check on the infiltration. But during the Bangladesh Liberation War, the borders were thrown open that allowed infiltration of immigrants to Assam and other North-eastern states (Ibid). It is alleged that the Congress government that was in power in the state during this period is complicit in allowing their unhindered immigration into the state (K. Boruah, 1980; H. K. Hazarika, 1989).

Even though immigration has been an issue for quite some time, it had not received adequate attention from the Assamese middle class. In fact, since independence, the Muslims have remained in the periphery until the late 1970s when the infiltration issue was raised in the media and by the comments of the Chief Election Officer (see B. Das, 2014). One of the reasons for this is that the immigrant Muslims never caused any problems for the Assamese middle class unlike the Bengali Hindus or the *Bohiragatas*[80]. For instance, unlike the Bengali Hindus[81] and the tribal communities

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[80] The word *Bohiragatas* is used to refer to people who are based in Assam but had come from other regions of India (like the Marwaris). During the 1978 assembly elections, the issue of *Bohiragatas* was raised by two political formations of Assam. Their main grievance with this community was that in spite of living in Assam for a long period of time, they did not show any interest of assimilating with

who had problems in accepting Assamese as the official language, the immigrant Muslims gave up their own language (Bengali) without being forced and started identifying themselves with the Assamese speaking majority of the Brahmaputra Valley[82]. This was particularly true of the large sections of immigrant population of the *char* (riverine) areas, who had been sending their children to Assamese medium schools and referred to Assamese as their mother tongue (U. Misra, 1999). As this section of the population started increasing rapidly, the Assamese socio-cultural organizations began to refer to them as the '*Na-Axomiya*' or the Neo-Assamese, and later as the Assamese (Ibid).

The immediate event that propelled the Assam Movement was the sudden death of Lok Sabha Member, Hiralal Patowari, in 1978 that necessitated by-elections in the Mangaldai constituency (Darrang District). During the preparation of the electoral rolls it was noticed that there was a sudden massive increase of electorate. Following this, in 1979, AAGSP was formed by a number of political and cultural organizations which, along with AASU, made the formal call for the Assam Movement or the Assam Agitation (*Axom Andulon*). The major objective of the organization was to focus on the unchecked immigration issue and to demand for the economic development of Assam (B. Das, 2014). The initial phases of the movement were comparatively peaceful and were joined by lakhs of people from different ethnic groups of the state (primarily from the Brahmaputra Valley). Unprecedented civil non-cooperation, strikes and lawlessness led to the collapse of four successive governments between 1979 and 1981 and President's rule had to be imposed intermittently for three times. The agitators also stopped the transfer of crude oil and other natural resources such as plywood and teak to the rest of the country. As a result of this, towards the end of 1980, the Central government became stricter in dealing with the agitators and brought in the Indian army to break the oil blockade (Ibid).

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the Assamese society and culture (A. Devi, 2017). However, the anti-*Bohiragata* campaign did not garner much support from the general masses because of which it was eventually abandoned (Ibid).

[81] Even though the Bengali Hindus of Assam speak fluent Assamese and have also contributed immensely to Assamese literature and the arts, they did not give up their linguistic identity of being a Bengali (U. Misra, 1999). Due to this reason, they were the primary enemies of the Assamese middle class.

[82] Unlike in the Brahmaputra Valley where the Muslims identified themselves as Assamese, in the Barak Valley, they identified themselves as Bengalis (U. Misra, 1999).

The center invited the leaders of the movement for several rounds of talks to discuss the issue, yet no decision could be reached regarding the cut-off year from which individuals can be identified as 'illegal immigrants' from Bangladesh and Nepal[83]. The agitators demanded that 1951 should be the cut-off year and those who crossed the border after this year should be expelled from the state. On the other hand, the national parties such as Congress and CPI as well as the central government demanded that 1971 should be the cut-off year. In 1980, following the path of AASU, students of the immigrant communities (Bengali Hindus and Bengali Muslims) formed the All Assam Minority Students' Union (AAMSU), which became the other front with which the centre had to negotiate on the issue of the cut-off year. The leaders of AAMSU demanded that all the immigrants who had come before 1971 should be given full citizenship. It further demanded state protection against unnecessary harassment of the immigrants (B. Das, 2014; A. Devi, 2017). The date of 1971, however, was not acceptable to the agitators of the Assam Movement and demanded that the immigrants who had entered after 1961 should be deported back. This caused immense tension between the two groups leading to violence, especially in areas where the immigrants had stronghold. Over time, the movement led to unprecedented violence, killings, bomb-blasts and other forms of furious carnages (J. K. Das, 2005).

In 1983, the central government announced elections on the basis of electoral rolls that were prepared without solving the foreigner's issue. The leaders of the movement opposed the elections. They tried all means to stop the candidates from filling their nominations and also urged the general masses through rampant violence to boycott the elections until the immigrants are detected and deported (A. Devi, 2017). Several ethnic communities[84], however, who had become disenchanted by the movement's ideology decided to participate in the elections, in order to ensure that they have a government that would make an effort for their well-being and security (Ibid).

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[83] The Nepali population came to Assam in successive waves, but the major push came during the British rule (see M. Devi, 2007).

[84] A large number of Assamese Muslims had participated in the Assam Movement, and during one period the organization AASU was led by Nurul Hussain in the capacity of vice-president. However, over time the movement created an identity crisis for them as in spite of their assimilation into the Assamese society, they felt somewhat alienated. This had happened to them for the first time in the nation's post-independence history during the Assam Movement (U. Misra, 1999). After their large scale victimization in the 1983 riots, many Assamese Muslims stopped supporting the movement (B. Das, 2014). In fact, after the movement, many Assamese Muslims were tempted to disown their Assamese cultural identity and to adopt pan-Islamic positions (U. Misra, 1999).

Following this, there were violent riots in Nellie[85] in Nagaon district and other areas[86] where persons from different ethnic groups were targeted by persons of other ethnic groups (B. Das, 2014; A. Devi, 2017). The entire year saw organized mob violence, communities pitting against one another and the building and breaking of community loyalty (Ibid).

After the elections Hiteshwar Saikia of Congress (I) formed the government. The Assam Movement leaders, however, considered this government to be illegal[87] and refused to recognize it. It is alleged that Saikia's government played a significant role in derailing the movement by targeting the weak links and breaking its support base (see B. Das, 2014). By this time, the movement was also losing its popularity amongst the masses who had grown dispassionate after the movement turned violent in 1983 (Ibid). In spite of this, the power of the movement refused to wane and the state ministry had to face constant strikes, boycotts, blackouts and protests. After Indira Gandhi's assassination in 1984, the new Prime Minister, Rajiv Gandhi began a new phase of negotiation with the movement leadership, which led to the signing of the Assam Accord on 15th August, 1985 with 1971 as the cut-off year (B. Das, 2014). Following this, the existing ministry was dissolved, and new elections were held in 1985, where two new regional political parties[88], Axom Gana Parishad (AGP, formed by ex-AASU leadership), and the United Minority Front (UMF) contested. The AGP won the state assembly elections with a sweeping victory in the Brahmaputra Valley, but remained unpopular in the Barak Valley (A. Devi, 2017). Prafulla Mahanta, ex-President of AASU, became the youngest and the first student Chief Minister of the country (J. K. Das, 2005). The AGP also won 7 seats in the Lok Sabha election (A.

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[85] Nellie is a small village in the southern bank of Brahmaputra that is located 45 km away from Guwahati. The village is inhabited by the plains tribes, Lalung (Tiwa). The Lalungs once had their kingdom in this area, but since their land rights were not protected, their land had been encroached by the Bengali Muslims. According to official records, nearly 1200 Bengali Muslim women and children were killed in the pogrom, although unofficially the number of deaths is considered to be much higher (B. Das, 2014).

[86] The massacre at Nellie was followed by similar carnages at Choulkhowa Chapori in Darrang District (where *Na Axamiya* Muslims were targeted, Silapathar in Lakhimpur District (where most of the victims were Bengali Hindus) and at Gohpur in Darrang District (where the victims were Bodos and the Axomiyas) (Hussain, 2000).

[87] The state elections could not be completed in 16 out of 126 constituencies, and in one of the constituencies, a candidate was murdered. Elections could not take place for 7 out of the 12 already unfulfilled parliamentary seats. The voter turnout was above 50 percent in the Bengali-speaking constituencies and as high as 70 percent in several Bodo-populated constituencies. However, in the Assamese populated constituencies, the turnout was between 5-20 percent (B. Das, 2014).

[88] AGP was in support of the Assam Accord, while UMF was against the Accord.

Devi, 2017). The AGP derived its strength from the popular sentiment that the *Axomiya* identity is under threat as a result of large scale migration (Goswami, 2003).

After AGP came to power, however, the party was not able to meet the expectations of the masses. For instance, the party did not represent Bengali Hindus or non-Assamese Muslims in the new government (A. Devi, 2017). Even though there were several tribal legislators and ministers in the AGP, they were neither influential in the AGP government nor in the party. Some of the leaders were also displeased with the way the AGP was handling the tribal problems (Hussain, 1989). Due to this reason, many tribals who had initially supported the Assam Movement, started to view the Assam Accord as a move to safeguard the identity and interests of only the Assamese-speaking people[89] of the state, while they felt that it completely ignored and overlooked the grave dangers that was posed to the identity of the tribals (U. Misra, 1999). Moreover, the AGP was not able to solve the immigration issue as the parliament had passed legislation making it very difficult to detect[90] the status of foreigners, due to which only about a thousand of them could be detected, and virtually none could be deported to Bangladesh (Srikanth, 1999). This made the government very unpopular among the masses as the agitators had earlier claimed that the numbers were in the hundreds of thousands (Sanjib Baruah, 1994; 2008; A. Devi, 2017). All of these factors resulted in the weakening of the support base of the party over time that in turn raised the popularity of the extremist group, the United Liberation Front of Assam (ULFA).

The ULFA[91] was formed in 1979. However, the group came into prominence only in 1983 a group of leaders from the Assam Movement took by the armed struggle in order to counter the highhandedness of the central government to defeat the largely peaceful Assam Movement by using strong arm methods (Sanjib Baruah, 2009; S. K. Das, 2012; A. Devi, 2017). The ULFA saw itself as being engaged in a battle to recover the lost sovereignty of Assam (Sanjib Baruah, 2009). The main aim of the

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[89] After coming to power, the AGP government imposed a new language policy which made it obligatory to learn Assamese for government services. The All Assam Tribal Students' Union (AATSU) along with the non-Assamese firmly opposed this decision (Pawar, 2015).

[90] The Illegal Immigrants (Determination by Tribunal) (IMDT) Act was passed by the parliament in 1983. The Act set out the procedures for identifying the immigrants. After the AGP government came to power, it was realized that detecting and deporting the immigrants is impossible under this Act as the onus of proving anyone a foreigner rest with those who made the complaint (Srikanth, 1999).

[91] The armed militants of the ULFA were basically a branch of the Assam Movement and were colleagues of the AASU leaders who formed the AGP government (A. Devi, 2017).

ULFA was to 'liberate Assam from Delhi's colonization' (Hussain, 2000) by 'establishing scientific socialism in Assam'. The group considered the Treaty of Yandabo, 1826, between the Burmese army and British East India Company that incorporated Assam into British India, as the event that marked the end of independence of Assam (Sanjib Baruah, 1994). The support for the group grew dramatically only when the political agitation of the Assam Movement was not able to fulfill its aims. However, it is important to note that unlike the Assam Movement's extreme rhetoric on 'foreigners' and 'Bangladeshis', the ULFA articulated a more inclusive and non-ethnic view of who is an 'Assamese' and had tried to spread its political appeal to all *Axom Baxi* (people living in Assam). Its recruitment strategy and the pseudonyms that its cadres adopted also reflected an inclusive and multi-ethnic vision of Assam (Sanjib Baruah, 2009). During the initial period of its existence, the ULFA leaders were very popular among the masses for their social agenda[92] and were often praised for their activities by the local press (Sanjib Baruah, 1994; A. Devi, 2017). Over time, however, a growing gap could be noticed between its inclusive and pluralistic rhetoric on the one hand and its political practice on the other, that coincided with ULFA's declining operational effectiveness (Sanjib Baruah, 2009).

The ULFA also established friendly relations with other more experienced militant organizations in the region like the National Socialist Council of Nagaland (Issac - Muivah) (NSCN-IM) and Kachin Independent Army (KIA) of Burma (J. K. Das, 2005; Grewal, 2013). By the late 1980s, ULFA shook the entire state when killings, extortions and kidnappings became very common (Ibid). By 1990, the ULFA had killed 113 people, out of which 58 were political party activists, while 19 were government officials. It is said that by this time the ULFA was running a parallel government with the AGP, as the latter was ill-equipped[93] to resist the growth of the

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[92] In the initial years, the ULFA was not only praised by the leading members of the Assamese society but it also earned goodwill from the general masses. The group engaged in activities such as construction of roads, banned alcohol drinking, chastised local thugs, conducted trails of people involved in drugs and prostitution, and punished corrupt government officials (Sanjib Baruah, 1994; A. Devi, 2017).

[93] According to Sanjib Baruah (1994), AGP's response to the ULFA was only half-hearted. This was because as a regional political party that was specifically working on the cause of the Assamese, AGP shared a common ideological space with the ULFA, because of which it was not able to effectively challenge the group. It is also alleged that the ULFA was able to blackmail certain AGP ministers against whom there were charges of corruption. Due to these reasons, the distinction between AGP,

militants, despite the pressure from the central government. The ULFA extorted huge amounts of money from local businesses, particularly the tea industry, the most important sector in Assam's economy, and the Marwari trading community, who have a highly visible presence in the state's commercial life (Sanjib Baruah, 1994).

The activities of the ULFA destabilized the AGP government, and in 1990, Assam was declared as a 'disturbed' state under the Disturbed Areas Act, 1955 (A. Devi, 2017). The central government also dismissed the AGP government one month before it was supposed to complete its term and imposed President's Rule on the state (see Sanjib Baruah, 1994; 2009). Simultaneously, the government of India banned the ULFA under Unlawful Activities (Prevention) Act, 1967. In 1991, Hiteshwar Saikia of Congress (I) came back to power. His government launched two successive counterinsurgency operations, 'Operation Bajrang' (1990-91) and 'Operation Rhino' (1991-92), through which the ULFA hideouts were raided and some were even killed during encounters with the security forces (Sanjib Baruah, 2009; A. Devi, 2017). This period also witnessed serious human rights abuses, from the militant groups, on the one hand, who bombed, kidnapped and assassinated dissident ULFA members and suspected informers, and on the other hand, from the state, that severely curtailed dissent and arrested human rights activists and journalists who reported on these abuses (Sanjib Baruah, 1994). From 1990-93, some 10,000 people were arrested and detained under the Terrorist and Disruptive Activities (TADA) Act, 1985, out of which only a tiny segment had any connection with the ULFA. Many of them were released after several months without any charges, among whom a great majority complained about maltreatment by the authorities (Hayes, 2012). Due to absence of any public investigations of counterinsurgency operations, such incidents resulted in the erosion of the legitimacy of state institutions in the minds of the masses (Sanjib Baruah, 1994).

With the escalating crackdown on the ULFA militants, a group of them (referred to as SULFA, surrendered ULFA) surrendered their arms in exchange for government protection and cash payments for rehabilitated (Sanjib Baruah, 1994; J. K. Das, 2005; S. K. Das, 2012). Instead of disarming them, the government allowed them to keep their weapons to defend themselves against possible retaliations (Hayes, 2012). Those

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AASU and ULFA was completely obliterated that made the Governor of Assam recommend the central government to immediately dismiss the state government in 1990 (Ibid).

militants, who did not surrender their arms to the state, shifted their base to the neighboring countries of Bhutan, Bangladesh and Myanmar, from where they continued their operations. In turn, the government of India solicited the cooperation of these governments in ‘counter-terrorism’ with varying degrees of success (Ibid). Despite its division, the ULFA has still not died down and continues to make its presence felt in the state through occasional threats and bombings from time to time (Pawar, 2015).

Apart from the use of the army to repress all voices of dissent, Chief Miniter Hiteswar Saikia was also accused of unprecedented corruption during his reign that made his party very unpopular among the masses (Baruah & Goswami, 1999). The authoritarian and corrupt rule of the Congress brought all the regional, ethnic and left parties together on the eve of the general elections in 1996. The AGP formed an alliance with CPI and CPI(M) (which is ironic as they had earlier labeled them as Bengali parties for not cooperating in the Assam Movement), and also wooed the Muslim community that enabled them to garner the support of United People’s Party of Assam (UPPA). These political adjustments enabled the AGP to come back to power 1996 (Srikanth, 1999).

After the AGP came to power for the second time, it gave up some of its militant rhetoric and avoided taking any drastic action against the immigrants that would enrage the minorities. The party also distanced itself from the ULFA, although many of their leaders earlier had close contacts with them (Ibid). In the late 1990s, the SULFA became a covert weapon in the government’s war against the ULFA, who along with the Indian army carried out hundreds of ‘secret killings’ and disappearances of the ULFA members, their families and associates (Hayes, 2012). However, when it came to administration, AGP’s performance was very poor. Due to rampant corruption, continuing militancy and divergence of huge funds for maintenance of the armed forces, Assam became bankrupt due to which it was not possible to pay the salaries of the employees. Further, it could not take up any developmental activities in the state as the activities of the militants continued unabated (Srikanth, 1999). The government was also not able to provide security to major tea houses such as the TATA, which are very vital for the economy of Assam. It was also found that the party including the Chief Minister, Prafulla Mahanta was involved in a large scale corruption, which also eroded the credibility of the party even among the Assamese masses, and provided the opposition a powerful plank in the 1998 legislative assembly elections to campaign against the AGP. Moreover, by this time the ULFA had also turned against the AGP because of its tacit support to the army operations and the SULFA militants (Ibid), and had urged the people to keep away from the elections (Baruah & Goswami, 1999). In addition to this, smaller ethnic and religious parties that had joined hands with the AGP in the 1996 elections did not join hands with the AGP during the 1998 elections, due to which it stayed alienated from the tribal electorate. All these factors tilted the balance in favor of the Congress which capitalized on its known pockets of influence among the *Na-Axamiyas* and *Adivasis*[94] (Ibid).

Apart from the ULFA, the Assam Agitation and subsequently the chauvinistic attitude of the AGP government towards the tribal communities of the state also gave birth to other militant groups in the state. Upendranath Brahma, a close collaborator of the AASU during the Assam Movement, launched the ABSU movement for self-determination of the Bodo people in 1987 (Basumatary, 2014). The ABSU demanded the division of Assam into two halves ('Divide Assam 50-50' was their slogan) to attain the state of Bodoland within the Indian union. This demand eventually got adopted by groups like Bodo Security Force (BSF), later renamed as National Democratic Front of Bodoland (NDFB), which demanded succession of the Bodoland area from India (Ibid). According to Basumatary (2014), the separatist ideology articulated by the movement leadership is rooted in a deep sense of alienation from the Assamese society that has considered the Bodos to be its peripheral parts. The leadership of the Bodoland Movement believed that political autonomy would remove the deprivations of the community (Ibid). It is also alleged that the central government under the leadership of Rajiv Gandhi patronized the Bodoland Movement in order to destabilize the AGP government. Due to this reason, the AGP government dealt with the Bodoland Movement very aggressively and terrorized the Bodos repeatedly with the help of Assam Police (Hussain, 2000).

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[94] The Adivasis are the descendants of tea plantation workers who were brought to Assam by the British from the Chota Nagpur Plateau three or four generations ago. Even though this term is commonly used in other parts of India to refer to original or indigenous inhabitants of a place, in Assam, the term Adivasi is used to refer to the tea tribes. Unlike tribals from other parts of India, the tribal population of Assam and the entire Northeastern region do not refer to themselves as Adivasis. Instead they use the terms 'indigenous people' or 'tribal people' (Sharma & Khan, 2018).

After the return of Congress (I) government in Assam in 1991, dialogue with the Bodo agitators started again. The leadership eventually gave up the demand for a separate state and agreed to have ‘autonomy’ instead under the First Bodo Accord of 1993 (Hussain, 1993). It, however, failed to deliver any results (see Basumatary, 2014) and in fact escalated the violence in the region[95]. By 1995, another militant group, the Bodo Liberation Tigers (BLT) came into being, allegedly as a rival to the NDFB. Like the AASU-led Assam Agitation, the initial phase of the Bodoland Movement was also relatively peaceful and was marked by efforts to mobilize the masses. However, in the 1990s, during its peak, the movement took a violent turn, which can be attributed to the two main Bodo militant groups constantly fighting amongst one another in the Bodo-dominated areas of the northern bank of Lower Assam, along with clashes with other ethnic groups in that region. These clashes, specifically between the BLT and the NDFB, had virtually restricted free movement in the Bodoland areas (see Basumatary, 2014). The Second Bodo Accord was signed in 2003 between the state government, central government and the BLT which created the Bodoland Territorial Council (BTC) under the modified provisions of the Sixth Schedule of the Indian Constitution. The BTC comprised of four contiguous districts: Kokrajhar, Baksa, Chirang and Udalguri, which are together referred to as Bodoland Territorial Area Districts (BTAD) (Basumatary, 2014). In spite of the accord, clashes between different fragments of the movement are quite frequent in the region (see ibid). Additionally, the Bodoland movement also saw a rise in militancy among other ethnic groups such as Koch Rajbongshis, *Adivasis* and Bengali Muslims to fight against the Bodo militants who had terrorized them resulting in their internal displacement. As a result several militant organizations are active in this particular region that target one another from time to time (see Hussain, 2000; Basumatary, 2014).

Apart from the Bodos, the Karbi leaders of Karbi-Anglong also felt betrayed by the Assam Movement (P. K. Nath, 2014). The ruling AGP government failed to fulfill their aspirations, and in fact alienated them further by imposing Assamese language on them, evicting them from government reserved forest lands and discriminating

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[95] In the 1990s, the two main Bodo militant groups, Bodoland Liberation Tigers (BLT) and National Democratic Front of Bodoland (NDFB) fought amongst each other, besides fighting with security forces and other ethnic groups such as the Bengali Muslims, Santhals and Koch Rajbongshis (Basumatary, 2014).

them in employment (Hussain, 2000). Due to all of these factors, the Karbis and Dimasas, who in 1969 had refused to join the state of Meghalaya and expressed their intention to remain with Assam, formed the Autonomous State Demand Committee[96] (ASDC) in 1986 to demand for the implementation of Article 244 A[97] of the constitution. This movement was at its peak from 1986-89 when strikes, protests and processions became very frequent events in Karbi-Anglong (P. K. Nath, 2014).

With increasing intensity of the movement in Karbi-Anglong, the Karbi-Anglong district council was upgraded to the Karbi-Anglong Autonomous Council (KAAC) in 1995, following a memorandum of understanding signed between ASDC and its allies on the one hand and the representatives of the central and state governments on the other. Over time, the leaders of this movement realized that the KAAC is insufficient and inadequate to fulfill the aspirations of the Karbis (Choudhury, 2014). The Karbis also formed insurgent groups such as the United Peoples' Democratic Solidarity (UPDS) in 1999 that blamed the ASDC for its failure to achieve the Autonomous State and started an armed struggle for the creation of a separate state. Following this, there was a reign of violence, terror and extortion in the region until 2002 when it came to a ceasefire agreement with the Indian government. The region also saw violent ethnic clashes between Karbis and non-Karbi groups such as Kukis and Dimasas of Karbi-Anglong. These ethnic groups also eventually formed their own insurgent groups to fight against Karbi atrocities as a result of which violence is rampant in the district (P. K. Nath, 2014).

These developments have further increased the aspirations of the other tribal communities to fight for their autonomy and identity. Some of the other tribes that have been granted autonomous district councils to satisfy their autonomy aspirations include Rabhas, Hajongs, Tiwas, Sonowal Kacharis, Thengal Kacharis, Mishings and Deuris (B. H. Boruah, 2018). Additionally, six other ethnic communities, namely, Chutiyas, Morons, Muttocks, Tai Ahoms, Koch-Rajbongshis and Adivasis, which were struggling for Scheduled Tribe status, were accorded the same in January 2019. However, it will not be very easy to implement this as the existing Scheduled Tribe

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[96] Many of the leaders of this organization were students who had actively participated in the Assam Movement (P. K. Nath, 2014).

[97] Article 244A ,1969 , empowers the Parliament to enact a law for constituting an autonomous state within the state of Assam. The article also provides the autonomous state with Legislature or a Council of Ministers or both with the powers and functions as may be defined by that law.

communities – Bodos, Karbis, Rabhas, Sonowal Kacharis, Hajongs, Dimasas among others, have vehemently opposed this move by stating that it would destroy the interests of the existing Scheduled Tribes of the state (http://www.thehindu.com/news/national/six-assam-groups-to-be-accorded-st-status/article25943 828.ece; http://m.timesofindia.com/city/guwahati/tribal-body-calls-bandh-against-bill-to-grants-st-status-to-ethnic-groups/amp_articleshow/674802063.cm).

There are also several active ethnically-based insurgent groups that are demanding for greater autonomy in the state. These include about 15 Muslim groups, most notably Muslim Liberation Tigers of Assam (MULTA), Muslim Liberation Army [MLA, formerly known as Muslim United Liberation Front of Assam (MULFA)] and Islamic Liberation Army of Assam (ILAA), representing the interests of Muslim-majority districts, that are demanding for forming a Muslim state. Many of these groups are believed to working under the command of foreign intelligence agencies such as Inter-Services Intelligence (ISI) and ultra-fundamentalist bodies such as Islamic Chhatra Shibir and Jamiat-I-Islami of Bangladesh. The activities of these organizations were earlier limited to only the multi-ethnic areas (Nagaon and Mariani) of the Brahmaputra Valley where Muslims constitute a sizeable proportion of the population. However, now it is believed that the activities of these groups have expanded to other districts as well (Barpeta, Goalpara and Dhubri and Cachar in the Barak Valley) (S. K. Das, n.d.). Other groups include the Dima Halong Daoga (DHD) that represents the Dimasa tribe and are demanding for a separate state to be formed out of Assam and the areas of some neighboring states and the Kamatapur Liberation Organization (KLO) is fighting for a state for the Koch Rajbongshi tribes. Other smaller insurgent groups include the Tiwa National Revolutionary Force, Bengal Tiger Force, Rabha National Security Force, People's United Liberation Front, Karbi National Volunteers, Karbi Longri North Cachar Hills Liberation Front, United Liberation Front of Barak Valley, Adivasi Security Force/Adivasi Cobra Force and Gorkha Tiger Force. Many of these groups are short-lived in nature that are formed and fractured in no time, giving birth to newer groups in short order. The rationale of many of these groups is connected with continuing tensions between various ethnic groups that occasionally result in massacres and ethnic killings (Cline, 2006).

To summarize, in this section, the attempt was to show that in no point in the history of Assam was it mono-ethnic or monolingual. However due to different historical processes the caste Hindu Assamese emerged as the dominant nationality in the state after the independence of the country. Even though most of the other tribal ethnic communities had assimilated with the dominant Assamese community, problems started to emerge when the latter ignored the multiethnic character of the state and started imposing their language and culture upon all other communities. As has been described in the above section, the ethnicity question in a multiethnic state such as Assam was like peeling an onion as more and more communities continued to emerge that demanded autonomy for themselves. However, one must realize that along with the chauvinism of the dominant caste Hindu Assamese, other factors also played an important role in creating the rift between different ethnic communities, one of which is underdevelopment and neglect from the central government in the initial years following independence. The following section throws light on this aspect.

Identity, Militancy and Underdevelopment in Assam: Perspectives from the Pre and Post-Liberalized Era

As noted above, the northeastern region (NER) became the periphery of India after the partition of the country in 1947 (G. Das, 1998). This event imposed a huge transport and access disadvantage to this entire region that has subsequently arrested its economic growth. Even though Assam was one of the economically prosperous states of the country at the time of independence, with a per capita income of 4 percent above the national average, in the year 1998-99, the per capita income of Assam fell below 45 percent of the national average (R. Barua, 2015). In spite of the rich reserves of natural resources, Assam is lagging far behind the rest of the country in economic growth and development, and is heavily dependent on the central government funds (J. Dutta, 2016). Some of the reasons for the poor growth in Assam include perennial floods, political disturbances, severely underdeveloped infrastructure of roads, railways and communication, abject poverty (Hussain 1993, cited in J. Dutta, 2016), geographical isolation of the region from the mainland of India and lack of well-developed links with the markets (R. Barua, 2015).

Although Assam's economy is primarily agrarian, its growth rate is not comparable to the rest of the country. The problem of perennial floods is one of the major causes of low agricultural development in the state, as it causes massive soil erosion, loss of livestock and heavy damage to infrastructure that arrests the agricultural productivity of the state every year (R. Barua, 2015). Due to this reason, Assam has to depend on other states for food grains (Hussain, 1993, as cited in J. Dutta, 2016). Industrial development in Assam is also not at par with the rest of India, in spite of the fact that the country as a whole has benefitted from the 'extractive industries' of tea, oil and plywood that are procured from Assam. Again the prime reasons for low industrialization are geographical isolation, ethnic strife, militant activities and poor infrastructure that have remained undeveloped from the time of independence (R. Barua, 2015). Tilottama Misra (1980) who had written her paper *"Assam: A Colonial Hinterland"* at the beginning of the six years long Assam Movement had demonstrated her frustration at the state of development of Assam, even after 30 years of independence. She had termed Assam as a 'colonial hinterland' where Assam's resources have been systematically exploited first by the colonial rulers before 1947, while after independence; the same tradition has been continued by the Indian state and the Indian capitalists (Ibid). T. Misra (1980) has shown her concern that the major industries of the region have not benefitted the people of the state. For instance, tea production in Assam constitutes more than 50 percent of the total production of the country. However, the huge profits made by these gardens are several times more than the total annual revenue receipts[98] of the state. But in spite of this, Assam does not get a share in the benefits as the foreign and Indian tea owners conceal their actual profits and also pay abdominally low wages to the tea garden workers (T. Misra, 1980; J. Dutta, 2016). Additionally, a majority of the big tea gardens are owned by foreign and Indian companies which are controlled from London and Calcutta, as a result of which the share of profits from the gardens flow out to these companies (T. Misra, 1980; J. Dutta, 2016). Crude oil, another important natural resource of Assam, has been a cause of contention between the state and the centre since the discovery of oilfields in Naharkatiya in Upper Assam in 1956, which was also the first major

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[98] While the state of Assam is entitled to an agricultural tax of 60 percent of the profit from the tea gardens, the state has hardly received the amount because, according to her, it has become a common practice for both Indian and foreign tea garden owners to hide the major share of their profits. This robs the state as well as the centre (which is entitled to an income tax of 40 percent of the total profit) of their due share of the revenue and taxes (T. Misra, 1980).

discovery of oilfields in India (see D. M. Baruah, 2011). The oil reserve has an estimated reserve of 1.3 billion tons of crude oil and 156 billion cubic meters of natural gas. What irked the people of the state was that instead of setting up the refinery in Assam, the central government decided to build one in Barauni, Bihar. After widespread protests from 1956-57, they built a small refinery in Noonmati, Guwahati (Ibid). Apart from these issues, the people of the state also feel that the centre is not giving adequate royalty for the crude oil (T. Misra, 1980; J. Dutta, 2016). Likewise, in the case of plywood also it can be seen that 80 percent of the produce of the 40 large plywood factories are transferred from roads and rails to depots outside of Assam as not a single sales depot is located in Assam. Furthermore, not a single plywood company was owned by the local people or by the state government. Besides, the local people of Assam were also not given jobs in the plywood factories as most of the recruitment is from outside the state (Ibid).

According to G. Das (1998), in the pre-liberalized era, the pattern of resource exploitation and the consequent production structure had evolved with a view to grow the national economy. Due to this reason, the surplus generated from the large scale exploitation of resources had moved out of the region. Production structure, on the other hand, had remained stagnant which in turn weakened the link between primary and secondary sectors in the local economy. As a result, while Assam was a supplier of raw materials, it had to import manufactured consumer goods (Ibid).

According to T. Misra (1980), one of the fallouts of the Assam Movement is the awareness among the general masses of Assam of being subjected to gross economic exploitation on a scale that is comparable to, and sometimes even worse than, in the colonial period. It is precisely due to this rising awareness that the agitators of the movement were able to mobilize thousands of people of the state to participate in the oil blockade during that period (J. Dutta, 2016). The ULFA that emerged from this movement, also thrived over this sentiment that the colonization of Assam continues unabated even in independent India, which is why they took up arms to free Assam from Delhi’s colonization (Hussain, 2000).

G. Das (1998), however, disagrees with this view. He argued that there is a difference between private and state forms of surplus extraction, in that while the former does not fuel the development of a region, the latter through central agencies like Oil India

Corporation, Coal India Limited, etc. has not been unilateral as is claimed by secessionist organizations such as ULFA and certain scholars from this region. According to him, apart from royalties on raw materials, these agencies transfer resources from the centre to the states through planning and other development agencies that more than compensate the loss incurred by this region (G. Das, 1998). By using world system analysis, G. Das (1998) explained that even though Assam (and the entire NER) is considered to be a peripheral area in India, it is not actually the case, as the peripheral syndrome continues to exist because the processes of core and periphery exhibit two sides of a larger process that is of uneven capitalist development. The working of the peripheral process in the NER is evident from the degree of dependence of this region on the core areas for its necessities. The big share of the central fund that is made available to this region goes out to purchase goods and services from the core areas that add little to the local productive capacity. The primary drawback of this region, according to him, is the locational disadvantage, as in spite of the incentives offered by the central government for the development of the industrial sector, it was too insignificant to overcome the market impediments (Ibid). The politics of regionalism as well as the politics of secessionism that have entrenched into the society of Assam and other states of NER have evolved because of this spatial inequality that grew under state capitalism (G. Das, 1998).

G. Das (1998) also listed out some of the other outcomes of state sponsored development programmes that had a lasting effect on the people of Assam. First, such programmes enabled the emergence of a nouveau rich class among the Assamese elites through rent seeking activities. As has been noted earlier, upon independence, the Assamese elites occupied the political space and emerged as the power elites, on the one hand, while on the other hand, the non-Assamese community (particularly the Marwaris) who had thrived in the non-agricultural sector in the colonial times retained their position even after independence. Prior to the emergence of the nouveau rich class, the power elites had little control over the economy of Assam and vice versa, which this class helped to bridge by giving birth to the Assamese bourgeoisie (G. Das, 1998). This, however, had far reaching effects as it not only intensified economic inequality within the Assamese community, but also widened the social inequality between the Assamese and the tribal communities in the state, which subsequently led to the multiple reorganizations of the state (Ibid). Second, none of the NER states are economically viable by themselves, one of the prime reasons for which is the insignificant ‘penetrative power’ of these states to mobilize the resources that lie within its territory. This is because unlike the other states of the Indian union, Assam (including Meghalaya, Mizoram and Tripura) comes under the purview of the Sixth Schedule of the constitution, in which district councils having constitutional power operate as a parallel political institution that occupy the space between the state and the people. Due to this reason, the state does not have any power over its available resources (Ibid).

According to Srikanth (1998), the Inner Line Regulations and the autonomous district councils have actually enabled the ethnic communities of NER to escape from both colonial and capitalist plunder and consequently have been able to avoid alienation, deprivation and dehumanization that other tribal communities from mainland India have been subjected to. He further argued that while the NER states have every right to demand for development of necessary infrastructure facilities, establishment of basic industries and modernization of agriculture, it however, does not guarantee that it would also improve the living standards of the indigenous people of the state. According to him, if economic development has to be meaningful, it will have to meet the specific needs of the region. According to Srikanth (1998), instead of depending on the grants and special assistance of the central government, the states of NER should be made to generate internal resources.

In addition to these points, multi-ethnicity and identity politics has also played a key role in the underdevelopment of the state. According to G. Das (2012), there is a two way connection between identity and development: while identity conflicts in multiethnic Assam has led to political instability and has adversely affected its economic development on the one hand, on the other hand, lack of economic development has led to the creation of limited economic opportunities, which in turn has sharpened inter-ethnic competition for access to resources and avenues for livelihood. As has been noted earlier, the caste Hindu Assamese occupied the political sphere upon independence. As a result of this, economic development in multi-ethnic Assam has also been largely biased in favor of the dominant Assamese community. This group has been able to channelize the limited central government funds available to the state for the betterment of health, education and infrastructure of areas that are mostly inhabited by the dominant group. Contrary to them, the minority groups have had little say over public decision making (Ibid). This *ethnocentric developmentalism*, according to G. Das (2012) has created both social as well as territorial inequality in Assam that in turn has given rise to ethnic assertion among the peripheral groups that have the intense feeling of relative deprivation. When the ethnic movements started adopting violent tactics to address its grievances, it disturbed the whole business environment as the risk of investment appeared to be far higher than the expected rate of return (Ibid).

These problems of underdevelopment have continued to persist in the post-liberalized era. In fact, the condition of the NER states is even worse now as, unlike the under centralized planning where the development of the internal areas were promoted (Srikanth, 1998), under the current regime, it is the responsibility of the individual states to attract private capital. In the race for attracting private investment by the respective states, the developed states with better infrastructural facilities and more lucrative incentive packages are far ahead of their underdeveloped counterparts such as the states of NER which hardly have any competitive terms to offer (G. Das, 1998). The NER states fail to attract private investment due to several reasons such as the industrial policies of some of these states that necessitates local participation in order to run businesses by outsiders and 'protective rent seeking activities' by the insurgent groups. The latter especially has tremendous impact on the economy of Assam (see G. Das, 1998). Apart from these problems, according to G. Das (1998), unemployment will also assume new heights in the post liberalized regime because of which the reservation of jobs for the scheduled tribes will lose its relevance. This would further enhance the social tensions and conflicts in the state (G. Das, 1998). According to Srikanth (1998), in order for liberalization to succeed in the NER, the government will have to invest crores of rupees for creating infrastructural facilities that are necessary for attracting capital. Additionally, the government will also have to take tough measures to ensure law and order in the region. Under liberalization, the NER will have to change its policies to suit the interests of the investors, which in turn would have serious repercussions on the already volatile social and political environment of the state (see Srikanth, 1998).

Socio-Political Situation of Assam in the 21st Century

After a tumultuous 1990s that resulted in a budget deficit of 7.8 billion rupees, Tarun Gogoi of Congress (I) formed the state government in 2001 and remained in power for three successive terms till 2016. As a result of what had happened in the decade of the 90s in terms of insurgency and counterinsurgency operations, during his first tenure, he had to faced dampened public spirit that had very little faith on the ability of the state to protect its citizens. Through his administrative acumen and the support of young ministers and experienced civil servants, Gogoi improved the condition of the state substantially (Mukherjee, 2010). Finance was one of the major challenges that his government had to face at the beginning of his tenure. In a situation where there was virtually no significant development, and the general masses were highly dissatisfied with the state, the insurgent groups found fertile ground for recruiting the youth. Unlike other Chief Ministers before him who believed that development cannot begin without first achieving peace, Gogoi decided to bring development first by taking small steps at a time (see Ibid). After the government's finances stabilized a bit and he was able to garner public support, Gogoi turned his attention towards the insurgent groups that continued to threaten the peace in the state. He also urged the Assam Police to stop the killings of militants and their family members. By 2006, the support of the public towards the ULFA had waned. After being ousted from the camps of the neighboring countries, two of the three of ULFA's 28th Battalion (its most violent wing) expressed their desire for a ceasefire. After two years of negotiations between the state government, central government and the insurgent group, the two companies of the 28th Battalion surrendered their arms in 2008. The government provided each former insurgent with a financial rehabilitation package of 2,00,000 rupees, after which, in the following year, civilian deaths decreased by 22 percent in Assam (Mukherjee, 2010). For the ethnic militants Gogoi had to pursue a different strategy was to grant them regional autonomy. He applied this approach with the Bodos with whom the government signed its second accord in 2003 (Ibid). In spite of all these developments, Gogoi's last term was marked by widespread corruption, administrative incompetence which was compounded with arrogance and increasing disconnect with the masses. Moreover, the Congress at the state level was also weakened by internal dissension and family politics. This gave the space to the Bharatiya Janata Party (BJP) who tactfully refrained from using the Hindutva agenda considering the specificity of the state. Instead the party pushed the agenda for development and identity appealing to the people of Assam to vote for the protection of the *maati* (land), *bheti* (hearth) and *jati* (nationality). This campaign needs to be seen in the light of the religious breakup of the 2011 census that was released by the National Democratic Alliance government, according to which, the rise of the Muslim population in the state was the highest in the country level, surpassing even Jammu and Kashmir (U. Misra, 2016). This created a lot of apprehensions in the minds of the different ethnic communities who felt that they would be completely marginalized in the state's politics. Regional political parties such as the AGP, which had lost much of its credibility but still had a substantial number of voters in the rural areas, also made the threat to identity a major issue. Seeing the flow of the wind towards ethnic insecurities, the BJP built up an electoral alliance with the regional forces and ethnic forces such as the AGP, the Bodoland People's Front (BPF) and the Rabha, Tiwa and other organizations that led to its landslide victory in the state elections (Ibid).

After the BJP came to power, however, it introduced the Citizenship (Amendment) Bill, 2016, which recommends that illegal immigrants who are Hindus, Sikhs, Jains, Parsis, Christians and Buddhists, people from all other religions except Islam, from Afghanistan, Bangladesh and Pakistan will be eligible for citizenship in India. The indigenous people of Assam have protested against this Bill as they do not want any immigrants, irrespective of their religion, in the state out of the fear that they will be turned into a minority. Bengalis from the Bengali-dominated Barak Valley, however, have supported the Bill, which had resulted in another conflict situation in the state (https://qrius.com/hindutva-politics-in-assam-an-overview/). In addition to this Bill, another burning issue in the state at present is the updating of the National Registry of Citizens (NRC), a product of the Assam Accord to remove illegal immigrants from the state. The NRC was last updated on March 24th 1971, which is the cut-off date to identify those who had entered Assam illegally from Bangladesh. The NRC demands legal documents or proofs of legacy data to prove the citizenship of an individual. If s/he cannot prove their citizenship, they are likely to be deported. According to the lists prepared by the government of Assam, most of the names that are missing from the NRC data are Bengali Muslims, which have resulted in widespread fear among the people of this community (Ibid).

Thus, the root cause of the current socio-political problems in Assam was sown much earlier in history by the colonizers, which unfortunately have continued to haunt the people of the state from time to time. The multi-ethnic character of the state makes it impossible to solve any issue affecting one particular community, as the solution creates problems for the other communities. The fate of the dispossessed communities such are particularly vulnerable in such a scenario. In such a volatile scenario, it is not surprising that the issues of women or that of disability do not get much attention. Let us now look at the position of women in the state, just to derive an idea about the lives of women with disabilities in the state, as research on this topic is particularly limited.

Women's Position in Assam

The previous section had traced the socio-political history of Assam from the pre-colonial up to the present period. This section traces the position of women in the society of Assam, particularly the Brahmaputra Valley, from pre-colonial to the present period from whatever scanty literature that is available on this subject. It is important to study women's position in a particular society historically because it has been found that their position has not been static across different time periods, and has changed according to the conditions prevalent in a specific historical period. Additionally, even though women's position differs from society to society, yet not much work has been done on women and gender relations in the context of Assam. Due to this reason, it is very important to study women's position in Assam more deeply. As can be deciphered from the previous section, the context of Assam is complicated by its multi-ethnic and multi-lingual character. This implies that upholding a singular image of the women of Assam is not plausible. In spite of this, unfortunately not many studies have focused on the experiences of women belonging to different ethnic communities of the state, due to which the present write-up will not be able to throw light on this topic. Before we begin this analysis it is important to state that there is a commonly held belief among the people of Assam and, in fact, the entire NER, that women enjoy greater freedom than their counterparts in the rest of the country. This is primarily due to the absence of any apparent restriction on their mobility as well as the absence of certain practices such as dowry, sati, female feticide and infanticide, the practice of wearing veil and so on (Buongpui, 2013). Despite this visible gender equality, this picture of women enjoying a higher status in the society of NER is only an illusion as women face strong discrimination mainly in the light of tradition and customary practices (see Xaxa, 2008; Buongpui, 2013). Keeping this perspective in mind, let us now examine the position of women of Assam in different historical epochs. The purpose of this exercise is to better contextualize the position of the study participants.

Women in the Pre-Colonial Era: The society of Assam during the pre-colonial period was largely patriarchal in nature, although among some ethnic communities such as the Bodos and Dimasas, matrilineal and matrilocal features were also prevalent (M. Deka, 2013). According to Meeta Deka (2013), due to this reason, in the historical writings of this period, women are almost non-existent. For the historical reconstruction of women from this period, historians have focused on different institutions and practices such as marriage, sati, *devasasi* system, the non-state legal system, the economic system, as well as, myths, legends and folklores (see M. Deka, 2013).

Different sources have shown that from the ancient period, women of Assam were proficient in the art of weaving. Under Ahom rule, women were allotted the compulsory work of spinning and weaving. During the rule of *King Pratap Singha* (1603-41), *Momai Tamuli Barbarua*[99], an able administrator and commander-in-chief of the Ahom army, promulgated an order that every capable woman should spin two copses of yarn and every man should make a basket or sieve before retiring to bed. The next day he would go around and gather information about this and take note of the progress (Bhuyan, 1965, as cited in M. Deka, 2013). Due to this reason, nobody was able to evade their responsibilities, and if someone was found neglecting their duties without any reasonable excuse, then s/he was punished. It was also mandatory for every household under Ahom rule to contribute one seer of home-spun silk annually to the royal stores (Bhuyan, 1965, as cited in M. Deka, 2013). Furthermore, weaving was not just an activity only for the household, but had economic, social and ideological implications as well. One interesting aspect about weaving was that it was associated with the magical or divine powers of the women. During the Ahom period, the warriors went to the battlefield by wearing a *Kavach-Kaapur* (talisman cloth), the

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[99] Momai Tamuli Barbarua is credited for making spinning and weaving universal among the women of Assam irrespective of their caste, class or social status (www.revolvy.com)

yarn of which must be spun and woven in the course of one single night. It is said that the Ahom general *Phrasengmung Borgohain*, husband of *Mula Gabhoru*, died in the battle field because he did not wear this protective garment (Bhuyan, 1965, as cited in M. Deka, 2013). Such beliefs and practices signify the important role that women played in the political battles and warfare (M. Deka, 2013).

In spite of this, the most important duty for the women during this period was to be a faithful wife and a devout mother (B. Borah, 1993). Even though men and women were assigned equal responsibilities for economic production under Ahom rule, this did not take into consideration the domestic work and the responsibilities of reproduction, childbirth and childrearing that were carried out exclusively by women. Thus, while the women crossed their boundary within the private sphere and ventured into the public sphere, which was the domain of men, the reverse was not seen in the case of men (M. Deka, 2013), something that has not changed much even in the present period as we will see in the next sections.

Apart from these customs, polygamy was much prevalent during the period of Ahom rule. Shihabuddin Talish, the chronicler who had accompanied Mir Jumla[100] during his conquest of Assam in 1662-63, had observed that most of the men of that period had four to five wives. According to M. Deka (2013), during that period a man's status in society and the village councils was determined by the number of wives he had, and the larger the number, the greater was his influence. Shibabuddin Talish had also observed that the women never veiled their faces in front of anybody, even in the market place (Ibid), which was perhaps not the case in the other regions of the country. J. G. Nath (2010-11), however, argues that he had mainly written about women in and around Gargaon, the Ahom capital, and more particularly about women from the Ahom community. According to her, since the Ahom society of that period had still not come under the grip of the Hindu scriptures, it had probably allowed its women free and liberal movement, in comparison to women from other communities

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[100] Mir Jumla (1591-1663) was appointed as the Governor of Bengal in 1659 by the Mughal Emperor, Aurangzeb. Thereafter, he invaded Assam heading a vast army. In 1662 he advanced as far as Garhgaon, the capital of the Ahom kingdom, and compelled King Jayadhvaj Singha to surrender Western Assam to the Mughals (P. Goswami, 2004). However, the difficult terrain and the malaria prone climate took a heavy toll on the Mughal army. This forced Mir Jumla to retreat in 1663 without having fully accomplished the subjugation of Assam. He was himself stricken by malaria, and on his way to Bengal he succumbed to the disease on 30th March 1663. His mortal remains are buried on a hillock in South Garo Hills, which is maintained by the Mazar Sarif committee (www.southgarohills.gov.in).

that were completely governed by Brahmanical laws (Ibid). Regardless of Shihabuddin Talish's observations, we have very little information about gender relationships during the Ahom period. The Ahom chronicles provided very little space to the women. Those who did find space were usually from the royal families and their depiction was usually based on their devotion towards their husbands and sons, or for the greater cause of the nation (B. Borah, 1993). It is, however, said that among the Ahom royal circles, the wives were supposed to address their husbands as '*Bangahardeuta*' meaning 'the god of the family' (Ibid), which shows the position of the royal men and women within the family.

As cited earlier in the chapter, Sankardeb's *Neo-Vaishnavism* played a key role in changing the material life of the people. These significant changes had a profound impact upon the women in the society of Assam. The Neo-Vaishnava reformers were advanced agriculturalists who introduced advanced methods of agriculture such as the move from shifting cultivation to settled cultivation, and the use of bullocks instead of hoe (P. K. Nath, 2014; B. Borah, 1993). As a result of these changes, women lost their main role in cultivation, which indirectly made them inferior to the men. Furthermore, Neo-Vaishnavism did not allow the women to keep livestock such as pigs and fowls which formed sources of their economic strength in the agrarian society of Assam. As a result of this, women lost their economic power (J. G. Nath, 2012).

Furthermore, Sankardeb vehemently disowned the Mother Goddess[101] who was worshipped by the tribal people of this region (J. G. Nath, 2012). Even though during the medieval period Siva and Shakti were worshipped together, according to J. G. Nath (2012), Sankardeb's attitude towards Siva was not similar to what he had shown towards Shakti[102]. Furthermore, in Sankardeb's religion, the female deity, *Radha*, the companion of *Lord Krishna*, was absent. According to Kakoti & Mahanta (2012), this was because in his religion the relationship of man to God was that of a servant to his master, and not that of a woman to her beloved, as postulated by the other Vaishnava saints of that period. Sankardeb's principle disciple, Madhavdeb, also insisted people to stop the worship of the female deities. It is in fact said that once he refused to take

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[101] Mother Goddess was worshipped as Sakti or Supreme energy. Her worship led to the growth of Saktism with its centre in Kamrupa with its chief temple at Kamakhya. For much of the period in medieval Assam, the leading religion was Saktism (B. Borah, 1993).

[102] Sankardeb in his literature had equalized Siva with Vishnu. According to one scholar this is because Siva, unlike his consort Parvati, was a male deity who arose out of a pastoral society where the father is the head of the group, and not the mother (Barman, 2011, as cited in J. G. Nath, 2012).

food served by Sankardeb’s wife when he came to know that she worshipped a minor female goddess inside her kitchen (J. G. Nath, 2012).

The Neo-Vaishnava reformers also discriminated against women by not allowing them to take initiation in the faith as *bhakats* in the *Xatras*. According to B. Borah (1993), this could be because he was skeptical that the women will not be able to observe the strict tenets that he had laid down for his disciples, as, for him, the primary duty of women was to devote themselves to their husbands. Sankardeb also stressed that an ideal woman was a chaste woman and he described such a woman as someone who had not glanced at any person other than her husband. In this way, according to B. Borah (1993), he advocated for the seclusion of women. They were not allowed to mingle with the religious affairs or to mix with the men in the religious congregations. Women were also not given any priestly roles in the *Xatras* as these roles were reserved exclusively for men (Kakoti & Mahanta, 2012). A few apostles of Sankardeb have, in fact, treated women as inferior to men. This is more prominent in the Barpeta *Xatra*[103] where women are still not allowed entry to the main prayer hall because it is alleged that women may pollute the sacred premises of the religious institution by entering it during the days of their menstruation[104] (B. Borah, 1993). It is said that in the course of conversion to *Vaishnavism*, the Hindu notions of purity and pollution were introduced in Assam in matters related to food, childbirth and death. Accordingly, menstruating women were considered to be polluted and were treated as untouchables and were not allowed to enter into sacred places such as the *naamghar*, *manikut*[105] and kitchen (J. G. Nath, 2012). During the period of a woman’s menstruation[106], men of the family had to cook the meals if other female members were not available. However, the prevalence of the joint family system during that period made such instances extremely rare (M. Deka, 2013). Women’s fertility,

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[103] Established by Madhavdeb in 1570, the Barpeta *Xatra* is one of the oldest *Xatras* of Assam.

[104] It is ironic that the menstruating Goddess, Kamakhya is worshipped by the people of Assam while a menstruating woman till today is forced into seclusion because she is considered to be impure. It is believed that the Goddess menstruates for four days in the month of June. In case a woman is menstruating during this period, she is expected to be stricter about observing her taboos and restrictions (M. Das, 2008).

[105] *Manikut* is an independent room that is constructed in the eastern-most part of a *naamghar* where the *guru-asaan* is installed. Guru-asaan (the seat of the guru) is a seven-tiered triangular wooden throne where the sacred scriptures of *neo-Vaishnavism* are kept.

[106] During the period of menstruation, a woman is considered to be impure in Assam. Due to this reason, they are not allowed to say their prayers or enter the kitchen, and are also supposed to eat and sleep separately (M. Deka, 2013). Such customs are still followed in certain regions of the Assam (see M. Das, 2008).

therefore, became a curse and source of shame, while men's potency was considered to be a virtue (J. G. Nath, 2012). Such kinds of instances clearly show that the Neo-Vaishnava preceptors maintained a strict notion of patriarchy in their religious expressions (J. G. Nath, 2012).

There were, however, many differences between the views of Sankardeb and Madhavdeb towards women. It is said that Sankardeb was somewhat liberal in his attitude towards women. For instance, he had led the life of a householder and did not advocate celibacy. On the other hand, Madhavdeb advocated puritanism and he considered women as a source of temptation. He also refused to marry Sankardeb's daughter because he said that he did not yearn for such beastly temptations (B. Borah, 1993). He had also suggested Sankardeb's wife to address and treat her husband as 'Gosain' (God) (Ibid).

In spite all these restrictions, a few women have been successful in claiming an honored position in the *Neo-Vaishnava* order through their intellectual caliber. The most prominent among them was *Kanaklata* alias *Laxmi Ai,* Sankardeb's granddaughter-in-law, who organized a group of 12 apostles and assigned them with the responsibility of expanding the *Xatra* network and to reach out to as many people in different places as possible (B. Borah, 1993; Kakoti & Mahanta, 2012). The 12 *Xatras* eslablished by these 12 apostles came to be known as *Kanak Bara Janiya Satra.* Following her, the other granddaughters-in-law and granddaughters of Sankardeb also set up *Xatras* which came to be known as *Sri Sankar Jiyari Vamsar Xatra* meaning 'monasteries set up by the female descendants of Sankardeb' (B. Borah, 1993). Another prominent woman was *Padmapriya*, daughter of Gopal Ata, who was a learned scholar and had composed many devotional songs of the *Vaishnava* faith. She is, in fact, credited to be the first women poet from Assam (B. Borah, 1993).

As cited above in the chapter, although in the initial period, the Ahoms who were followers of the Shakti cult, were opposed to *Vaishnavism*, the growing popularity of the religion among the masses forced the rulers to recognize the faith towards the middle of the 17th century (Bhuyan, n.d.; P. K. Nath, 2014). As a result of these developments, from the late 17th century onwards, women of Assam came under patriarchal control where both the state and its religion played a major role in their oppression (J. G. Nath, 2012). J. G. Nath (2012) has argued that the Ahom state and the Neo-Vaishnavite movement emerged and developed under the same social condition of the Brahmaputra Valley. This was because the aim of both the systems was to bring the tribal population of the region under their fold. Another similarity is that both the systems are patriarchal by nature as they were based on the hierarchies of caste, class and gender (Ibid). This decline in their status was further enhanced in the 19th century, when the most backward communities and castes began imitating the rules of the high caste in order to obtain a higher social status to be recorded in the census reports (J. G. Nath, 2012). In spite of all these problems, due to the influence of the tribal cultures, several evil practices such as sati and prohibition on widow remarriage were absent amongst most communities of Assam, except the Brahmans (Ibid). According to M. Deka, (2013), some of the social practices of Assam, in fact, were, and still are, in favor of women, in contrast to the dowry system prevalent in the rest of India. These practices include the custom of *juroon* where the bridegroom sends ornaments, clothes, sweets, fish, betelnut and coconut to the bride before the actual marriage ceremony and the practice of *gadhon* or bride price which was prevalent among different tribal communities of Assam such as Bodos, Mishings, Dimasas, Koches, Tiwas and Rabhas. The Karbis, however, did not have the practice of bride price. Among tribal communities, the parents of marriageable girls can demand for the *gadhon,* both in cash and in kind, from a potential suitor. If a young man or his guardian fails to fulfill the demand, the marriage negotiations either fail or the young man is given the chance to serve at the girl's house for a year or two as a replacement for the cash and kind demands. After the settlement of the marriage is made and a date for the ceremony is fixed, the bridegroom and his relatives go to the bride's house where they formally offer all the demands made, in the presence of the invited guests, through which the marriage acquires sanction from the community. In cases where the guardians of the bride and the groom fail to come into a consensus regarding the marriage settlement, the couple sometimes agrees to elope, or in certain cases, the girl is forcibly abducted. In such cases, the couple will have to obtain the sanction from the guardians and the community at large by holding a feast, where they formally announce their marriage (M. Deka, 2013). In certain cases, the young man stays in his father-in-law's house either for a certain period or for the entire life. This is known as the system of *ghar juwai rakha*. Different tribal communities also had different classifications for different types of marriage (see ibid). According to M.

Deka (2013), these practices have an economic element to it, which is that a woman is an economic asset to her parents' household before her marriage, in terms of maintenance, farming, weaving and childrearing, who is taken away from her parental home at the time of her marriage through the payment of bride price[107].

As mentioned earlier in the chapter, *King Siva Singha* (1714-44) took initiation in the Sakta cult from Krishnaram Nyayvagish from Bengal, who was an upholder of the *navya-smiriti* of Raghunandan. Raghunandan Bhattacharya, a 16th century Brahmin from Nadiya, Bengal, had redefined the codes of behavior related to demarcation between castes, and rules related to marriage and childbirth. In addition to other things, he had emphasized upon pre-pubertal marriage of women in order to protect the purity of caste. This code was followed in Assam under the royal patronage, but its effect was imposed mainly in Upper Assam, the seat of Ahom power. Under the initiative of Krishnaram, the *Brahmavaivarta Puran*, where the origins of various castes were narrated, was translated into Assamese (J. G. Nath, 2012). According to J. G. Nath (2012), these two developments are historically significant in the process of development of the caste system in Assam as well as the imposition of a subordinate status to women in the society of Assam. She also speculated that as the caste system grew in rigidity, women became the focus of male mistrust as a source of danger for their social status, which consequently resulted in increased male domination (Ibid).

As stated earlier in the chapter, the Ahoms had introduced the *paik* system for which manpower was indispensible. Even though this system was apparently concerned with adult men alone, in actual practice, women also played a crucial part in the production process (see J. G. Nath, 2012). Additionally, in the chronicles and biographical literature of this period, there is mention of a class of female vendors called *pohari*. During the Ahom period, money economy had not developed in its full sense and barter was the usual way of transactions. In this system, the exchange and distribution of goods was mainly in the hands of women, who had the power to decide which items to sell, barter or acquire. Such an experience made the *pohari* women vocal and argumentative, one of whom even dared to rebuke King Jayadhvaj Singha for his inability to protect his people from foreign aggression. Their frequent mention in the

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[107] Even though the prevalence of the practice of bride price is considered to be an indication of high status of women, in the current scenario, research has shown that in several such communities, women are treated as mere commodities that can be easily procured by men through the payment of bride price (see Xaxa, 2008;

chronicles of that period suggests that they were an important class of people and were under less patriarchal domination. The *pohari-s* belonged to all the caste groups, except the Brahmins and Kayasthas (J. G. Nath, 2012). J. G. Nath (2012) further said that the women who were associated with the production system and had some economic power in their hands, irrespective of their castes, experienced less patriarchal subordination and occupied almost equal position as the men in their families. This feature, however, gradually changed as the state and religion, backed by the Raghunandan code of Bengal, combined to regulate the brahmanical social norms and began to exercise power over society (J. G. Nath, 2012). Due to these changes gradually, the profession of *pohari* along with spinning, weaving and other manual work done by women outside of the house, began to get treated as low and impure professions. These changes had a profound impact on the gender relations in the society of medieval Assam, which were characterized by reciprocity and not by exploitation of one sex by another. Concepts such as chastity and sexuality were not much emphasized upon during this period, which means that young women from all other communities, except the Brahmans and Kayasthas, exercised considerable choice in their own marriages. Dissolution of marriage was also permissible on the initiative of either of the partners, and children born outside the wedlock were not unacceptable to the society. Widow remarriage was also acceptable amongst most of the castes except the Brahmins till the 19th century. However, with time, this practice began to be despised by the society. Among the Brahmins, marriage was considered to be a sacrament for the women, while other castes and communities were free to marry as many times as they wanted. From the late 19th and early 20th century this began to change as the code of conduct of the upper castes began to spread across different communities. Other practices such as keeping the son-in-law in the father-in-law's house (*ghar juwai rakha*) and taking bride-price (*gadhan*) which were once popular among the people of Assam were gradually condemned as low in the Raghunandan code (J. G. Nath, 2012).

In the medieval period there have been a few courageous women who have played exemplary roles in the political arena and the battlefield and have laid down their lives for the cause of the nation. These women are celebrated as heroines by the people of Assam. A closer look at them, however, would show the supreme devotion of these women towards their husbands was the cause for their acts.

Mula Gabhoru (also known as *Nang Mula*) was an Ahom princess, who was married to the Ahom general *Phrasengmung Borgohain*. He fought against the invading Mughal army in 1527 and died after seven days in the battlefield. As mentioned earlier, it is said that he got killed because he did not wear his *Kavach-Kaapor* on the battlefield (M. Deka, 2013). After his death, Mula Gabhoru got down in the battlefield to take the revenge of her husband's death, but eventually got killed in 1532 by the commander of the Mughal Army, Turbak Khan, who had earlier also killed her husband. It is said that her death inspired the Ahom army to fight more vigorously which helped them in defeating the Mughals.

Soti Joymoti (also known as *Joymoti Konwari*) was an Ahom princess who laid down her own life in order to protect her husband, Prince Gadapani, from being mutilated or executed. Between the years 1671-1681, Assam was ruled by many incompetent kings who were mere puppets at the hands of the nobles and Prime Ministers. One of such kings was *Sulikhpaa* (his Hindu name was *Ratnadwaj Singha*), who ruled over the kingdom as a puppet king of the Prime Minister, *Laluksola Borphukan* from the period of 1679-1681. King Sulikhpaa was merely 14 years old at that time because of which he is also known as the *Lora Raja* (Boy King). During this period, *Lora Raja*, at the advice of his Prime Minister, ordered the mutilation of all the princes of *Sukaphaa*'s[108] clan, the motive of which was to keep the puppet king on the throne for long so that Laluksola would have the sole power of ruling over the state. In such a situation all the Ahom princes, including Prince Gadapani, who was the most obvious heir to the throne, escaped to the Naga Hills. When the King's men were not able to find Gadapani, his wife Joymoti was called upon to disclose his whereabouts. Joymoti had two young sons, aged 14 and 12, and was also pregnant during that period. For 14 days Joymoti suffered from different kinds of inhumane physical torture at *Jerenga Pathar* at Sibsagar. In spite of the torture, she did not give out any details about her husband. It is said that during this period Prince Gadapani had visited her in disguise, but she indicated him to leave immediately. After 14 days of torture, she passed away at the hands of the Lora Raja's men in March 1679. For her courageous battle, Joymoti was given the title of 'Soti' (Sati). It is to be noted that Prince Gadapani, who came to be known as *King Gadadhar Singha*, came to power in 1681 and ruled over

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[108] *Sukaphaa* (1189-1268) was the founder of the Ahom kingdom, who reigned over Assam from 1228 up to his death in 1268.

Assam till 1696. It was due to his efforts that the region of Lower Assam was reclaimed back from the Mughals in the year 1682. Such a feat, however, would not have been possible without the help of his wife Joymoti[109], who laid down her life for the cause of the nation (B. Borah, 1993)

Apart from these two women who belonged to Ahom royalty, there were also other women who had been at the forefront against the Ahom kings during the Moamaria rebellions. In the first rebellion (1769-1770), the two wives of the Moran leader, Nahor Saikia, Radha and Rukmini, had led the rebels into the battlefield. With their martial genius, they were able to create chaos in the royal camp (C. K. Sharma, 1996). It is sometimes said that Radha and Rukmini possessed supernatural powers[110] through which they were able to catch the enemy's bullets through the corners of their *chadars* (B. Borah, 1993). These two women also held important state portfolios under the rebel administration. During the third Moamaria rebellion (1786-1794), a woman armed force was led by Chandramala, a Brahmin woman (C. K. Sharma, 1996). Apart from such scattered information, not much is known about the political participation of women during medieval Assam.

The Burmese incursions that overthrew the rule of Ahoms from the Brahmaputra Valley, also had a profound impact on the status of women in the society of Assam. According to Konwar (2017), this event curtailed the freedom of women considerably as there was a fear of abduction by the invaders. In order to avoid such insecurities, the Hindus of Assam preferred to marry off their daughters at an early age to men of the same community, some of whom were previously married. Over time, these security measures turned into social customs like early marriage and polygamy (Ibid).

From the above discussion we can see how the women of the Brahmaputra Valley were brought under patriarchal domination through different religious orders during the medieval period. As we will see in the next section, religion continued to play an important role in their subjugation throughout the 19th century, after which they got involved in the freedom struggle that brought about significant changes in their

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[109] Over the years, Joymoti's valiant struggle has been immortalized in Assamese folklore. The first Assamese film, made in the year 1935 by Jyoti Prasad Agarwala, was also a biopic about her. March 27th is celebrated as Soti Joymoti Divas in Assam.

[110] In various religious texts, Assam has been associated with the prevalence of magic and sorcery (B. Borah, 1993).

outlook, even though their devotion towards their husbands and families continued to persist.

Women of Assam during the Colonial Period: As mentioned earlier in the chapter, Assam was annexed by the British in the year 1826 and a decade later, in 1836, influenced by the clerks from Bengal, the British replaced Assamese with Bengali language as the medium of instruction in the schools of Assam (M. Deka, 2013). As a result of this, certain Assamese intellectuals from that period urged the need for the revival of the Assamese language. Around the same time, the American Baptist missionaries arrived in Assam for the purpose of proselytization and established the 'Shivsagar Mission' in 1846 (P. Goswami, 2004; M. Deka, 2013; Konwar, 2017). The missionaries adopted the Assamese language for this purpose, and also started publishing the first ever Assamese monthly magazine, *Orunodoi*, from Sibsagar in the same year (M. Deka, 2013; Konwar, 2017). The magazine published articles on world news, moral education, stories, history and geography. Most of the contributors to the magazine were male writers. Through its contributions, the magazine helped in forming public opinion about issues prevalent during that period such as women's education, child marriage, polygamy and widow remarriage (Ibid).

It is noteworthy that like in the rest of the country, the British tried to justify their rule in Assam through the women's question (M. Deka, 2013). In the first volume of *Orunodoi*, published in May 1846, there was a description of the practice of widow immolation followed by its legal ban in India. The journal then described a case of sati that was prevented in a village in Sibsagar, through the intervention of British authorities. The article presented the British as 'the savior' of the race (M. Deka, 2013). This, according to M. Deka (2013), was one of the few instances of sati that was reported in Assam, as widow remarriage was allowed among most of the communities, except the upper castes. Apart from these articles, colonial writers presented the women of Assam as having 'low morality' and 'low status', which was nothing uncommon for them, as they had to justify their 'civilizing mission' in order to continue their rule over the territory of Assam unhindered. Additionally, certain social practices of the tribal communities such as *gadhon* were intentionally misrepresented in colonial historiography as a custom of trading of girls, again in order to justify British rule on the grounds of their moral responsibility of the 'white man's burden' (Ibid).

The American Baptist Missionaries started the first schemes for girls' education in Assam. Before 1826, formal education was restricted only to men. The wives of the missionaries set up schools for boys and girls. According to them, the main barrier for women's education was their own ignorance about their capabilities that have been forced on them since the time of their birth (Konwar, 2017). Some of the other barriers include, child marriage, female seclusion, suspicion of the motives of the white women, superstition among the Hindus that if a girl is educated she would become a widow and so on. Unable to make any advances in this respect, the missionaries began to establish boarding schools where they educated orphaned or destitute children and abandoned girls (Ibid). The women's question and their lack of education, therefore, became the basis of justification for British rule in Assam. Regardless of the women's position in pre-colonial Assam, the colonial administration imposed traditional 'male' Western values regarding the proper rules of men and women according to the dominant values associated with the Victoria era of England (Viswanathan, 1997, as cited in M. Deka, 2013). Furthermore, the missionary schools introduced during that period imparted different home science education for the boys and girls which eventually reinforced the stereotypical roles of men and women (see M. Deka, 2013).

It is important to note that social reform movement that began in neighboring Bengal in the beginning of the 19th century, took a long time to reach Assam. One of the reasons for this could be that very few people from the Assamese intelligentsia were aware about the developments in Bengal. Additionally, those who were aware belonged to the conservative caste-Hindu society and were suspicious about such developments (J. G. Nath, 2010-2011). It was only towards the end of the 19th century, that visible changes were seen in the outlook of a few men who supported the cause of women's education as an instrument of changing their subordinate position in the community (M. Deka, 2013; Konwar, 2017). Influenced by the reformist enthusiasm of Bengal, particularly the ideas of Ishwar Chandra Vidyasagar, a few intellectuals such as *Anandaram Dhekial Phukan* (1828-1859), *Hem Chandra Barua* (1835-1896) and *Gunabhiram Barua* (1838-1894) fought for women's equal rights in the matters of education, polygamy and widow remarriage through their own examples (M. Deka, 2013). Anandaram Dhekial Phukan taught his wife, Mahindri Devi, at home by himself and formally started his daughter, Padmawati's, education at the age of five years (Konwar, 2017). Hem Chandra Barua did not remarry after his wife's death by stating that if it was the other way round, his wife would have been unfairly treated as an outcaste by the society. Gunabhiram Barua got married to a widow, Bishnupriya Devi, who had two children (M. Deka, 2013). These men, therefore, argued against polygamy and advocated for women's education and widow remarriage.

The reformist views on women's education were attacked by the conservatives whose viewpoints were published in another journal, *Assam Bandhu.* The latter group was concerned about protecting the sanctity of Hindu law and traditions from contamination by western ideas imported through western education. They had apprehensions that education would make women idle, luxury loving and unfit for doing household chores, all of which, in their opinion, will have a disastrous impact on the family and the society at large (J. G. Nath, 2011; Konwar, 2017). Some among them advocated that women's education must be approved only in regards to creating an ideal wife and mother. Several debates ensued in the various Assamese magazines of that period delineating the pros and cons about women's education. In spite of the efforts of the reformists to initiate the education of women, the people of the state largely remained indifferent to this cause till the end of the 19th century perhaps because of their conservative mindset. Gradually, however, the work of the missionaries and the debates between the reformists and the conservatives in the magazines had a positive impact on the outlook of some western educated men towards women's education (Ibid). The situation also changed after the publication of the *Hunter Committee Report* on education in 1883 that strongly recommended the government to take steps regarding women's education. As a result of this, in 1884, a government M.E. school was established in Shillong, and in 1885, a girl's M.V. school was established in Dibrugarh, which was the first school for girls' in the entire NER (J. G. Nath, 2011; Konwar, 2017). As a result of these developments, girls from certain upper caste families were allowed to go to Calcutta for their collegiate education by the beginning of the 20th century which brought about considerable change in the outlook of the women towards their experiences (M. Deka, 2013).

The publication of *Orunodoi* became irregular by 1860. However, from the period of 1836-1860, several European and American women began to write textbooks, story books, biographies and dictionaries. Although these writings were not of high literary standards, they helped in breaking the taboo against women writers and encouraged Assamese women to make similar attempts (Mahanta, 2008 as cited in M. Deka, 2013). Towards the end of the 19th century, several upper caste women, who belonged to the families that were exposed to English education in schools and colleges of Calcutta, began to write about their experiences through literature and poetic narratives. Some of these women also questioned the prevailing social norms and tried to bring about social change through their own examples (M. Deka, 2013). The contribution of three first generation women writers from the 19th century who advocated for women's education is particularly noteworthy in this regard. These women were *Bisnupriya Devi*, *Swarnalata Devi* and *Padmavati Devi Phukanani* (Konwar, 2017). Bisnupriya Devi and her daughter, Swarnalata Devi, remarried after they became widows, which was a bold gesture during that period (M. Deka, 2013). Padmavati Devi Phukonani, daughter of Anandaram Dhekial Phukan, had written, what can be considered the first novel (*Sudharmar Upakhyan*) in Assamese language in the year 1884, where she highlighted the social problems and gender relations of the main characters (M. Deka, 2013). In their views, however, these women upheld the management of the domestic sphere as the primary aim of women's education (Konwar, 2017).

One of the most remarkable women writers, who eventually also became a prominent agent of social change, in the early 20th century, was *Chandraprabha Saikiani* (*nee Das*) (1901-1972). As a young girl, Chandraprabha had witnessed how her widowed sister, who had remarried, was ostracized by the society for being from a lower caste. Chandraprabha herself was engaged to an older man as a child, but when she came of age, she refused to marry him. In 1919, when she was working as the headmistress of a girls' school, she came into contact, and later fell in love, with Dandinath Kalita, who was a poet and a writer. Kalita, who was already married, refused to acknowledge Chandraprabha as his wife. He also did not allow her to use his surname, as she was from a lower caste. Following this scandal, she had to leave her job and return back to her village, where she gave birth to her son in 1923. Since that time she began using the name 'Chandraprabha Saikiani' in order to tell the world that she was married. In her writings, Chandraprabha boldly dealt with the topics of child marriage, social hypocrisy and sexual exploitation of widows and prostitution. From 1925, she became involved with the activities of the *Assam Mahila Samiti* and

Congress activities and devoted herself completely for the cause of the nation, and also of women (M. Deka, 2013), as we will in the following paragraphs.

Even though the issues regarding the women's question had not been resolved, in the beginning of the twentieth century, newer situations emerged that helped in awakening the women's consciousness. As cited above, the years 1919-1920 were very important in the history of India as the struggle for freedom from British rule intensified under the leadership of Gandhi. He had launched three important movements to overthrow the rule of the British. These movements were the Non-Cooperation Movement (1921), the Civil Disobedience Movement (1930) and the Quit India Movement (1942) (N. Saikia, n.d.). What was noteworthy about these movements was the large-scale participation of women from all walks of life. Unlike the 19th century reformers who believed that women were objects to be reformed, Gandhi believed that women were active, self-conscious agents of social change. He also believed in radical social reconstruction, and for this he involved those who had hitherto been powerless, that is, the women (and also the people from lower castes, whom he rechristened, *Harijans*) (Nandy, 2006). Gandhi had realized the important role that women could play in the freedom movement and so he introduced the spinning of the *charkha*. This was a good political strategy because women could spin the wheel even by staying at home, while attending to their household chores. This also reassured the men in the family of the women's safety and thus their honor, as women did not have to step out of their homes to engage in political activities. This was also a very pragmatic strategy because Gandhi had realized that women generally have greater say in the domestic domain, especially what their children should wear, in comparison to the men (Patel, 2006).

Gandhi's strategy worked effectively on the women of Assam because, as shown earlier, they have always been proficient in the art of weaving. Due to this reason, the boycott of foreign clothes was highly successful in Assam (Puzari & Mazane, 2001) and the women from the state have received enormous praises from Gandhi and other national leaders, who believed that due to the women's skill of weaving, Assam would achieve *Swaraj* earlier than the other provinces (M. Phukan, 2011; Sagar Bourah, 1999). In spite of the effective participation of women in the Non-Cooperation Movement, their number were still limited to women from upper caste and middle class backgrounds, most of whom belonged to families of Congressmen.

Participation of women from the younger age group and those belonging to tribal communities and from the rural areas was especially limited, mostly due to social constraints (Ibid). Moreover, during this period there was no women's association at the state level[111] to help in the mobilization of women. This need was fulfilled in the year 1926 with the establishment of *Assam Mahila Samiti* (AMS) with *Chandraprabha Saikiani* as the President. In the initial period, the AMS was not politically inclined and worked on issues of women and children. By 1927, however, it got drawn to the freedom movement when the President of the first annual conference of the AMS, *Durgaprabha Bora*[112], urged women to boycott foreign goods by practicing *Swaraj* and to take up spinning and weaving (M. Phukan, 2011). In 1928, an AMS representative was invited for an All Parties Convention to deliberate upon the *Nehru Report*[113]. The meeting was attended by Chandraprabha Saikiani who actively participated in the discussions and decisions. It is important to state this because it was the first time an AMS representative was formally invited to attend a provincial level political conference (Ibid).

When Gandhi launched the Civil Disobedience Movement in 1930, people from different parts of the Brahmaputra Valley participated in the movement in greater numbers. The women took part in processions, picketing of shops selling liquor and foreign clothes, boycott of government run schools and colleges. They also organized meetings to mobilize women and to demonstrate their solidarity with the *Salt Satyagraha.* In response to this, the police resorted to arrests and *lathicharge*. Let us now look at some of the exemplary women who participated in the movement (M. Phukan, 2011).

Pushpalata Das (*nee Saikia*), a student of the Pan Bazaar Girls' High School, organized *Mukti Sangha,* an association to mobilize girls. She along with one of her

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[111] The first women's association, *Dibrugarh Mahila Samiti,* was established in Dibrugarh in the year 1915. This was followed by similar initiatives in Tezpur, Nowgong and other towns. The primary concern of these *Mahila Samitis* was the welfare of women and children (M. Phukan, 2011).

[112] Durgaprabha Bora was the first Assamese woman to Matriculate in the year 1903 (J. G. Bora, 2011).

[113] In 1928, under the leadership of Sir John Simon, a commission of seven exclusive British members reached India to enquire about the reforms that were introduced in 1919. This commission was boycotted by the Congress for not having any Indian members and held several demonstrations against it. Lord Birkenhead, the Secretary for State for India challenged the Indians to produce a constitution that would be acceptable to all. The Indians responded to this challenge by producing the *Nehru Report* which was drafted under the leadership of Motilal Nehru. Among other recommendations, the report proposed dominion status for India (M. Phukan, 2011).

associates, Sarala Saxena, took a pledge, with their own blood, that complete independence is their only goal. She had successfully organized a picketing in front of her school to protest against the death sentence on *Bhagat Singh*, after which she was expelled from the school (Puzari & Mazane, 2001; M. Phukan, 2011). *Chandraprabha Saikiani*, who had played an important role in the Non-Cooperation Movement, was also active during the Civil Disobedience Movement. She collected funds for the Congress, and delivered electrifying speeches in meetings that awakened the patriotic spirit of the masses. As a result, she was issued orders under Section 144 Cr. Pc. to abstain from making speeches for various lengths of time. In 1930, she was prosecuted under Section 108 Cr. Pc. for delivering seditious speeches in remote areas, under reserved forests of Kamrup district by violating the Forest laws. Later in the year, she along with other Congress leaders were sentenced to 18 months imprisonment for violating the Forest laws in Goalpara (M. Phukan, 2011). She was set free in a few months as a result of the Gandhi-Irwin Pact of 1931.

It was found that arrest of male members often inspired their female counterparts to participate in the movement with greater determination. One such example was that of *Kokai Sonowal's* wife, who picketed for five consecutive days after he was sentenced to six months rigorous imprisonment in 1932. She had an 18 months old baby at that time. She was arrested every day for her activities, but was let off every evening because of her baby. On the sixth day she left her baby and went for picketing. This time she was arrest for six months rigorous imprisonment. She was allowed to bring her baby into the jail after a month (M. Phukan, 2011). Another such case was that of Dariki Dasi Baruah who was sentenced to six months rigorous imprisonment and put in Sibsagar jail in 1932. At that time she was in an advanced stage of pregnancy. During her period in jail, she suffered from blood dysentery and had a miscarriage. The jail authorities asked her to request for a conditional release in order to seek healthcare, but she stubbornly refused. Dariki passed away on 26th April, 1932 (Puzari & Mazane, 2001; M. Phukan, 2011).

In the same year, the Communal Award was announced by the British Prime Minister. In protest, Gandhi undertook a fast unto death, which eventually led to the 'Poona Pact' between Gandhi and Ambedkar. Thereafter the issue of *Harijans* and untouchability became an integral part of the Congress movement. In Assam too the impact of the Poona Pact was felt even though the issue of untouchability did not constitute a serious problem in the province (M. Phukan, 2011; Puzari & Mazane, 2001). In 1934, Gandhi undertook a tour of Assam to collect funds for *Harijan* welfare. During this period people donated generously for the cause. During his stay at Jorhat, he had also opened the private temple of a Congress leader, *Krishnanath Sarma*, for the *Harijans* (Ibid). It is to be noted that this move of abolishing untouchability was opposed by most of the *Xatradhikars* (heads of *Xatras*). In 1934, the *Xatradhikar* of *Auniati Xatra*, *Hem Chandradev Goswami* even said that Gandhi's advocacy for eradication of social evils is misguided because such customs of purity and pollution are ordained by the scriptures, and no one has the right to break them (D. Nath, 2005-2006). It was only the *Xatradhikar* of *Garamur Xatra*, *Pitambardeva Goswami* (1885-1962), who had supported[114] this move (D. Nath, 2005-2006). It is to be noted that Pitambardev Goswami was equally supportive of divorce and widow remarriage, and for this he gave adequate references from the scriptures (see J. G. Nath, 2010-2011).

In spite of the large scale participation of the women in the freedom movement, the social prejudices against women had not been fully eradicated from the minds of the Congress leaders. This became clear when the Assam Pradesh Congress Committee did not nominate Chandraprabha Saikiani to contest elections in 1937 after the Government of India Act, 1935 gave provincial autonomy to India. The reason given for this refusal was that she may not win the seat! During the elections, women were given the opportunity to vote for their leaders. However, no woman from the Brahmaputra Valley was elected to the Assembly (M. Phukan, 2011)

In 1939, the Second World War broke out where India was declared as a belligerent without any consultation with the Indian leaders. Following this event, the Congress Ministers resigned and demanded complete independence. Gandhi again called the Civil Disobedience Movement (1940-41) and asked people to not assist the British in their war efforts. This movement, however, was not launched as a mass campaign, and women were debarred from participating in it in the first two phases (M. Phukan,

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[114] In order to eradicate untouchability in the early 20th century, the fishing community of Assam (Kaibartas, previously known as *Doms*) led a movement for upward mobility in order to obtain a more respectable position in society. For this purpose they demanded entry into temples, and the replacement of the word Dom with Kaibarta. Unfortunately, their demand did not get any response from the *Xatradhikars*, except Pitambardeb Goswami. The response from *Xatradhikars* was important because the decision depended on them. Pitambardeb forwarded their claim to the then Governor, who eventually conceded to the demanded of the Kaibartas in 1921 (D. Nath, 2005-2006).

2011). In the third phase, all permanent members of the Congress were considered to be eligible for the *Satyagraha*. Gandhi added another instruction that no woman with a baby of age eighteen months and below should participate in the *Satyagraha*. The movement helped considerably in awakening the masses. Due to the popularity of the movement, the government of Assam had to issue externment notices to the Congress leaders. Due to the growing involvement of the women in the freedom struggle, the Congress Working Committee (CWC) opened a women's wing of the Congress both at the national and provincial level in 1940. In Assam, *Pushpalata Das* and *Amalprobha Das* were appointed as joint secretaries of the women's wing. It helped considerably in drawing women into the Congress fold (M. Phukan, 2011).

In 1942, Gandhi launched the *Quit India Movement* demanding immediate withdrawal of British rule. Subsequently, several male leaders were arrested and Congress Party was declared illegal. As a result, several Congress leaders had to remain underground. Many women enrolled themselves in the *Santi Sena* and took charge of the movement through processions, demonstrations and picketing (M. Phukan, 2011). In the course of the movement several men and women from different parts of the Brahmaputra Valley became victims of police brutality and succumbed to their injuries (N. Saikia, n.d.). On 18th September 1942, a prominent leader of Nowgong, *Bhogeswari Phukanani* was shot at in close range, while trying to protect her 12 years old daughter, Ratnabala, from a police officer (N. Saikia, n.d.). Two days later, on 20th September 1942, *Kanaklata Barua*, an 18 year old woman was shot at her chest in Gohpur, when she was leading 5000 other people to hoist the Indian flag at the Gohpur police station. Kanaklata's martyrdom became a source of inspiration for many others who sacrificed their life for the greater cause of the nation (M. Phukan, 2011; D. Deka, 2019). While maximum women participated in the non-violent struggle, a few also got attracted to violent activities and participated in *Mrityu Bahinis* (Suicide Squad) to carry out subversive activities such as destruction of bridges and railway tracts. This group was later suppressed due to lack of support from the mainstream leaders. Eventually the Quit India Movement failed in its immediate objective to achieve independence due to the brutal suppression by the British. However, it was successful in making the British aware that they will not be able to rule over India for long (M. Phukan, 2011). The movement also gave the confidence to the women to walk out of their homes for the cause of their motherland.

While from the above section we can gather that women played a very active role in the political sphere during the nationalist movement, almost nothing is known about their personal aspirations during this period. As a result, feminist historians have used alternative sources, namely personal documents such as autobiographies, memoirs, journals, diaries and letters, for the study of women's history (J. G. Nath, 2011). J. G. Nath (2011) had tried to understand the social history of Assam in the colonial period through the autobiographies of three Assamese women that were written in the latter half of the 20th century[115], but give a detailed description of their lives from the period of 1900-1947. This period, as detailed above, is very important in the colonial history of India, as well as of Assam, as it witnessed the rise of the nationalist movement and the movement for emancipation of women. The first autobiography considered by J. G. Nath (2011) is *Tinikuri Doh Bosoror Smriti* (*Memories of Seventy Years*), written by *Rajabala Das* (1893-1985), who was one of the first educated women of Assam, and the founder principal of the Handique Girls College of Guwahati. Her autobiography was also the first women's autobiography written in Assamese and was published in the year 1971. The second autobiography considered by her is *Eri Aha Dinbar* (*The Bygone Days*), which was written by *Nalinibala Devi* (1898-1977), who is known for her poetry and was the winner of Padmashree award. Her autobiography was published in the year 1976. The third autobiography is *Jeebon Jeebon Bor Anupam* (*The Incomparable Life*) by *Nirmalprova Bardoloi* (1933-2004), an eminent poet and writer, and Professor of Assamese, Gauhati University. Her autobiography was published in 2004. One of the drawbacks of using these autobiographies, however, is that all of the autobiographers hailed from the upper caste middle class and educated Assamese background, due to which their experiences cannot be generalized to the rest of the population (J. G. Nath, 2011).

The autobiographies of these women provide a detailed account of the transitional period where newer ideas were being introduced in a society where deep rooted traditions and customs still prevailed. The autobiographies show that, unlike the previous generation, these women did not face any restrictions while attaining education. However, how this education was attained gives a glimpse about the

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[115] Even though the practice of writing autobiographies began in Assam in the latter half of the 19th century, with Sadar Amin Harakanta Barua, women started writing about themselves only by the latter half of the 20th century. One of the reasons for this was that women in Assam were debarred from getting education till the early decade of the 20th century (J. G. Nath, 2011).

traditional mindset of the parents, especially fathers, which completely restricted the mobility of the women. Nalinibala Devi, for instance, had written that her father, who was educated in Calcutta, decided not to send his daughters to school, because the girls' school at Gauhati was a Bengali school and it was located at the Bazaar area. Instead he appointed a teacher from the best school of Gauhati and also the librarian of the Curzon Hall library as her tutor. Nalinibala had written that due to these reasons, she never got the opportunity to go out of her home and interact with other people outside of the confines of her home (J. G. Nath, 2011). In contrast to Nalinibala, Rajabala Das was sent to the Bethune School at Calcutta at the age of eight years with her brother, who was leaving for Calcutta to attain his college education. In her autobiography, Rajabala had written that respectable families of that time who did not like to send their daughters to the local schools, taught them spinning, weaving, embroidery and house-keeping at home. Rajabala herself also had to return back to her home soon because she realized the fate that school-going girls had to face at that time, and so got engaged in the learning of spinning, weaving and housekeeping. She also said that the male members of her family did not allow her to go out of her home during that period. She wrote that even though young girls did not like to be secluded, they were not able to protest because of the prevailing patriarchal control (Ibid).

These women also throw valuable insights on the marriage and conjugality among upper caste families of Assam. As per the social customs of her community of that period, Nalinibala was married at the age of 11 years, before she had attained puberty, and went to live at her husband's home at Sibsagar. She gave birth to her first child at the age of 14, and by the age of 19, she was a mother of four children, and was expecting her fifth child. She became a widow before this child was born. After her husband's death, she and her five children were brought back to her natal family, where she had to live under stringent conditions that were imposed on a widow in an upper caste Hindu family. Thereafter, her father encouraged her to do spiritual exercise and to devote herself to the study of scriptures. Nalinibala did not rebel against the cruelty that was meted out towards her and instead submitted to it. In her autobiography, however, she wrote about the miseries that girls and women are subjected to in case they become widows, in the name of teachings of the scriptures (J. G. Nath, 2011). Similarly, Nirmalprova Bardoloi, who was born several years after

Nalinibala, did not have a very different life from the latter. She was born in an upper caste family in Sibsagar, and was married off at the age of 11, before she attained puberty, to a man thirty years older than her. This was in spite of the fact that the Sarada Act, 1929 was passed by that time. Nirmalprova wrote in her autobiography that she was much intimidated by her husband, but was forced to have physical relations with him, which resulted in her pregnancy. She gave birth to her daughter at the age of 13 years when she was still living at her parental home. Nirmalprova never left for her husband's home, who later married another woman, but lived as a separated wife for the rest of her life. She further wrote that her parents did not force her to leave for her husband's home, and encouraged her to continue her education (Ibid). Nirmalprova had also elaborated on her experience of being a separated wife whenever she attended any social and religious functions. She wrote that she was treated as inauspicious and unlucky. She also had to face sexual harassment as a result of her marital status (Ibid).

In addition to themes about their own lives, these autobiographers also commented over the status of other women in their surroundings which are also invaluable in understanding how women lived their lives during that period (see J.G. Nath, 2011). Nalinibala wrote that she realized what liberty for women was only when she went to Shillong, the then capital of Assam, and saw the freedom that the *Khasi* women enjoyed there. Rajabala had also noted the freedom of movement that girls who did not belong to upper caste households enjoyed. Nalinibala wrote about the plight of her mother, who like her, was married at the age of nine to a man 37 years older than her. Nirmalprova also commented on the change in the outlook of the society towards women especially after their mass participation in the Quit India Movement which, according to her, was a direct assault on the private/public demarcation of spaces (Ibid).

To summarize, during the advent of colonial rule, women in Assam, like elsewhere in India, were living a miserable life, and were oppressed in the name of religion, customs and traditions. From the beginning of the 20th century, however, women's position, especially for those who belonged to upper caste middle class households had somewhat changed for the better, as they got drawn to the nationalist movement. Largely this was due to the political strategy of Gandhi of including the women in the movement by appropriating their '*inherent feminine qualities*' of non-violence and passive resistance to fight against the British (Kishwar, 2006). Although his strategy has been considered to be ‘radical’ for the period (Norvell, 1997), but it is necessary to argue that he did not critique the status quo within the family (Kishwar, 2006), and thereby allowed the exploitation of the women within the family to continue. Regardless of this critique, it is necessary to appreciate his contribution to the emancipation of women in the early 20th century in Assam, as well as in India as a whole. Additionally, while women’s participation was necessary in the movement, the Congress did not allow women leaders to contest elections as has been shown in the case of Chandraprabha Saikiani. Sadly enough, this fate of women continued even during the Assam Agitation as we will see in the next section.

Women of Assam during the Post-Independent Period: At the advent of independence in 1947, there was a great deal of hope and optimism for Indian women. The Indian Constitution guaranteed equal rights to men and women under Articles 14, 15 and 16. In the initial decades after independence, however, there was an apathy in the women’s movement (Norvell, 1997). In fact, after the departure of the British, the feminists became fragmented in their concerns because a common enemy did not exist anymore. Several feminists who had fought against the British during the colonial period were now members of the Congress government, who in paper, stood for an improvement in women’s condition. Disillusionment set in only gradually. The feminist movement of the seventies and eighties was very different in form and was a result of a number of radical movements of that period (Kumar, 1993), which had nothing in common with the issues that were raised during the colonial period.

There is not much literature on women’s position in Assam from the years immediately following independence even though Assam was facing a number of problems with its hill and plain tribal populations during this period. According to available literature, women began to appear again in the public domain from the period of late 1970s. The distinguishing features about this period was the six years long *Assam Movement* (1979-1985), which as cited above, had far-reaching consequences in the socio-political history of the state in terms of the rise of regionalism, of the ULFA, the Bodoland Movement and similar other ethnic movements and insurgent organizations. Although there is a lot of literature on all of these developments, not much work has reflected on the participation of women in the Assam Movement, even though their participation was as widespread as that of men

(N. Sharma, 2017). Nabanita Sharma's (2017) paper *"Role of Women during the Anti-Foreigners' Agitation in Assam 1979-1985"* is one of the few papers on this topic. In the course of her study, it was found that women did not make a conscious decision to participate in the movement, but were drawn to it as a result of the state-inflicted violence on the 'boys' of AASU. Most of the early participants were women from middle class upper caste households who had full faith on the AASU members, which included both male and female students. With time women from other ethnic communities also participated in the movement (N. Sharma, 2017). One can draw a number of parallels between the freedom movement and the Assam movement. Like in the freedom movement, in the Assam Movement, the women participated in all sorts of activities including *Satyagraha*, picketing, processions and for raising funds. Their participation was particularly high in the first two years when the movement was peaceful and did not take an ultra-nationalist turn (N. Sharma, 2017).

During the period of the movement, numerous *Mahila Samitis* sprang up in almost every locality of the state. These *Samitis* raised funds and contributed to the AASU's coffer to carry forward the struggle. Since the *Mahila Samitis* were not initially connected to one another, the AASU created the *Jagrata Mahila Parishad* (JMP) in order to organize the women's associations. One of the important things about these *Samitis* was that they did not have their own agenda and were largely mobilized by the AASU and the AAGSP leaders for different programmes and propaganda (N. Sharma, 2017). Due to this reason, once the agitation came to an end, these *Samitis* either disintegrated or did not stay in touch with the AASU (N. Sharma, 2017).

During the second half of 1980, when the government was exerting pressure on the government employees and students to return back to their workplaces and educational institutions respectively, the AASU leaders had to turn to the women as the main group to carry forward the movement. Much like Gandhi, the AASU leaders talked about the importance of women in society and how their participation would add a unique color to the movement. The AASU leaders exploited the idea that *Axomi Aai* (Mother Assam) is in danger because of which everyone must come out of their homes to save her from the intruders (N. Sharma, 2017).

It was also found that while the AASU or AAGSP leaders addressed the masses, they rarely joined the crowd during the protests. It was ordinary agitators, mainly women, who had to bear the brunt of teargas, water canon or *lathicharge*. As the movement progressed, there have been a few instances where the women were molested and even raped by the Central Reserved Police Forces (CRPF) *jawans* due to which parents often debarred their daughters from joining such events. The AASU leaders, instead of curbing such insecure situations for the women, capitalized on one such incident of rape in Kamrup District in January 1980, in order to gain sympathy against the government from the masses. It was usually the women's associations that protested against army brutality and provided financial assistance to the rape victims (N. Sharma, 2017).

It is also found that during the initial phase of the movement, the AASU leaders provided the girls with the opportunity to become organizers at the grassroots level. The same opportunity, however, was not provided to them at the higher levels of the hierarchy (N. Sharma, 2017). After the agitation was over, the AASU leaders subdued the women's concerns by the notion that the 'boys' will save the motherland from the hands of the 'foreigners'. After the resolution of the movement, and the formation of the AGP government, only two women joined politics and got elected as Members of the Legislative Assembly. Most of the other women went back to their homes, after the resolution of the movement (D. Phukon, n.d.; N. Sharma, 2017). In the post-agitation period, many women were mute victims of army atrocities that resulted from ULFA's demand for *Swadin Axom* (Independent Assam). Many disheartened women joined the ULFA, some worked as peace workers at the local level, while majority went back to ordinary life (N. Sharma, 2017).

The fate of the women who joined the ULFA was not much different from those who had joined the Assam Movement. ULFA started recruiting women cadres from around 1988-89. This was a strategic move that, according to D. Deka (2019) was rooted in the gendered femininities that does not suspect women as agents of violence in an insurgency situation. Apart from this, some of the women cadres joined the ULFA because they wanted to break away from the violence that they either witnessed or experienced themselves in their immediate surroundings. For them the ULFA provided an avenue to reform social discrimination and injustice. To achieve this goal, they saw violence as a means that would promote social change for the betterment of the society (D. Deka, 2019).

In spite of their zeal to work for the motherland, studies have found that women cadres were hardly given the opportunity to participate in combat. This is in spite of the rigorous training that men and women uniformly undergo (D. Phukon, n.d; D. Deka, 2019). Women's roles in the organization were reduced to mere cooks, informers, transporter of arms from one place to another, or simply wives of active male combatants (Ibid). Additionally, in a few cases women cadres of ULFA have also alleged that they were not given arms training but were used as mere 'sex objects' for the sexual gratification of the male cadres (D. Phukan, n.d.). During her interviews with ex-women combatants, D. Deka (2019) found that women never participated in combat out of the fear of losing their modesty, except in certain emergency situations such as the Operation All Clear in Bhutan (2003). In fact, she found that the thought of losing the purity of their bodies was terrifying for the women as well as for the organization, both when they were underground as well as when they were over ground. According to D. Deka (2019), ULFA's downfall is, in fact, related to its decision of approving marriages in order to have a new generation that would sustain the movement. To achieve this purpose, women insurgents often had to give up their combatant roles in order to take care and protect their children. It is also one of the main reasons that several women had to surrender during the Operation in 2003 (Ibid). Their exclusion from active combat also has other consequences which is that they find it very hard to acquire rehabilitation and postwar reconstruction facilities which are important for them to be able to live over ground and to fight the social stigma associated with their combat role. As a result women often prefer to hide their military past out of the fear of facing social disapproval (D. Phukan, n.d.). Studies have also found that women find it very difficult to negotiate with their lives over ground, which takes a toll in their physical and emotional health. Some of them felt frustrated by the monotony of their lives and for their failure of not being able to do anything for the cause of the motherland as earlier (D. Deka, 2019).

Research has also shown that while male cadres who had died while working for the organization were addressed as *'swahid'* (martyrs), the same was not the case in the case of the women (D. Deka, 2019). Upon further probing, D. Deka (2019) learned that women attained martyrdom under three circumstances, all of which were 'accidental' in nature: first, when women died under tough training and difficult physical conditions; second, when women cadres were raped or killed by the armed forces under fake encounters; and third, controversial deaths of women cadres within the organization. D. Deka (2019) termed these deaths as '*accidental martyrdom*', that is,

> spontaneous and violent deaths of insurgents devoid of their voluntary fervor of dying for their organization […] recognizing such deaths as martyrdoms would be both deceiving and overstatement. Martyrdom here emerges as a closure from interrogating violence (p: 11).

D. Phukan (n.d.) in her paper has also argued that women play multiple roles and face different kinds of dangers during the pre-conflict and conflict periods. But in spite of this, during the post-conflict period when the government initiates formal discussions for policies on restoration and rehabilitation, women's concerns are often sidelined. In a study conducted by *North East Network* (R. Goswami et al, 2005), it was found that women fall under seven different categories[116] in reference to the varied roles played by them during the time of the conflict. In spite of this, women are primarily looked as victims of violence (Ibid). Using this study as her reference, D. Phukan (n.d.) has argued that while it is true that women are the worst sufferers during armed unrest, but it should not negate the multifaceted roles that they play in response to the situation.

As has been shown earlier in the chapter, post-independence, Assam has faced numerous protests, reorganizations, ethnic identity based movements and conflicts. Women's involvement during these events is only coming to light now as more and more researchers are getting interested on this aspect. As can be seen there has not been a women's movement in Assam, unlike some other parts of the country. Instead women have come out of their homes for the cause of the nation and their *jati* (nationality) at different points in history. But once the movement got over, they were again pushed back to their traditional sphere. This has been observed both during the freedom struggle as well as the Assam Movement and in the ULFA (D. Phukan, n.d.). The Assam Movement and the ULFA has led the precedent for other similar movements and insurgent organizations in different parts of the state, as has been noted above. However, not much research has been done on women's participation in such movements and organizations.

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[116] These categories include women relatives of armed activists, women relatives of state armed forces, women militants or combatants, women as shelter providers, women as victims of sexual and physical abuse, women as peace negotiators and women's rights activists (R. Goswami et al, 2005).

Women's Position in Assam in the Globalized Era: The political situation of Assam in the last quarter of the twentieth century, coupled with the liberalization of the Indian economy in the 21st century, has resulted in contradictory developments in the position of women in the state. While on the one hand, we find middle class women from the urban areas trying to make the best of the newer opportunities available to them in the wake of globalization (Bhattacharyya, 2009), at the other end of the spectrum, we find women from the poorer pockets of the urban areas who are still struggling, and yet negotiating, with their fear of the public spaces (Mahadevia et al, 2016). There is yet another category of poor women, especially in the rural areas who, due to the multifarious problems prevalent in the society, fall into the trap of sex trafficking (Ray, 2015). Let us look at these problems more closely in this section.

Bhattacharyya's Ph. D thesis (2009) on the changing status and role of young Assamese middle class university women students from Guwahati has shown that their access to higher education and career aspirations has been facilitated by their familial background, where their parents, who are either high profile officers or white collar job-holders, have encouraged them to compete for powerful, status oriented and prestigious jobs as a matter of family pride. The study, however, found that their career-mindedness is context-dependent as they are brought up with the mindset that they will always have to prioritize their domestic and family roles. This creates a lot of hurdles for the women in the pursuit of their ambitions as they have to subordinate their careers to the powerful cultural expectations of their husbands, children and parents-in-law (Ibid). While the husbands of the women were considered to be 'supportive', they usually did not support the women in their domestic chores and childcare. In fact, Bhattacharyya (2009) has argued that while women in Assam have gone out into the public domain to work since the 1980s and 90s, it has not transformed the deeply entrenched division of labor within the household as domestic chores and childcare responsibilities are still considered to be women's work. In spite of their enormous workload, Bhattacharyya's research participants cherished their abilities to earn an independent income (Ibid).

Due to the changing circumstances and opportunities in the society in the 21st century, more and more women are found in the public spaces than ever before. One of the fallouts of this increased visibility and movement through public spaces is that a lot of women experience sexual harassment in the roadsides and public buses, which ultimately curtails women's freedom. Additionally, official statistics on crimes against women have shown that there has been a steep increase in the cases of 'kidnapping and abduction' and 'molestation' in Guwahati in the period of 2001-2011. While cases of molestation have doubled, kidnapping and abduction have increased five times. The statistics also shows that there have been a few incidents of dowry deaths as well in 2001 and 2011 (Mahadevia et al, 2016. This is shameful for the society of Assam especially because, as cited earlier, the absence of such deaths is one of the examples that is given to argue that women's position is better in Assam in comparison to other regions of India.

Several studies have shown that women in Guwahati feel equally unsafe in deserted places due to their fear of assault or rape, and in crowded places where men take advantage of the crowd and sexually harass them (Bhattacharyya, 2009; NEN, 2013; Mahadevia et al, 2016). Studies have also shown that women of all ages and from all socio-economic backgrounds experience sexual harassment in public spaces on a regular basis. The younger women (between 17-21 years) in Bhattacharyya's (2009) study complained that they experience verbal sexual violence ('eve-teasing') especially on deserted roads on their ways to college or work. The comments usually comprised of unsolicited and offensive remarks about a woman's appearance like the shape of their nose, or their physical shape. Women also experience more serious physical abuses such as groping and bottom slapping, but in this case the perpetrators are usually older men. The research participants also said that other people in buses rarely come forward to help them in situations where they are facing harassment (Ibid). Similarly, Mahadevia et al.'s (2016) study on the safety of low income women and female students in Guwahati found that women of all age groups faced verbal and physical sexual harassment while walking on the roads. The study also found that usually older men in the age group of 35-45 are the main perpetrators. School going students also shared their experience of sexual harassment but they reported not getting any support from their family members. In other cases, the students were found to be scared that their mobility would be restricted if their parents come to know that such incidents occur so often. Married women also shared their experiences of being stalked all the way to their homes but they shied away from sharing such experiences at home either out of the fear that they would be blamed for the incident or the apprehension that their husbands would pick up a fight with the perpetrator

(Mahadevia et al, 2016). Additionally the study also found that Bengali Muslim women, who work as daily wage laborers, were particularly vulberable to harassment on the roads due to her ethnicity. Most of the women in the study reported that bystanders never come forward to help them as a result of which women are being pushed back from public spaces completely. During an FGD, women shared that there were reasons for feeling unsafe in the public spaces included lack of street lights, floods and bad roads, but they can still deal with such problems if they did not have to deal with sexual harassment when they are alone on the streets. They fear retaliatory violence which in turn has affected their self-confidence (Ibid).

Thus from the above discussion we can see that due to the newer possibilities of education and employment opportunities, it is now possible for women to walk out of their homes, get an education and earn an income. These possibilities, as we have seen earlier, were unimaginable for women a century ago. While these possibilities have widened the gap among different social groups on the one hand, it has also exposed women to sexual harassment in public spaces. Unfortunately, Assam does not have a concerted women's movement to effectively deal with such issues of harassment.

While this is the case in the urban areas of the state, more particularly in the city of Guwahati, in the recent years it has come to light that Assam is a major source and transit point for sex trafficking in India. Some of the important reasons that have triggered trafficking in Assam include poverty, unemployment, lack of basic infrastructure such as schools, population displacement due to floods and developmental projects, decades of insurgency and conflicts, communal clashes, political apathy and increasing violence against women due to counterinsurgency operations, son preference and domestic violence (Ray, 2015). The study also found that usually the women who are trafficked are either the first or the second siblings, due to which the burden of earning fell on their shoulders as compared to their male or younger siblings. In certain cases it was also found the family had already suffered from previous instances of trafficking, but their poverty compelled them to set aside their apprehensions and also send their next child in pursuit of employment (Ibid). The study also found that soft trafficking is more rampant in the study area than hard trafficking, but in both cases the traffickers are known by the women and they had used violence. The study did not find any instances of cross border trafficking, which according to the author, could be due to the difficulties of rescuing a girl once she had crossed the national border. The study also found that the women are largely trafficked to metropolitan cities or to states like Haryana which have skewed sex ratio. The study also found that in certain cases women are also trafficked multiple times (Ibid).

The aim of this section was to show the position that women have occupied in Assam since the historical period in order to position the study participants in such a context. It was found that women have experienced different forms of atrocities in different historical periods due to the norms and traditions associated with appropriate feminine behavior. Due to the change of time, women from middle class households are now able to walk out of their homes to pursue a career. However, once they are married they are expected to push aside their career aspirations in order to prioritize their families. This has resulted in extra burden for the women as men have not similarly shouldered the responsibilities of the household. In contrast, women from poorer social backgrounds from both rural and urban areas continue to suffer due to lack of adequate opportunities for them to prosper, coupled with the fear of sexual harassment in public spaces and being trapped in the nefarious world of sex trafficking.

Even though a lot has changed over the years certain customs and traditions continue to exist which both facilitate and hinder women in today’s generation. The former is the skill of weaving which is still considered to be a way of life among different ethnic communities of Assam. In spite of this, due to lack of entrepreneurial skills, women have not been able to make economic gains through it (Chutia & Bhuyan, 2014). The latter is the custom of secluding menstruating women for 3-7 days every month due to the misconception that women are dirty and impure during this period. Although such views are much relaxed in the natal family, studies have shown that in the family of the in-laws women have to strictly adhere to the customs till today (M. Das, 2008).

As mentioned above, this review of women’s position in Assam is incomplete as women from other ethnic communities have not been included in it due to the paucity of adequate research. In the future researchers must study this aspect in greater detail.

Conclusion

The purpose of this chapter was to elaborate on the socio-political and historical context of the society of Assam and the position of women in this society in order to situate the study participants in this context. Keeping this context into consideration, the following chapters elaborate on the lived experiences of women with locomotor disabilities.

Chapter 4

‘Why Me?’: Making Sense of the Occurrence of Impairments

This chapter elaborates on how the research participants and their family members, particularly their mothers, have made sense of the occurrence of their impairments in the specific context of their lives. This is important to understand this because existing studies have shown that making sense of threatening life events such as the occurrence of illness or disability are crucial for the process of adjustment (Pakenham, 2008). Furthermore, beliefs about the cause of impairment can influence the way a person with disabilities and his/ her family members are treated by the society (Stone-MacDonald & Butera, 2014). The chapter elaborates on the events surrounding their impairments and the causes they attribute to the occurrence of their impairments. It then contrasts these narratives with the explanations of healthcare providers, namely general medicine physicians, orthopaedics and physiotherapists of the Guwahati Medical College and Hospital (GMCH) and a private hospital, in order to understand their perspectives about and experiences of treating persons with disabilities. Such an understanding is important in order to critique the widely held understanding prevalent in disability studies that negate the importance of impairment and usually point out the barriers present in the environment. The theoretical approaches of *social suffering* and *structural violence* are used in order to better understand the life situations of the women and their family members.

As has been explained in Chapter 2, the study participants have different types of locomotor impairments, some of which are congenital, while others are acquired due to infective causes in childhood, while still others are acquired due to traumatic causes in adolescence. Due to this reason, the women and their family members also describe the causes of their impairments in different ways. Four different themes have been identified in this chapter, which are explained with the help of long narratives of 11 women and their family members. The reason for selecting these 11 women for the purpose of this chapter is that they had talked at length about the occurrence of their impairments, which provide interesting insights on the topic of subjective interpretation of impairments. The explanations from health personnel about how they understand a particular impairment is also elaborated in order to understand the divergence of their views.

Making Sense of Congenital Anomalies

This section elaborates on the narratives of women who had acquired their impairments through congenital causes. Congenital anomalies (also called birth defects/ congenital disorders/ congenital malformations) are defined as structural or functional anomalies that occur during intrauterine life and can be identified prenatally, at birth, or sometimes may only be detected later in infancy (WHO, 2016). About 303,000 newborns die within four weeks of birth every year due to congenital anomalies. It can contribute to long-term disability, which can significantly impact the individual, his/ her families, healthcare systems and the society in general. About 50 per cent of all congenital anomalies cannot be linked to any specific cause and very often it is difficult to identify the exact cause of the impairment (Ibid). In this study, the causes of congenital impairments of the research participants were sporadic in nature. Due to this reason, it was found that the women and their family members think about different reasons that may have caused the impairment, as explanations from the health personnel are usually lacking. The following narratives illustrate this point.

Narrative 1:

Minakkhi, 42, was born with a congenital impairment which is clinically referred to as syndactyly[117]. She lives with her parents, two older brothers and their families in a village in the Joonaki Block. She works at Sanjeeboni as a weaver. During the interview, Minakkhi said that she had never asked her parents about her impairment, but she had heard them talking to other villagers and relatives about it. She had heard that either her hands turned out to be like this because of ‘polio’ or because when her mother was pregnant with her, her father had a fight with the other villagers, and to block these people from coming to their home, he had cut a log of a tree to create a

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[117] Syndactyly is the fusion of adjacent digits, and is the most common of all congenital hand deformities with an incidence of 1 in 2000 live births (Jordan et al, 2012). It can be both hereditary as well as sporadic in nature. Syndactyly has a large functional and aesthetic significance for those who are born with this condition. Operative management is the only definitive care for persons with this impairment (Ibid).

barrier between their household and the other households in the village. Minakkhi elaborated that in their community, there is a belief that one should not cut a tree or kill an animal when there is a pregnant woman in the household. She believes that her hands turned out to be like this because of her father's actions.

A few months later her mother was interviewed at their home. She said that many people in the village feel that Minakkhi's hands are like this because her father had a pet tortoise which he had left in their family pond with the help of a plastic net. Her mother said that she is *unsure* if her daughter's condition is because of this reason, or she has been like this since her birth. She also said that it is because of her *beya kormo* (bad deeds) and *bhagyor dux* (faults in her destiny) that this has happened to her daughter.

> *It just happened. Maybe I had done something bad. I say that this has happened due to our mistakes. All such things happen due to the mistakes of the mother. Due to her beya kormo. Some things happen due to the mistakes of the mother. Only if I do bhaal kormo* [good deeds], *only then I will get bhaal phol* [good fruits], *isn't it? That is the thing. If I do beya kormo* [bad deeds], *I will get a beya phol* [bad result] [she weeps].

Minakkhi's mother further elaborated,

> *Maybe I had made fun of someone earlier, only then this would happen. I may have said what kind of hand she has got, she is so beautiful but she has hands and legs like this. If I do this, isn't it bad for me? It is bad for me. There are so many lengera* [physically disabled] *people who roam around in Taamnagar*[118] *and in Guwahati. Some people crawl while some don't. We happen to say certain things to them. Maybe that has affected me. Who knows I may have done such a thing. Earlier. Now God might be showing this to me. That is the thing.*

From Minakkhi and her mother's narratives, it can be seen that both of them have internalized the traditional animistic beliefs about the cause of disability, that it is a cause of punishment for bad deeds or the result of witchcraft exercised by other people (Stone-MacDonald & Butera, 2014). While Minakkhi thinks that her impairment is a result of her father cutting the log of a tree during her mother's pregnancy, her mother is unsure about the exact cause of her impairment and has speculated different reasons like her husband leaving the tortoise in the family pond, her own *beya kormo* and for ignorantly talking about another person with disability in a denigrated manner in her youth. Stone-MacDonald & Butera (2014) in their review

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[118] Taamnagar is a pseudonym for the actual name of the place that she was referring to. This has been done in order to protect the identity of the disability organization (as it is the only disability organization in this area) and thereby the research participants.

of literature on cultural beliefs and attitudes about disability in East Africa have noted that among the Nandi of Kenya, it is considered a taboo to kill animals without good reason during a wife's pregnancy (Ogechi & Ruto, 2002). The review also found that laughing at persons with disabilities can cause an individual to have a child with disabilities, cause an accident that would harm that individual or cause the future generations of the family to be cursed (Stone-MacDonald & Butera, 2014). Minakkhi's mother also seems to have internalized the widely prevalent notion in India that the disability in the child is due to the faults of the mother (Ghai, 2003). Similar beliefs also exist in other countries of Asia such as Turkey (Koydemir & Tosun, 2009) and the United Arab Emirates (Crabtree, 2007).

Minakkhi's mother further said that they were not able to cure her daughter's hands, and this could be one of the reasons that she feels that Minakkhi's disability is a result of her faults. She elaborated that when Minakkhi was about three-four years of age, they had taken her to Mohendra Mohan Chaudhury Hospital[119] (hereafter MMCH) for a checkup. In the hospital, the doctor told her parents that they can cure her impairment by surgically separating her fingers. However, they told them to return a few years later as she was too young for the surgery. When she was eight years old, Minakkhi's *Aita* (paternal grandmother) accompanied her to MMCH for the surgery. Her mother could not accompany her because she had to look after Minakkhi's sister who was very young at that time. In addition to this, she also had the responsibility of the entire household and agricultural chores on her shoulders. She did not comment on why Minakkhi's father did not take her to the hospital. An important reason for this could be that as the sole adult male member in the family he had the responsibility of not only his own family, but also his aged mother, and two widowed sisters and their children, because of which he was not able to skip work even for a day. Minakkhi's mother said that at MMCH, the doctors were able to separate only two of her fingers in both her hands and they asked her to return back a few weeks later to complete the procedure. Unfortunately, at that time her *Aita* fell sick and passed away, because of which Minakkhi was not able to return back to the hospital, and her surgery remained incomplete. According to both Minakkhi and her mother, her fingers joined back as a result of abruptly stopping her treatment.

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[119] Mohendra Mohan Choudhury Hospital (MMCH) is the oldest government hospital in Guwahati and is located in the Pan Bazaar area. From 2013, it became an annexe hospital to Guwahati Medical College and Hospital (GMCH), in order to ease the huge rush of patients in the latter.

Her mother's guilt was further accentuated by a recent encounter with a *Gonok* (a sub-group of Brahmins who are in the hereditary occupation of astrology), whom she had consulted to know if and when Minakkhi would get married. The *Gonok* told Minakkhi's mother that when she was pregnant, a *beya xetro* (bad spirit) had entered her body because of which her daughter was born with this impairment. Hearing this, Minakkhi's *Bou* (elder brother's wife), who was within earshot at that time, started laughing and said, *"They are from the older days. They believe in such things".* Minakkhi's mother, however, did not care about what her daughter-in-law thought about her beliefs. Her *Bou* further said that at that time the healthcare facilities were not very adequate and it is due to this reason that Minakkhi's hands remained like this. She feels that a child with the same condition in the present generation would have been cured because of the advancement of medical facilities and the availability of healthcare services nearby. Minakkhi's mother interrupted her and said that Minakkhi could have been cured even at that time, but it was because of their mistake that they were not able to continue her treatment. She feels that if they had taken Minakkhi to the hospital at the age of 12-13 years, probably her fingers would have been cured. But unfortunately, this thought did not occur in their minds at that time because they had to look after so many things.

From the above narrative, it can be seen that different family members have different explanations about Minakkhi's impairment. While Minakkhi's mother largely blamed herself and her bad deeds for her daughter's impairment, her *Bou,* on the other hand, has pointed out the various historical and structural factors that hindered Minakkhi's access to cure. She, however, completely negated the contextual factors that hindered Minakkhi's parents from accessing cure for her condition. This difference of opinion suggests that Minakkhi's mother acutely felt the ramifications of her daughter's congenital impairment as she may have also been stigmatized for giving birth to a daughter with such an impairment. On the other hand, Minakkhi's *Bou,* who was more educated than her mother-in-law (Minakkhi's mother had never gone to school) considered it backward thinking to regard bad spirits to be a cause of impairment. Her opinion also shows that she was not able to completely empathize with the contextual difficulties that the family had faced while seeking treatment for Minakkhi's impairment. From this narrative it can be seen that there has been a definitive shift in the perception of disability among the younger generation as a result of changes in the nature of the society. Similar patterns have also been found in the way disability is viewed among older and younger generations in the context of China (Zhang, 2007, as cited in Mehrotra, 2013).

The following narrative gives another example of how a woman with congenital locomotor disability describes the occurrence of her impairment.

Narrative 2:

Uma, 34, lives with her husband and young son in a village in Joonaki Block. She was born with weakness on her left lower limb. During the interview she said that when her mother was about five or six months pregnant with her, she once fell down near the *kuwa* (well). Uma and her family members believe that her disability is a result of this fall. When she was young her parents took her to GMCH for treatment. At the hospital they came to know that her leg cannot be treated. She said,

> *When they* [parents] *took me to GMCH in childhood, they gave me medicine. But no, nothing happened. If one leg is bhaal* [without impairment], *why is the other like this? The doctor said that this cannot be cured. If I had fallen down, they could have inserted an iron rod, it could have been cured that way. But this cannot be cured, as this is there from birth.*

In her parents' quest for cure, they had also taken her to an *ojha* [folk healer], but he also said that her disability cannot be treated, since it is congenital.

> *Deuta* [father] *had heard about an ojha, so he took me there. I was just able to walk at that time. I remember that. Deuta took me there in the belief that I would be better. But the ojha said that the condition cannot be corrected since it has been there from birth. If I had fallen down and injured myself, then it was a different issue. Then I can put a cast or so.*

She said that after several disappointments, she no longer believes that her condition can be cured either by a doctor or by an *ojha*.

> *When I was a child, I was taken for treatment. Now, not anymore. Now I do not believe in it. Because it cannot be cured. Whatever God has given to me, it will remain like that. No matter how many doctors or ojhas I go to, it will not be cured.*

Uma came to know about her impairment when she was about five years old. She said that as a child she was always very upset as she was concerned about what she would do in the future. In her childhood, when she went out with her friends and was having fun with them, at the back of her mind she was always depressed because she was aware about her difference from others. When she came to know about the Pulse

Polio Immunization Programme in her early adolescence, she said that she had insisted to have the drops as she wanted to be cured of her impairment.

> *When I was young I did not know about polio. Much later I came to know that one should have polio* [vaccine] *to prevent disability. When I was young there was nothing like that. When I came to know about it, I remember, I told everyone in my surroundings, I will also go and have polio* [vaccine]. *I told them that my leg is like this because I did not take the medicine in childhood. If I take it now, I will be cured. They all laughed at me.*

In her desperation, Uma sometimes shared her inner feelings with the people around her. *"I used to ask them, 'What kind of paap* (sins) *I must have committed that this has happened to me?'"* She said that the good people tried to console her by saying that there are many people with disabilities in the world. On the other hand, those who were not good made fun of her physical difficulties, and this hurt her immensely.

She further said that she does not blame anybody else but herself for her condition.

> *I blame myself. What to do, no other option. God has given me this. Everyone else is alright, why am I like this? I think about God.*

After her marriage and the birth of her son, she is no longer depressed as she has found a meaning to her life. Moreover, when she came into contact with Sanjeeboni after her marriage, she started appreciating that there are many other people like her. Now she no longer thinks of herself as a sinner. Instead she has started to accept her disability as something that is written in her *kopaal* (fate).

> *Whatever is written in my kopaal has happened. Now how to improve my life by doing good deeds, how to mingle with people, I think about that. Since it has already happened, now I cannot do anything to make it better. That is what I think.*

The above narrative shows that Uma and her family believe that her impairment is a result of her mother's fall during pregnancy. During the interview it was found that Uma pondered over the cause of her impairment for a long period of time as she was not able to make sense of why she had to suffer from this condition. It was also found that her family members also actively sought cure for her condition. But over time she has realized that hoping for cure is not an option because time and again she has been told that her condition is not curable. According to Dr. Yogesh Basumatary, post graduate student at GMCH, in the case of congenital disability, prognosis becomes very difficult, and the attempts to cure it become increasingly limited. From the above narrative, it can be seen that even though her parents tried to pursue her treatment from practitioners of modern medicine as well from folk healers, over time, after a series of disappointments, she gave up hope for cure. Her narrative also shows that growing up as the only disabled person in her neighborhood, she has always felt inferior to her peers because of her impairment. This was compounded by the fact that the people in her village were insensitive towards her predicament. However, after her marriage with a disabled man, when she came into contact with Sanjeeboni and met other people with disabilities, she began to realize that she is not the only person who is different from others. Over time, it has become clear that she has accepted her impairment as something that was written in her *kopaal* and this acceptance has enabled her to think about improving her own life and the lives of her husband and son.

In this theme I have tried to show how women with congenital impairments make sense of the occurrence of their impairments. It was found that since they did not get any information about the cause of their impairments from the health services system, both Minakkhi and Uma and their family members are seen to dwell upon different explanations about the cause of the impairments. These women also blamed their *beya kopaal* (bad fate) to be responsible for their conditions.

'This had to happen. I do not ponder over it now'

In the cases of some of the women and their family members, it was found that they had received adequate medical explanation from doctors, as a result of which they did not ponder over their situation much. These women have accepted their impairments as something that was written in their *kopaal* and would have happened no matter what they had done to prevent it. The following narratives give a glimpse of this:

Narrative 3:

When Risha, 36, was asked about her disability, she replied that she has Athetoid cerebral palsy[120]. She further explained, *"When Ma was pregnant, maybe she had*

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[120] Cerebral Palsy is a general term for a group of disorders impacting a person's motion, balance and posture. It can be caused by abnormal brain development or injury to the developing brain. The brain damage usually occurs before birth or in the first years of life. In many cases, the exact cause of cerebral palsy is not known (www.healthline.com). Athetoid cerebral palsy is one of the four types of cerebral palsy. It results from damage to the part of the brain called the basal ganglia. It is a less

hurt her abdomen, due to which some parts of my brain had been damaged. This is how I am like this". She was diagnosed with her condition when her parents consulted a doctor for not being able to walk till the age of about 3 years. She came to know about the exact details of her disability through her association with Senehi, where she had studied from the age of 8-9 years. On the second day of our interview, she gave me new information, after confirming with her parents. She said*, "When I was born, there was also a twin baby. She passed away few days after birth"*. Risha also said that she had suffered from jaundice a few days after her birth in the hospital. Both of these factors can put a baby at an increased risk of cerebral palsy (www.healthline.com).

It is probably due to the counseling that she had received in her school that Risha accepted her impairment without any negative feelings. When asked if she blames anyone for her impairment, she replied, *"This had to happen, so it has happened. There is no point thinking about it or blaming someone else for it now"*. The disability has affected her gait, making it difficult for her to balance her body. When she was young her father had appointed a physiotherapist to correct her condition, but after two-three years, due to financial difficulties, they were no longer able to afford his services. Her parents, however, tried their best to continue Risha's exercises at home by planting two bamboo sticks in their front yard, so that she could hold them and walk. She feels that her parents have done everything in their capacity to cure her. Over the years, her physical difficulties have increased manifold (which will be explained in the subsequent chapters), but Risha continues to hold a positive attitude towards life. She feels that in this way, she is giving inspiration to younger girls in her neighborhood to persevere and achieve their dreams in life.

During the interview it became clear that the knowledge about cerebral palsy in Assam was very limited in the early 1980s when she was born. As a result of this, it took her parents a lot of time to realize that something was amiss with their daughter. In her narrative it also came out clearly that she has never asked her parents about her impairment, but has heard them talking about it to others. However, at Senehi her teachers gave her a detailed explanation about the cause of her impairment. It is

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common form affecting between 10 and 20 percent of all cerebral palsy patients. It causes involuntary movements, such as slow writhing of the body and jerky movements of the arms, legs, hands and feet. It often affects oropharyngeal muscles which can make eating and speaking difficult. Despite these symptoms, intelligence is rarely affected (www.cerebralpalsy.com).

probably because of this that she has not pondered over the ‘why me’ question during the interview, and was able to accept her impairment without any negative thoughts. It is also important to note that Risha has not communicated to her parents about the cause of her impairment, because of which, I assume, there is absolute silence between them about her condition. Risha’s positive attitude towards life, however, shows that persons with disabilities should be informed about the cause of their impairment, so that they do not unnecessarily think about it and learn to accept it as an integral part of their being.

In the following narrative also it can be seen that the participant and her mother were adequately informed about her condition, because of which they did not ponder over why she was afflicted by the impairment.

Narrative 4:

Suchismita, 57, was diagnosed with poliomyelitis[121] when she was one and half years old. She is the founder of Sanjeeboni, which works for persons with disabilities in two different rural Blocks in the vicinity of Guwahati. I had interviewed her in the very beginning of my study, mostly to understand the functioning of her organization. She did not talk much about her own experience of living with polio, and instead asked me to read a book[122] written by a friend of hers about 12 Northeastern women who have achieved extraordinary accolades in their lives, in which one of the chapters was on her life. Since she did not show any interest in being interviewed about her condition, one and half years later, I decided to interview her mother and understand the difficulties that she had faced in bringing up her daughter. The interview with her is replete with medical knowledge, reflecting a lot about the particular historical period, the social strata to which they belong and the support she had received from her natal family.

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[121] Poliomyelitis (polio) or infantile paralysis is an infectious disease which is cause by an intestinal virus that may attack nerve cells of the brain and the spinal cord (Miller, 2004). The disease ranges in severity from a nonspecific illness to paralysis with permanent disability, which is the most severe and typical manifestation of the disease. There is no cure for polio, and it can only be prevented by vaccination (Yotsu et al, 2012). Supportive treatments such as analgesics, physiotherapy and good nutrition for better immunity are the only treatment available for this disease (Ibid). According to the 58th round of NSS (2002), polio was the largest cause of locomotor disability in India. According to Dr. Alok, the number of cases of disability due to polio has been limited in the case of Assam, as this disease was never endemic in this region unlike other states such as Bihar, Uttar Pradesh and West Bengal. Instead there have been sporadic outbreaks of polio cases in the state.

[122] Raimedhi, I. (2015) *My Half of the Sky: 12 Life Stories of Courage.* New Delhi: Sage Publications.

Suchismita was born in the late 1950s. She grew up in Shillong where her father was posted at that time. When Suchismita was one and half years old, she and her mother paid a visit to her mother's natal family in Guwahati. At that time, they had gone to visit one of her mother's cousins. Suchismita's mother believes that her daughter had contacted polio from her cousin's son who was defecating on his pot, while Suchismita was standing close to him and talking to him. She said that at that time they were not aware that polio spreads in this way and they were also not aware that the other child was infected by polio. Within a few days, her mother observed that Suchismita had very high fever, and was unable to turn on her right side. She also observed that her right upper and lower limbs would cling to her body. Suchismita's mother consulted her *Pehadeu* (father's sister's husband), who was a doctor and had received training in polio management from Bombay (now Mumbai). With one look at her, the doctor was able to identify that this was a case of polio. Thereafter, he took her blood samples and was able to confirm that this was indeed polio. She said that Suchismita was his second polio patient in Guwahati.

Suchismita's mother said that at that time they had never heard of a disease called polio and so she asked for details from her *Pehadeu*. The doctor then explained to her in great detail about it. She, for instance, was able to explain to me that polio spreads through the feces of the infected child, and due to this reason she kept herself and her daughter locked up in a room in the top floor of her mother's home in Guwahati for three months. She did not allow her daughter to interact with any of her *Bou's* children during that period, lest they would be infected. She explained,

> *We stayed locked up in that room for three months, even though the infection subsides after three weeks. I did not want to take any chances with the other children. I would have felt very sad if the infection had spread to the other children.*

She also remembers that the doctor massaged Suchismita's body with 'Bahamas Oil' in the daytime and with 'AD Massage Oil' at night to bring back the strength of her body. The doctor started living at her mother's home at that time and took it upon himself to massage his patient. She said,

> *We did not have to apply pressure on her while massaging her. That would have worsened her case. The oil had to enter her skin and go to her bones in order to be effective. Pehadeu told me that I do not have to worry, he would massage her.*

Suchismita's mother also remembers that the doctor had advised her to give Suchismita 'sepatin' biscuits as it had a lot of 'vitamins'. She feels that it is because of the care from her *Pehadeu* that Suchismita recovered from her illness within one and half months and was able to move her hands. She said that her happiness knew no bounds when she saw Suchismita move her hands after her illness. Suchismita's mother is deeply indebted to her *Pehadeu* for curing her daughter in such a short span of time. She said that some people had advised them to take Suchismita to Bombay (now Mumbai) for treatment, but her *Pehadeu* stopped them from going anywhere and told them that he would provide the best quality care to her in Guwahati. Reflecting on the help she had received from him, Suchismita's mother exclaimed, *"I do not know what would have happened to her without him!"* She also feels lucky that both of them were in Guwahati at the time of onset of her impairment, amidst her family members. She does not know if she would have found someone to care for her daughter in Shillong.

The above narrative shows that the perception about polio was absolutely limited at the time when Suchismita had acquired her impairment. In spite of this, she had recovered from her infection without severe damage because fortunately she was in Guwahati at that time and received proper medical care from her relative who was trained in polio management. During the interview with Suchismita's mother it became clear that she had substantial medical knowledge about her daughter's impairment. Because of this reason, even though she came to know how her daughter got afflicted by the disease, she never pondered about why this disease afflicted her daughter. She simply said, *"It happened naturally. This was in our bhagyo* [destiny]*."* This comment shows that the women and their family members conveniently switch between theological and biomedical explanations in order to make sense of the occurrence of impairments (Mehrotra, 2013). The narrative also brings out clearly the oft repeated refrain in the narratives of several other participants about seeking treatment from outside Assam, as the condition of the healthcare services has been in tatters since eternity, and has not recovered much over the last 72 years since the time of independence.

In this theme I have tried to show how women with locomotor disabilities and their family members who have appropriate knowledge about the cause of their impairment explain about its occurrence. It was found that in such cases, the women and their family members provide exact medical information about their impairments. Such women were also found to be psychologically better adjusted in their lives, even though they also referred to impairments as something written in their *kopaal/ bhagyo*. These narratives show that women with disabilities should be given proper information about their impairments so that they adjust well in their lives.

Disability as a Consequence of Poverty

It is now widely acknowledged that disability is both a cause and consequence of poverty (Klasing, 2007). The study found that some of the research participants and their family members consider their impairments to be a consequence of poverty. It can be seen that poverty limited the access to healthcare and rehabilitation facilities for the first two participants (Lata and Sobiha), while for the third participant (Dolly), poverty forced her to quit her studies and start working at a hazardous workspace that eventually exposed her to her impairment and limited her life opportunities in the future.

Narrative 5:

Lata, 31, had started working as a Community Based Rehabilitation (CBR) Worker only a year before the interview in 2015. She lives with her parents in the Kushal Block of Kamrup Rural District. Lata is of short stature, and her condition is more commonly known as *dwarfism*[123]. According to her, she was born '*bhaal*' (without disability), but acquired her impairment at the age of three years after a bout of 'typhoid' fever. When I asked if the doctor gave this reason, she said,

> *I was not taken to a doctor. I do not know how it all happened. The thing is we are very poor people. My parents did not have money to take me to a doctor. Someone said let it be like this. I think they had not even given me a tablet. Earlier they only did home remedies. And when they did not have money from where they will take me to a doctor? We did not have money to eat even. They provided me whatever treatment they could at home. That is why I remained like this.*

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[123] Dwarfism is a medical or genetic condition that causes a person to be shorter than an average-sized man or woman. The average height of an adult with dwarfism is 4 feet. The term 'short stature' is more preferred to refer to such persons than the terms 'dwarfism' or 'dwarf' (www.healthline.com/health/dwarfism).

Lata's parents came to know that she has some problem only because others in their neighborhood made fun of her looks. She said,

> *Ma-Deuta came to know that I have some problem when I was about 10 years old. This is because people made fun of me when I went out in the streets. They did not come to know when I was very small. If they had known earlier, maybe they would have done something about it. Maybe they would have taken me to a doctor. I was very thin when I was young. I was also very dark. That is why nobody paid attention to me* [She laughs]. *It is only when the child is cute that parents and other people pay attention to the child. It is a truth. That is why I was not given any attention.*

According to Lata, therefore, her parents did not come to know about her impairment because she was not a 'cute' baby, which is why, she felt that they paid less attention to her growth. It was only after people started making fun of her that her parents realized that something was wrong with her. Lata, herself also came to know about her impairment when people started commenting on her looks (this will be elaborated in the subsequent chapters). When asked if she blamed anyone for her condition, Lata replied,

> *I do not blame anyone. Ma-Deuta, I do not blame anyone. I just think about it myself. They could have cured me if there was money, when they had no money, from where they would treat me? My bhagyo is bad.*

She feels that her *bhagyo* is bad not only because of her impairment but also because of her poor socio-economic condition that restricted her from studying further (which will be elaborated in Chapter 7).

From the above narrative, it can be seen that Lata perceives that her impairment was caused by a bout of 'typhoid' fever in her childhood. This, however, is just her perception as she has never been taken to a doctor for consultation about her physical condition. Her parents came to know about her condition only when she was about 10 years old, and it is very likely that they missed reading her condition after her birth, and have just devised an explanation for her condition for their own satisfaction. Lata's narrative also shows that she feels very inferior because of her skin color and appearance, as a result of which she feels that her parents never noticed her condition in her childhood. Although she did not say it explicitly, but there was a quiver in her voice when she said that her parents could not even afford to give her a tablet during her sickness, so consulting a doctor was out of question. She has accepted that her impairment and her socio-economic condition is a part of her *bhagyo* (fate) which has not only given her a stigmatized life but has also restricted her from better education and employment opportunities.

Narrative 6:

Sobiha[124], 18, has cerebral palsy that has affected her intellectual abilities, speech and her gait, as well as the ability to balance her body while walking. She lives in Guwahati with her *Ma*, *Bhonti* (younger sister) and *Mama* (maternal uncle) in a rented room. On the day of the interview, Sobiha was alone at home. She seemed to be very enthusiastic to share her story, but it was very difficult for me to understand her speech. Few minutes later her *Bhonti* came to the room and interpreted what Sobiha was saying. Later her mother joined us, and the interview was conducted mostly with her[125], with minor interjections from Sobiha, her *Bhonti* and her *Mahi* (mother's sister) who joined us towards the end of the interview.

Sobiha's mother, a Muslim woman, was married to a Christian man, who was more than double her age. He had another wife before her, and had converted to Islam to marry Sobiha's mother. Sobiha's sister explained,

> *When Ma was pregnant with her* [Sobiha], *seven months, she had gone to take dry clothes from the terrace. Deuta* [father] *was there at that time* [He was alive]. *He was not at home. She had gone to take the clothes from the stairs, and it was raining. She slipped and fell down from there. So after her fall, all the water that was there in her belly came out. Ma did not go to the hospital immediately. Deuta was not at home at that time. He had gone somewhere for work. When he came back after few days by that time all the water was lost so she* [Sobiha] *was in a dried state in her belly. She was not able to move her hands and legs* [inside the uterus]. *That is why she became like this. Her birth was premature. She was also in the ICU for observation. For about 7-8 days.*

Listening to her sister, Sobiha reflected, "*Ma fell down, that is why I am like this. What to do now? This is my kopaal*."

Sobiha was born at GMCH. Immediately after her birth, when the doctor realized her problem, she referred Sobiha to the disability organization, Senehi, for physiotherapy,

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[124] I was introduced to Sobiha by Suchismita. Sobiha and her family lives at the backside of Suchismita's house in Guwahati. Sobiha, 18, and her younger sister, 17, consider Suchismita as their *godmother* (they used the term godmother in their narrative), for always helping them out from their various difficulties. Their mother also considered Suchismita to be of one of her greatest supporters over the years, the other one being *Upparala* (the Almighty).

[125] My inability to understand Sobiha's speech could be considered a limitation in this narrative, as she did not get the opportunity to share her side of the story. Unfortunately, I could not make a second visit to her home.

which was located very close to their home at that time. Sobiha's mother took her to the organization for physical management for a few months, until she was pregnant again and was no longer able to take her. But she continued the exercises at home. Their father passed away when Sobiha was only 2 years old, and her sister was nine months old. After his death, there was no financial support for the three of them, as her father's pension along with his property went to his first wife. As a result, the responsibility of running the family fell on Sobiha's mother's shoulders. Soon she started a small *paan-tamul dukaan*[126] in the footpath. Following this, her mother had little time to spare on Sobiha's physical management at home, neither was she able to buy any medications prescribed for her. She said,

> *The doctor* [at Senehi] *checked her very nicely. She told us, "You do not have to take her anywhere. You need not take her outside for treatment. We would cure her". But my second one came to by body, so I could not take her for checkup or for her exercises. That is why everything got messed up. She was also cesarean. The other one was also cesarean. After that their father passed away when she was 2 years old. After that we could not take her for treatment. The doctor had given medicines. We did not know that they were given for her illness. I could not even buy milk for her, from where could I buy her medicines? How could I take her for treatment? I just dropped it. I did not even know so many things. I did not know that if I did not continue her exercises she will be like this. Then she started getting fits. She falls down when she gets the fits. We think what has happened to her. She begins to shake when she gets the fits. Then we showed her to a doctor, he said that it is due to problems in her medication. Then he prescribed another medicine for her. He said, "These medicines are not very expensive. It is only 1 rupee for 1 tablet. Buy it and give it to her. Otherwise your daughter cannot be cured". That is why I gave her the medicines. I took her for exercises also. We had to reach CRC*[127] *every day at 12. I had to close my shop and take a rickshaw. The fare was Rs. 30 at that time. It was Rs. 60 both ways. We did not have so much money. We could not take her every day. I took her once in a while. Sometimes I did not take her. Due to the absence of other people, how can I, alone, run in every direction? On the one hand, I had to work for our livelihood, and on the other, I had to take her for treatment. I could not do it. That is why I could not take care of her. I could not give her full treatment.*

In the above narrative it can be seen that different family members made sense of Sobiha's impairment in different ways. While Sobiha evokes her *kopaal*, her sister who was a science student gave a medical explanation about her disability. Sobiha's

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[126] Paan-Tamul Dukaan: A small shop by the road side that sells paan (betel leaves) and tamul (betel nut/ areca nut).

[127] Composite Rehabilitation Centre (CRC) is an initiative of Government of India, Department of Empowerment of Persons with Disabilities, Ministry of Social Justice & Empowerment. The center is located at Guwahati Medical College and Hospital (GMCH), Guwahati, Assam. The Centre has been functioning from 2001 under the administrative control of Swami Vivekananda National Institute of Rehabilitation Training and Research (SVNIRTAR), Odisha. The aim of CRC, Guwahati is to provide services to the persons with disabilities and to develop human resources in the field of disabilities in the North Eastern Region (www.crcguwahati.com).

mother, on the other hand, had accepted her daughter's impairment as a part of the many hardships that she has had to endure over her life course. During the interview, she did not ponder so much on the cause of her daughter's impairment as much as the socio-economic difficulties that she has faced in raising her daughters after the death of her husband. In Sobiha's case also it can be seen that different family members applied different coping strategies to deal with her impairment and this was influenced by their social and cultural beliefs (Mehrotra, 2013).

Another important aspect about Sobiha's narrative is that for her medical help was readily available, the reason for which was her mother's fall during pregnancy leading to an emergency situation, her location in an urban context as well as the historical period of her birth. By the late 1990s when Sobiha was born, Senehi had firmly established itself in the disability sector. As a result of this, doctors of this era were able to refer their patients to the organization for physical management. It is a different matter that in spite of knowing about this, her physical rehabilitation was limited because of the financial difficulties that her mother faced.

Narrative 7:

As cited earlier, unlike Lata and Sobiha, Dolly acquired her impairment as a consequence of poverty. In this study, only Dolly has a disability due to a traumatic cause. According to Dr. Satish Chaudhury, Professor, Department of Orthopedics, GMCH, in his 34 years long career in this field, he has observed that in the recent years the number of cases of locomotor impairments due to congenital conditions have declined and have gradually been replaced by the increasing number of post-trauma cases, which are largely reported from the urban areas. While he was referring mostly to road traffic accidents leading to impairments, these are predominant among men. Dolly acquired her impairment as a result of an accident at her workplace.

Dolly's (34) right hand was amputated when she was about 13 or 14 years old. One year before this incident her father, who was the only working member in the family, had passed away. Dolly has three siblings, out of which her older sister and younger brother were studying at that time, while her youngest sister was only one year old. Dolly was not much interested in studies, so she voluntarily dropped out of school after class 5 to help her mother earn a livelihood. Dolly's mother had received a sewing machine from the garment shop where her father had worked before his death.

With the machine she used to sew *mekhela* (the bottom portion of the traditional Assamese dress) for her neighbors, but this fetched them only a small amount of money, and was not sufficient to run a family with five people. In order to supplement the family income, Dolly started working as a helper for a printing press. She had only worked there for a few months when a wood cutting machine, which was not working properly, fell on her right hand, severely injuring it. After the accident, she was taken to MMCH where the doctors said that they cannot treat her and referred her to GMCH. At GMCH, the doctor told her mother that they would give it a try, but it is a very serious case. He also asked her mother if she would want them to save her daughter's life or her hand. Her mother replied that she wanted both of them to be saved. The doctor replied that it is not possible, as her hand might get rotten from inside. After hearing this, her mother made the decision to save her daughter's life by amputating her right hand. When I asked her if she blames anyone for her accident, she replied,

> *No, I feel that this was there in my kopaal. Whom to blame? Ma had told me not to go there for work. She said she would do the sewing work. But we had not eaten at home. My tikla Bhonti* [little sister] *she did not want to eat. She kept on pulling me. She would say "Baideu* [elder sister] *I am hungry". She was very young at that time. She was just one year old. I thought what should I do? Now whatever is there in my kopaal. I do not blame anybody. It was written in my kopaal.*

Her accident caused a severe blow to the family. Even though her income was less, they were able to pay the house rent with her salary. Additionally, she was also able to help her mother in her sewing work. After her amputation, she is no longer able to do these things. Her *Bhaiti* (younger brother) had to drop out of school in order to take the responsibility of the family. It is one of her biggest regrets that her *Bhaiti* was not able to complete his school education because of her amputation.

From the above narrative it can be seen that it was the death of her father and poverty that exposed Dolly to her impairment. Dolly blames her amputation on her *beya kopaal,* which brought misfortune not only for herself but for her entire family as they lost a productive member because of this reason. She also regrets that because of her, the entire family had to go through very rough times. She had joined Moromi, an organization for the economic empowerment of persons with disabilities, about six years earlier, and is very happy working among other persons with disabilities.

However, since the 'salary' is very less, she hopes to quit her job in the future to start her own business.

In this theme I tried to show how some of the participants and their family members made sense of their impairments as a cause or a consequence of poverty. It was found that the women considered poverty to be a result of their *beya kopaal* or *beya bhagy* which not only exposed them to their impairments, but also limited their own as well as their family's life opportunities in the future. It has been argued by Ingstad (1990) that among poorer households, having a member with disabilities affects all other family members as the resources available to the household have to be redistributed keeping into consideration the needs and concerns of the disabled person (cited in Grut, Olenja & Ignstad, 2011). This was also found to be true in the case of the study participants.

Making sense of the 'bad doctor' narrative

In the above narratives it can be seen that access to appropriate healthcare at the right time along with other intersecting factors has played a significant role in the improvement of the health conditions of some of the research participants, while for others lack of access to healthcare has deteriorated their health condition. In some of the cases it has also been seen that the women consider their impairments to be a result of medical intervention by healthcare professionals, particularly doctors. Their narratives reminds one of the claims that Ivan Illich had made in 1976 that *"an expanding proportion of the* **new** *burden of disease of the last fifteen years is itself the result of medical intervention in favor of people who are or might become sick. It is doctor-made, or iatrogenic?"* (p: 1, emphasis in original). According to him, *"iatrogenic disease includes only illnesses that would not have come about if sound and professional recommended treatment had* **not** *been applied"* (p: 5, emphasis in original). In this study it has been found that some of the research participants and their family members think that their impairments/ aggravation of their conditions are a direct result of the intervention of a 'bad doctor'. The following narratives give a glimpse of this.

Narrative 8:

Nayana (30+) had developed very high fever when she was about two and half to three years of age. At that time her parents had only recently shifted to Guwahati, and had started working as live-in domestic workers for a family. During the one week when she had high fever, her parents gave her different medicines. These medicines, however, did not work on her and she also lost her appetite. Nayana said that for seven days she was not able to eat or drink anything. Thereafter, she developed a *gha* (abscess) in her belly button and this really scared her parents who immediately took her to a doctor. This doctor was ‘not able to identify’ her condition and gave her medicines for ‘malaria’. After taking the medicines her condition deteriorated further. After this her parents took her to another doctor, but he told them that Nayana’s condition is very critical and he did not want to take any risks. After much pleading, this doctor gave her one medicine which, according to her, stabilized her condition.

This, however, was not the end of her parents’ agonies. After a few weeks, her parents started to notice that Nayana did not move at all, and would only lie down on her bed all the time. When one month passed like this, her parents got very scared and took her to an orthopedic. When he checked her, he explained to her parents that she was infected by ‘typhoid’ and cannot be cured. He also told her parents to stop seeking treatment for her condition as she cannot be cured even if she is taken for treatment to Calcutta (now Kolkata). The doctor further said that her condition would not have been so severe if they had put some water in her head at the time when she had high fever. Nayana said that her parents were from the village and did not know about such things. The doctor also taught her parents some exercises which they continued at home.

Nayana’s father was a strong believer in God, and when she fell sick he was not able to make sense of her condition. According to her, he was very depressed for a long time. However, her parents did not blame God for their sufferings. Instead they consoled themselves by thinking that it was God’s will, and therefore, it would have happened anyhow. Nayana also said that since her parents were ‘non-literates from the village’, it is understandable that they were unaware about what to do when a child has fallen sick. She is, however, not able to accept that her parents’ employers were also not aware about this. She said that her parents had to meet all the needs of their employers which left them with very little time for themselves. According to Nayana and also her parents, it is because of this reason that she had to suffer from the debilitating effects of ‘typhoid’.

During my interaction with Dr. Indrajit Hazarika, Professor, Department of Medicine, GMCH, and his colleagues, it was found that many people consider fever-induced impairments to be a result of ‘typhoid’. According to them, this is because people have the memory of a period when typhoid drugs were not available, and typhoid fever often left some or the other impairments in the sufferers. They said that even though at present most fever-induced impairments are a result of Japanese encephalitis, many people, especially from the rural areas, still consider it to be a result of typhoid. In Nayana’s narrative, and several others that are to follow, it was found that she and her parents considered any kind of fever to be typhoid, and did not know about the difference between typhoid and polio.

In her narrative it can also be seen that in the initial stages of her illness, her parents delayed in seeking treatment for her condition and instead gave her over-the-counter medicines. It was only when these medicines did not help and she developed an abscess in her belly button that her parents understood the severity of her condition and took her to a doctor for treatment. According to her, it is because of the first doctor who mistook her condition to be malaria that deteriorated her condition even further. In her narrative, Nayana also blamed her father’s employers for not taking her condition seriously and not advising her ‘simple-minded’ parents on how to bring down her high fever in the initial stages. She also blamed them for overburdening her father with work to such an extent that he was not able to give any time to his family. Her parents, especially her father, who was a strong believer in God, took some time to reconcile to the fact that his daughter is permanently impaired by the fever. Over time, however, he reasoned with himself that this was all part of God’s plan and would have happened no matter what he had done to prevent it. This narrative also shows how poverty robs people off their agency and makes young children and their parents vulnerable to ill-health and subsequently to life-long impairment. It is questionable whether her condition was aggravated by the delay in seeking treatment from the doctor or because of having wrong medicines from a doctor who was not able to recognize her condition. Blaming a doctor, in any case, is an easier way of making sense of her illness, than blaming her beloved parents for the delay in seeking her treatment.

In other cases also even though the women have accepted their impairment as a part of their *kopaal,* they also consider their doctors to be responsible for their present predicament.

Narrative 9:

Jeuti, 25, was born in Nagaon[128] where her parents lived before they shifted to Guwahati. When Jeuti was a few months old, she had very high fever, but her mother was not able to understand this. One day, one of her neighbors who was holding her, while Jeuti's mother was doing her household chores, brought attention to the fact that she has very high fever. At that time, Jeuti's father was not at home, so her mother went to her *Bhindeu* (elder sister's husband) for help. He took her to a doctor who administered two injections at a time on the same hand, one for 'typhoid' and the other for 'fever'. Jeuti said that these injections helped her in recovering from her illness. A few weeks later, while playing with Jeuti, her mother's *Baideu* (elder sister) and *Bhindeu* observed that while she played with her right hand, her left hand clung to her body. When they took her to a doctor for examination, he said that her right hand is paralyzed because of the administration of both the injections at the same time. Thereafter, Jeuti's mother said that they had done whatever they were asked to do in order to cure her. From feeding her *jiya kusia maasor tez* (the blood of a particular local fish) to massaging her with *gahorir tel* (pig fat), they had done everything. Her mother said that for a few months she lived with her mother after Jeuti fell sick. During this period, her mother killed the *kusia maas* and took out its blood and handed it over to her to be fed to Jeuti. Jeuti's mother then mixed it with salt and gave it to Jeuti to drink. She said, *"Jeuti was a baby at that time. She did not understand anything, so she had it".* But in spite of all their efforts, Jeuti was not cured of her impairment. Few years before the interview, Jeuti decided to undergo a corrective surgery on her paralyzed hand which has enabled her to do tasks that were unimaginable for her earlier. Jeuti's mother said that a lot of people made fun of her daughter in her childhood because she is a *lengeri* (physically disabled). A lot of

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[128] Nagaon (Nowgong) is a city in the Nagaon district of Assam. It is situated 121 km towards the east of Guwahati.

people tried to harm her also but, according to Jeuti's mother, they were not able to do anything because God was always there to help her.

In her interview, Jeuti said that the doctor is responsible for her impairment, but still she does not blame anybody for her hardships. She said that this is because she has never experienced any kind of pain or sorrow from her family members. If she is not able to do something, her mother and her younger sisters have always helped her out. Even after her marriage, she said that her husband or his family members have never taunted her for her impairment. However, she did mention that outsiders have often teased her because of her impairment and that often made her sad in her childhood.

From this narrative it can be seen that Jeuti's mother was unable to understand that her daughter had very high fever which made them delay in seeking treatment for her. Eventually when they took her to a doctor, he gave her two injections at the same time, and this is what led to her paralysis according to another doctor. Even though Jeuti referred to her paralysis to be a result of 'typhoid', in the documents that she had submitted to the Helen Keller Charitable Trust, her impairment is referred to as 'post-polio residual paralyses'. In the clinical literature on polio from India it can be seen that children who have recently been administered with intramuscular injections are at a heightened risk of contracting polio through oral polio vaccine (OPV) (Addlakha, 2000; Sathyamala et al, 2005; Jeffery & Jeffery, 2011). These injections are a common way of treating children in South Asia (Jeffery & Jeffery, 2011) and other third world countries and are administered to children for symptoms such as fever, vomiting or diarrhea, which could be subclinical manifestations of polio (Addlakha, 2000). Injections increase the blood supply to the motor neurons serving the muscles which may convert a non-paralytic attack to paralysis. Such injections are given by pharmacists, paramedical workers, private doctors and traditional healers, and are often used without proper sterilization procedures which heightens the risk of infection and paralysis (Ibid). Due to such findings, many Indian studies have cautioned against using injections in children for the treatment of low grade fever which is one of the early signs of polio.

While in the above narratives the women blamed their doctors for either giving them wrong medicines, or for administering wrong injections, in the following narrative

Anamika narrates how a surgical procedure severed a nerve leading to limb inequality on her left side.

Narrative 10:

Anamika, 38, had developed an abscess in her hips when she was about three weeks old. She was born in the month of *Aahar* (a month in the Assamese calendar that roughly falls between mid-June to mid-July), when the monsoon showers begin in Assam. Her home is situated in a village in the Joonaki Block, which is surrounded by rivers on all four sides. It is only recently that a sluice gate has been built to connect the village with the other parts of the Block and also to protect them from the wrath of the monsoon floods. During this season, her parents braved the high current of the Digaru River to reach the nearby railway station, so that they can take their new born child for a checkup at MMCH. Anamika was their first child, and so according to her, her parents did not know how to deal with her abscess. Due to this reason they decided to take her to the tertiary centre directly instead of the nearby health facilities which were anyways rendered inaccessible in the monsoon months. At MMCH an inexperienced doctor allegedly severed one of her nerves while surgically removing the abscess. The procedure left a big wound in her hips. Anamika has heard her family members saying that since that day she cried incessantly and her parents could not do anything to pacify her. She said that one time her father was so irritated with her cries that he wanted to throw her into the river while crossing it on a boat. Finally her parents consulted a doctor in her mother's hometown, Tezpur[129]. This doctor gave her an ointment to relieve her pain. Her family only came to know about the actual nature of her disability when she started walking at the age of three to three and half years. Due to the severing of one of her nerves on the left side of her body, her left leg is shorter than her right leg, and she walks with a limp.

She said that her parents never went back to MMCH to confront the doctor because they were 'simple villagers' who were not much aware about the ways of life of the city, and were also scared of the 'city people'. What she did not reveal, and perhaps was not aware of, was that at the time when she was born, the Assam Movement was already underway. Apart from the Bengali Muslims, the movement also targeted Nepalis as 'foreigners'. This could be a very important reason why her parents never

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[129] Tezpur is a city in the Sonitpur district of Assam. It is situated 175 km northeast of Guwahati.

went back to confront the doctor as they were scared of persecution. However, since her father could not be interviewed, this can only be speculated.

Anamika's mother passed away when she was 3 years old while giving birth to her brother (who also passed away at the age of six months). After this incident, her father whiled away much of his time by drinking with his friends. She and her *Bhonti*, who was one and a half years old at that time, were brought up by her *Burhi Aita* (paternal great grandmother). Anamika and her *Bhonti* grew up with much difficulty, attending to both household and agricultural chores, which left them very little time to concentrate on their lessons. As a result, both of them failed in their matriculation examination.

When asked if she blames anyone for her disability, she replied,

> *It is because of the doctor. I had a fuha* [abscess] *and he used a pair of scissors. If he had used a needle to drain out the fuha, this may not have happened, I suppose. He had inserted the scissors into my body. You can say that it is because of the doctor. Sometimes I think maybe this is what is written in my kopaal. Isn't it? No one can wipe out what is written in my kopaal… This* [the impairment] *just happened. In people's life, we have sorrows, happiness and difficulties. We will have to undergo all of these feelings. This is how things have been since the very beginning. Brohmo, Bisnu and Mohesh have not come about just like that. Isn't it?*

Looking back she feels that it was because of that inexperienced doctor that she had to suffer from her impairment. But she also blames her adversities on her mother's untimely death at a much younger age, their poverty and lastly what was written in her *kopaal*. Anamika has been working as a Community Based Rehabilitation Worker since 2013. Her work experience has made her more aware about her rights. She also said,

> *Had it been at present, then I would have punished the doctor for his deeds. But at that time I did not know anything, my parents also did not know anything. They were 'old'. They did not have much knowledge. They were scared also. They were scared of government officials, thinking they might do something to the public. It is no more like that. Now if someone does something like that, the public would beat up the doctor.*

The above narrative shows the unequal power relationships that doctors share with their patients, whereby patients and their families, especially from the rural areas, do not even have the confidence to confront these people. Anamika, however, does not blame her parents for their lack of confidence, stating that they were 'simple village folks' who did not know the way things were in the world outside. Her narrative also shows how after working for the organization her confidence level has increased, and she was ready to punish the doctor for his deeds. This should be read in a context of increasing mob violence against doctors and other healthcare personnel in Assam as also in parts of the world (see Khan et al, 2010; Ambesh, 2016; Krishna, 2017; Nagpal, 2017; Ahmed, Memon & Memon, 2018), where doctors are beaten up for poor treatment. For her, more than her impairment, it was her mother's death that has created the greatest hindrance for her. She, however, does not hold any grudges because she feels that this was written in her *kopaal* and would have happened anyhow.

In the following narrative, we see another narrative where the woman blames her doctor for the aggravation of her health condition that eventually led to her amputation.

Narrative 11:

Hema, 35, lives in Guwahati with her parents. Her older brother and his family live next door but they eat separately and do not talk to Hema and her mother due to property disputes. According to her, her right leg was pierced by a nail when she was about 16 years old (puncture wound[130]). This wound developed sepsis which eventually led to a lot of physical difficulties. Around the same time her younger brother passed away in an accident. As a result of this, her parents were overpowered by their grief and delayed in seeking treatment for her. One year later when her family realized that her physical difficulties were still persisting, her father took her to a doctor in a private hospital in Guwahati. There she was diagnosed with bone tumor, and was recommended to go for surgery immediately. According to her, this doctor gave her wrong treatment, as a result of which her condition deteriorated further, and she has not been able to walk ever since. Later they had shown the x-rays to other doctors who told them that even though she had bone tumor, it was a *bhaal bhori* (good leg) and did not require surgery. One year later, her father arranged some money from different sources and took her for treatment to Bombay, where she stayed for 6 months. In spite of this, when she was not cured, and also because their money

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[130] A puncture wound is a forceful injury that is caused by a sharp, pointed object that penetrates the skin. It is generally narrower and deeper than a cut or scrape. Puncture wounds increases the risk of infection because they are hard to clean and provide a warm, moist place for bacteria to grow (which can lead to sepsis) (www.uofmhealth.org).

was running out, they returned back to Guwahati and consulted other doctors. Hema said that by the year 2004, the difficulties with her leg had aggravated quite a lot. Her leg had become a lot heavier and it was very painful for her to walk. At that time, the doctors tried to explain to her that it would be better for her if she amputates her leg. She said,

> *In the beginning I did not want them to amputate my leg. Who would want to cut their own body part? I thought that I would get better for many years. But what happened was that the leg was getting damaged, it was rotting from inside. It was very painful. My leg was getting heavier and because of all this I was facing a lot of difficulties. The doctors tried to explain to me that if I cut my leg, it would be good for me. The leg was so heavy at that time that I felt that if they amputate it I will find some peace. In fact, there were days when the pain was so severe that I felt like I would do something to my leg myself... Even though the thought of cutting my leg was very painful, I felt it would be better if I just listen to the doctors.*

After her amputation, Hema said that she actually felt better, as she no longer had to bear the pain. She started using crutches for her mobility. Her father had also bought her prosthesis, but she found it very painful to walk with the help of it, and so she finally gave up. She also said that after her amputation, her life has become more restricted now as even though she wants to walk like before, she is no longer able to do so. She also has to do a lot of pre-planning before she actually goes out of her home.

> *Now I cannot do anything spontaneously. I cannot go anywhere at an instance. I feel like going, but I am not able to go out. Now if I go a little far, I need a vehicle. I have to think about such things. If I would have had my leg, I can simply walk. I do not need a vehicle. I feel like that.*

Norlyk, Martinsen & Kjaer-Petersen's (2013) study on the experience of loss of a leg on patients' individual lifeworld in the post-discharge period (2-4 weeks) in Denmark found that the amputation was experienced as a source of exclusion from life. Similarly, Hema also feels isolated sometimes and feels sad that her life had changed so suddenly. But with time she has adjusted to her disability by consoling herself that perhaps this was something written in her *kopaal*, and does not blame anyone for this. She further said that in the last few years, more than her impairment, it is the daily feuds between her older brother and his wife on one side, and she and her mother on the other side that has made life unbearable for her (this will be elaborated in Chapter 7).

From the above narrative it can be seen that Hema’s treatment was initially hindered due to the death of her younger brother. The following year when she consulted a doctor, he did not give her proper information about her condition and suggested to undergo a surgery. Her narrative also shows that she blames the first doctor for worsening her condition by operating on her leg, which did not require surgery according to the other doctors. The narrative also shows that over time her leg was creating so many hurdles for her that she decided to listen to the doctor and go for the amputation of her leg. It was found that after her amputation, she had found some peace as she no longer had to bear the physical pain. However, the condition in her family had worsened over a period of time, that did not leave her and her mother with much mental peace.

Conclusion

The aim of this chapter was to understand how women with locomotor disabilities and their family members make sense of the occurrence of their impairments. It was found that most of the research participants made sense of their impairments as something that was written in their *kopaal* or their *bhagyo*. However, how each of the participants have used this refrain depends on a host of factors. In the case of most of the participants, access to healthcare has been significantly limited either due to the lack of knowledge of their parents or due to certain inevitable circumstances because of which their parents were unable to take them to the healthcare facility on time. In the case of Nayana and Anamika it can be seen that they feel that their parents lacked sufficient knowledge about what to do when a young child is unwell. They considered their parents ‘simple’ and ‘old’ to know the ways things functioned in the healthcare system. In Jeuti’s case, her mother considered herself to be naïve that she was not able to understand her daughter’s condition initially. In other cases, it can be seen that the treatment of the women has been hindered due to certain inevitable circumstances in their families. In the case of Minakkhi, it is seen that the death of her grandmother led to the end of her cure seeking, as no other family member was free thereafter to take her to the tertiary care center in the city for treatment. For Sobiha, her mother’s second pregnancy and subsequently the death of her father left very little time in the hands of her mother to seek physical rehabilitation for her condition. In Hema’s case also the untimely death of her brother delayed her treatment seeking which resulted in worsening of her condition in the years following her initial injury. In still other cases it is seen that when the research participants were taken to the healthcare facility, they either did not receive adequate treatment or were provided wrong treatment. This was observed in the case of Nayana, Jeuti, Anamika and Hema, all of whom blamed their respective doctors for their negligence, which according to them, eventually exposed them to their impairments. But as explained earlier in the chapter, it cannot be ascertained whether their conditions were actually a result of poor treatment or a result of delay in treatment seeking. From the above narratives, it can be seen that several of the research participants had lack of access to health care. *Access* here refers to the

> […] actual use of personal health services and everything that facilitates or impedes their use. It is the link between the health services system and the populations they serve. Access means not only visiting a medical care provider but also getting to the right services at the right time to promote improved health outcomes (Andersen & Davidson, 2007: 3)

The doctors I had interviewed for this study acknowledged that a lot of patients, especially from the rural areas, face several hurdles in accessing healthcare for their conditions. Some of them also believed that instead of coming to the tertiary center for cure, they lose a lot of time by going to folk healers and quacks, who eventually deteriorate their condition even further. According to Dr. Alok Kalita, a retired orthopedic from GMCH, who now works as a senior consultant at a private hospital,

> *One of the foremost difficulties that I have faced in my work is that of ignorance, lack of exposure and awareness about disabilities. If people treat disability as God's gift or as Karma, retribution for the sins that they had committed in their previous birth, then they do not seek treatment for their difficulties.*

In this study it can be seen that only Minakkhi's mother considered her daughter's impairment to be a result of her *beya kormo* (bad deeds), while the rest of the participants blamed it on *beya kopaal* (bad fate) or their *beya bhagyo* (bad destiny). At this point it is necessary to make a distinction between *karma* (*or kormo, as it is pronounced in Assamese*) on the one hand, and between *kopaal* and *bhagyo* on the other. While *karma* is used to refer to the outcomes of bad deeds committed either by the individual or his /her family members in their present or previous lives, *kopaal* and *bhagyo* are used as refrains to reconcile themselves to their fates, instead of fighting against it. As has been elaborated above, such an internalization of impairment liberates oneself from the feelings of sorrow and guilt and provides a newer perspective to life. The study has also shown that several of the research participants and their parents are staunch believers in God, and regardless of the severity of their impairments and their hardships in life they do not doubt their belief on the Supreme Being. Belief on God also gives them the strength to realize that their impairments were written in their *kopaal* and would have happened no matter what they had done to prevent it. Such a belief helped the research participants in psychologically coping with their impairments.

The study has also shown that even if the research participants and their family members considered their impairments to be an outcome of their *beya kopaal* or *beya bhagyo*, they did not stop seeking cure for their conditions. Seeking cure for the condition of their child is, in fact, of paramount importance to the parents and for this they look for different avenues, including biomedical cure, folk healers, home remedies and even quacks. While in certain cases parents give more priority to folk healing traditions, the younger generation is seen to give more priority to biomedical cure. Parents also go to folk healers or quacks for treatment, when they are unable to visit a healthcare facility due to its distance or due to inevitable circumstances that are beyond the control of the parents. In many cases the parents of the women did not even realize that their daughters' conditions were treatable until much later when curing the condition was impossible. It was also found that while parents gave adequate stress on cure, the same was not true in the case of physical and other forms of rehabilitation. This was also observed by Mehrotra (2013) in her study on women with disabilities in rural Haryana.

In other cases, it is also seen that poverty is a prime factor in the occurrence of impairments among the women. Lata, for instance, has cited that her family was so poor that her parents did not even have the money to buy a tablet for curing her condition, going to a doctor or to a healthcare facility was out of question. Sobiha's mother had also said that buying food was so difficult for them that buying medicines was out of question for them. In contrast, Dolly was exposed to a hazardous workplace because of the poor socio-economic circumstances of her family. During the interviews, it was found that all of them had made sense of their impairments by invoking their *beya kopaal* or their *beya bhago*.

The narratives have also shown that several of the participants have referred to mysterious fevers as a cause of their impairments. In their narratives either they have referred to their impairments as a result of typhoid or a result of polio. During my interview with Dr. Alok Kalita, when I asked him about these fevers, he replied that untreated very high typhoid fevers can lead to cerebral palsy among children. He also said that this is more common among the children in the rural areas than among the urban areas due to the problems of accessibility to healthcare. During my interaction with Dr. Indrajit Hazarika, Professor, Department of Medicine, GMCH, and his colleagues, it was found that many people from the rural areas of Assam considered fever-induced impairments to be a result of either typhoid or polio. According to him, this is because people have a collective memory of a period when typhoid drugs were not available, and its occurrence often left some or the other impairments in the sufferers. He said that even though at present much of the fever-induced impairments are a result of Japanese encephalitis, many people, especially from the rural areas still consider it to be a result of typhoid. On the other hand, people have an increased knowledge of polio induced impairments because of the highly visible Pulse Polio Programme. Such a perception shows that people are usually not aware about the actual cause of their impairments and how it can be prevented. In the narratives, it can be seen that many participants such as Lata, Jeuti and Nayana considered their impairments to be a result of typhoid fevers. On the other hand, others with congenital impairments such as syndactyly and congenital weakness of limbs considered their impairments to be a result of polio and wanted to have the oral polio vaccine in their quest to find a cure for their impairments.

Such a scenario makes it imperative that we move beyond the distinction between impairment and disability as has been espoused by the social model of disability, while dealing with disability in the majority world context. It was found that the concepts of '*social suffering*' and '*structural violence*' were more relevant for this study. Social suffering is defined as *'collective and individual human suffering associated with life conditions shaped by powerful social forces'* (Benatar, 1997: 1634, cited in Muderedzi & Ingstad, 2011). On the other hand, *structural violence* is the negative impact of social structures that are beyond the control of individuals and groups (Muderedzi & Ingstad, 2011). These two concepts seem more relevant because the narratives have clearly shown that the impairments of the women have been created by factors that are outside of their own control. The narratives shows us that their impairments were a result of the circumstances in which they and their family members were living, and in order to understand their experiences more deeply it is imperative that we also study the causes of their impairments.

Chapter 5

Family Support for Women with Disabilities

In the previous chapter, I had elaborated on how women with locomotor impairments and their family members make sense of the occurrence of their impairments. These explanations were then contrasted with the explanations given by the healthcare providers, namely orthopedics, general medicine physicians and physiotherapists to understand the divergence of their views. The aim of the present chapter is to elaborate on the support and care that the women have received from their family members across different phases of their lives after the onset of their impairments. It throws light on the way parents, siblings and other kin members make space for their disabled family member not only in their formative years, but also later, even after they are married and have children. It is extremely important to study this aspect, because in majority world contexts, where social security benefits are inadequate and level of education and employment opportunities are poor, persons with disabilities have to depend on their family members for their care, sometimes throughout their lives. Due to this reason, western notions such as individualization of disability are inadequate to explain the life situations of the women in this context. Due to this reason, the concept of *'disabled household'* (Ingstad, 1997 cited in Ingstad, Baider & Grut, 2011) was found to be very useful in this study. It means that when there is an impaired individual in the family, the entire family has to reorganize their resources in order to accommodate the needs of the impaired person. This further means that it is the family that becomes disabled, due to which rehabilitation of person with disabilities should also take into consideration the needs of the family unit (Ingstad, Baider & Grut, 2011). Even though this concept is mostly used to explain the life situations of poorer families, reorganization of resources was also visible among the more affluent families.

The chapter elaborates on different themes that look at different aspects of the women's life course and how their families have supported them during this period. The chapter incorporates both long and short narratives to explicitly state the struggles that the women and their family members have faced in their lives.

Initial Reaction of Parents towards their Daughter's Disabilities and the Grief Cycle

When parents are expecting a child, they generally assume several attributes of the child like his / her gender and appearance, and also hold expectations about the child's future. However, when this idealized picture of a normal child is shattered due to prenatal complications or postnatal discoveries of developmental disabilities, parents may experience a grief cycle, which can be compared to the death of a loved one (Barbosa, Chaud & Gomes, 2008; Dhar, 2009). Barbosa, Chaud & Gomes's (2008) study with five mothers of children with disabilities (four of whom had cerebral palsy, one had Down's syndrome) conducted in Brazil found that having a child with disabilities is a hurtful process for the mother, who finds herself unprepared to deal with the situation. The study noted that the conflicting emotions that the mothers have towards their disabled children are compounded by the lack of sensitivity of healthcare professionals, who find themselves unprepared to give a diagnosis to the family (Ibid). In Vaidya's study (2015) on the families of autistic children in Delhi, it is seen that parents come to know that something is *wrong* with their child only around the second year of his / her life. The study found that the process of obtaining diagnosis for the child's condition is a painful one, and usually involves a number of visits to the family doctor, followed by visits to a specialist. Parents reported that finding out about the child's condition is devastating, and is compounded by the lack of accurate information, appropriate intervention, education, training and uncertainty about the future. Her study also found that the grieving process is a gendered one. Even though both the parents reported intense emotions about their children, the mothers were more deeply affected by the diagnosis possibly because of their greater proximity with very young children (Vaidya, 2015). Ghosh's (2016) study on women with locomotor disabilities in Bengal found that the parents' experience shock, anxiety, helplessness and react by questioning why this happened to them. According to her this reaction towards their disabled children are influenced by the visual impact of the disability, severity of the disability, the birth order of the child, along with the reactions of relatives and neighbors (Ibid).

In this study, as shown in Chapter 4, some of the women had congenital impairments, while others had acquired their impairments in childhood or adolescence through infective or traumatic causes. This theme looks at the initial reaction of the parents when they discovered their daughter's disabilities and if they also underwent a grief cycle like the other parents cited above. Following are three narratives of women with different locomotor disabilities acquired at different ages. The parents' initial reactions towards their daughter's disabilities are described in detail.

Bandana, 30+, is of short stature. She was born at GMCH, and is the eldest among four siblings. She grew up in Guwahati, and at the age of 15-16, she had joined the disability organization Moromi at the insistence of its founder Kishore Kamal Bora. Bandana is now married and lives with her husband in the same city. When asked about her parents' initial reaction about her impairment, she said,

> *...I have heard them talking about it to others, they got to know about it after I was born, the doctor told them* [parents] *this has happened, what do you want to do? Deuta* [father] *said however she is, she will be like that. We have nothing to say.*

Bandana was interviewed in her shop, where her husband was also present, attending to the customers. In spite of a few attempts, it was not possible to interview her mother, as either she was reported to be unwell, or Bandana herself was unable to leave her shop and accompany me to her mother's home which is located at a very remote place in Guwahati. During the interview, Bandana mentioned that she has never asked her parents about her impairment, although she has heard them talking to others about it, and this is how she became aware about the cause of her impairment. She said that after her birth the doctor informed her parents that Bandana had acquired her disability because her mother had suffered from *boxonto* [chicken pox] and 'typhoid' and 'pneumonia' during her pregnancy, and due to this reason, their daughter was born with this impairment. This information perhaps helped her parents in easing the process of accepting their newborn child.

Korobi, 51, had acquired her disability at the age of three and a half years of age. In an interview with her mother, she recounted that Korobi was underweight when she was born, but did not have much difficulties. She had started going to a Montessori School in Shillong at the age of two, where her *Pehi* (father's sister) was working as the Headmistress. At that time Korobi was very active in school, and participated in all the activities like playing and running. She also talked a lot at that time. But one day when she was about three and a half years old she fell down in a concrete drain near their home in Shillong. Korobi's mother said that it was one of her favorite pastimes to go and watch the water flow in the drain from the hills, while brushing her teeth in the morning. Korobi had probably picked this habit from her mother, and went there unaccompanied and fell down. She was taken out from the drain by her Bordeuta (father's older brother) and a boy who worked as a domestic worker at their home. Although Korobi did not have any external injuries, probably she had hurt her head as it was stuck at the bottom of the drain. From that day her behavior in school changed completely. She stopped participating in PT classes, she did not write anything in her classes, and kept her hands in the pocket of her school uniform. Out of embarrassment, her *Pehi* often scolded her in school, but this had little effect on Korobi's behavior. Her *Pehi* also informed Korobi's parents about it, but her mother was in denial. She thought that probably since it was very cold in Shillong that is why Korobi never took out her hands from her pocket. After constant complaints, her parents decided to take her out from the school, and get a home tutor instead. But the tutor also beat her sometimes when she was not able to follow her lessons. She often cried out loud, and this infuriated her *Aita* (paternal grandmother) who urged Korobi's parents to stop forcing her to study, and instead look into what the matter was with her.

Korobi's mother was not able to understand the sudden change in her daughter's behavior. She started observing her, and realized that when she played with other children of her age, she often fell down and was unable to get up by herself. She also observed that she was able to walk straight, but she fell down every time she took a turn. When she consulted a doctor, he examined her and told Korobi's mother that there was nothing wrong with her daughter physically. During the interview, Korobi's mother had mentioned that there were not many 'child specialists' in Shillong at that time, and due to this reason, they brought her to Guwahati. The doctor in Guwahati advised Korobi's parents to take her outside for treatment. Her Deuta and *Aita* took her to Calcutta (now Kolkata) for treatment, where one of her *Pehi* worked as an Army Doctor. Her mother was not able to accompany them as she had just delivered a baby, and was unable to travel. In Calcutta they were told that she has brain tumor and she will need to undergo a surgery immediately. Korobi's *Bordeuta* (father's older brother) came to Guwahati and gave the news to her mother. She was expected in Calcutta to be by her daughter's side. Her family had arranged for her to travel and had also arranged a room for her to keep the baby in the hospital. Hearing this, Korobi's mother was in deep shock and was not able to control her tears. She cried all night. At that time, Korobi's other *Pehi* told her mother to think about [Sathya] Sai Baba[131], and to have faith on him. She assured Korobi's mother that nothing would happen to her daughter. Korobi's mother said,

> *I did not know what to do. I was crying and was filling in my suitcase. I was not able to sleep at night. I got up every now and then and I saw that Sai Baba came to me and said, maybe it was because I was thinking so much. I did not know who Sai Baba is. I had never seen him. Her Pehiyek, she was a doctor, she gave me his photo and said think about him every day, he would look after her. I did not know who is Sai Baba but still I lit up an incense stick and thought about him. I was thinking so much about him that I really started seeing Sai Baba in my dreams. I was sleeping and the other one she was a baby at that time. When I was sleeping I suddenly saw that Sai Baba was in the room. I woke up and saw that there was no one in reality. I heard his footsteps that he is coming. I saw him every time that night. I cried all night, and the pillow was all wet. Then I turned the pillow and slept again. Then Sai Baba came again and said that this is not your tears, it is her tears that are coming out from your eyes. These are not your tears. You do not cry. I thought is Sai Baba really here? I have never seen him, I have only seen his pictures. Pehiyek said that it could be him, you think about him, she may not have her operation. Then for real, I was done packing, her Deutak called and said you do not need to come. Her operation is not required.*

That night when she was sleeping, Korobi's mother felt the presence of a person in the room, who came to her and told her to stop worrying and showed her his hand as a sign of blessing. When she woke up from her sleep, she realized that the person had left, but she was able to hear his footsteps. After this, she was not able to sleep the entire night. She was restless for the dawn to break so that she can tell someone what she had seen. In the morning she told Korobi's *Pehi* that she had seen Sai Baba at night. Hearing this, Korobi's *Pehi* told her mother that this is an indication that Korobi will not have to undergo an operation. Meanwhile, in Calcutta after a surgery on her spinal cord, the doctors realized that it is not brain tumor, and recommended them to go to [Christian Medical College] Vellore for further treatment.

From the above narrative it can be seen that parents are usually in denial and disbelief when they are told by others that their once 'normal' child is no longer the same. Parents' reactions are further complicated when they consult different healthcare providers who give them different explanations about their child's condition. In the case of Korobi's mother, hearing that her daughter has brain tumor came as a shock, because all this while she was expecting her to be cured of her 'behavioral problems'.

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[131] Sathya Sai Baba was an Indian guru who claimed to be the reincarnation of Sai Baba of Shirdi. It is believed that he was capable of doing miraculous healing.

She also felt guilty about not being able to accompany her daughter during her hour of need. In such a situation, it was her faith on Sai Baba that helped her in dealing with her distress. It was purely coincidental that the doctors in Calcutta informed Korobi's father and grandmother that she did not have brain tumor, and referred her for treatment to Vellore.

Gargi, 18, lives in a village in the Joonaki Block with her mother, younger sister and the families of two of her paternal uncles. She uses a wheelchair for mobility. Gargi was born in the seventh month at GMCH. Her mother recounted that at the time of her birth there was also a twin baby, who passed away six days after birth. Her mother said that she and the other family members did not even expect Gargi to survive, because at the time of birth she weighed only 2 kilos. According to her mother, it was God's will that she has survived. Her parents came to know about her disability when she was not able to stand or walk till the age of two and half years of age and consulted a doctor at GMCH. The doctor told them that she is paralyzed below her waist since her birth, and she will not be able to walk in her lifetime. Few months after her diagnosis, her father passed away in an accident. During the interview, it came out clearly that Gargi was not aware about the cause of her disability. She said that she has polio, which was refuted by her mother, who said that she has been like this since her birth, but did not refer to any name about her condition. In the records of Sanjeeboni, from where she was contacted, her condition is identified as cerebral palsy.

In the above narrative it can be seen that Gargi's family had to deal with a lot of things in the years immediately following her birth. This included the death of her twin sister, the birth of her younger sister after a year and the death of her father. Gargi's survival is considered the will of God as no one had expected her to survive. So when her disability was discovered, it did not come as a great shock to her mother, who was already dealing with a lot of problems. Gargi's narrative also shows that the women and their family members are sometimes so engrossed with their daily struggles that they are not interested in knowing about the medical term about their conditions.

To sum up this section, it can be seen that different parents had different reactions when they initially came to know about their daughter's impairments. While in

Bandana's case, her parents did not have much difficulty in accepting her after her birth, as they came to know about the medical reasons why she has the impairment, Korobi's mother was in denial for a very long time as she was not ready to believe that her once 'normal' daughter was no longer the same. This was further complicated by the fact that different doctors gave different reasons regarding the cause of her impairment, one of whom went as further as to say that she has brain tumor. It is these kinds of comments from the doctors that made her mother more apprehensive about her daughter, than the impairment per se, which was accepted later much more easily. In the case of Gargi, her family was going through so many difficulties at that time that her diagnosis did not cause as much pain or shock to her mother. Thus, the parents of these women did not report going through a 'grief cycle' while coming to terms with their daughters' disabilities. One of the reasons for this could be that disabilities of these women are were only physical in nature, unlike the studies that have been citied earlier which mostly include developmental disabilities (Barbosa, Chaud & Gomes, 2008; Chakravarti, 2002; 2012; Vaidya, 2015). These findings reflect that even though the women share the common characteristic of having a locomotor impairment, the way they had acquired it and the particular familial and socio-economic circumstances in which they lived influenced the way their parents initially reacted to their impairments.

Gendered Nature of Care-Giving: The Overburdened Mothers and the Distant Fathers?

In the case of children with disabilities, studies have shown that mothers are usually the primary caregivers, while fathers usually remain at the background (Chakravarti, 2002; 2012; Mehrotra, 2004; 2006; Vaidya, 2010; 2015; Ghosh, 2016). This is seen to have an adverse effect on the relationship of the parents and may even lead to psychosocial problems for both. Vaidya's study (2015) found that in many cases mothers, even those with high professional qualifications, opted to stay at home and look after their children. Many of these women internalized the *mothering ideology* which glorifies sacrifice and self-denial, and neglected their own health and well-being, self-care, emotional and sexual needs. Fathers, on the other hand, did not actively participate in providing physical care to the child but they were emotionally attached to them while at the same time they were struggling hard to meet standards at the workplace, succeed economically, and survive in a difficult and expensive city such as Delhi. As a result, they were not able to spend quality time with their families, and felt left out from the intimate mother-child dyad, which further accentuated the loneliness of the stay-at-home mothers. The study also found that the fathers were also not able to find a culturally sanctioned space to talk about their worries and insecurities with their wives, coworkers or friends (Ibid). In Chakravarti's studies (2002; 2012) also it is found that the 'burden of caring' falls on the shoulders of the mothers who is the primary caregiver even in instances where mothers are into paid employment. According to her, this gave these women the necessary space where they can vent out their emotional distress, which in turn gave them the opportunity to emerge stronger to face crises situations. For instance in the process of caregiving, the mothers of her study came into contact with the disability organization, from where they gained a lot of information about their children's disabilities and met several other similarly placed women to share their grief with. This process gave the mothers an outlet to vent out their feelings about their children, which was not available to the fathers who were not encouraged to participate in the organization meetings. As a result, the fathers were found to be suffering from depression and loss of will because they were unable to find an outlet to share their anxieties with anyone (Ibid).

This gendered division of labor in nurturing the child was also observed in the current study. Sanjeeboni provides community based rehabilitation for persons with disabilities. One of the aims of the organization is to provide home-based training to the family members of the child to deal with their physical management. This is done with the help of community based rehabilitation (hereafter CBR) workers. As a result of this interaction, mothers get more involved with the lives of their disabled children than the fathers. During an interview with one of the CBR workers I asked him if they also make attempts at involving the fathers of the children. He replied,

> *No we do not try to do this. This is because our social norms are such that the man goes out for work. In general, the man does not stay at home in the day time. So I never wanted that the father should also stay at home. I did not want this, because if I do that it is the family that would suffer.*

The above narrative shows that the CBR worker is empathetic towards the work schedule of the fathers of children with disabilities, who are not available at home in the day hours, when the CBR worker makes the home visits. The organization members do not disturb the social arrangement of the families of children with disabilities by imposing that fathers also should be present during the home-based programmes. However, by doing so, they imbibe the gender biases prevalent in the society, by overburdening the mothers on the one hand, and by physically and emotionally distancing the fathers from their children. Similar finding was also observed in Ghosh's study (2016) among women with locomotor disabilities in Bengal, where the staff of a disability organization insisted to teach the physiotherapy exercises to the mother, even when the child lived with her maternal grandparents and aunts. When her mother insisted that these exercises must be taught to her mother or sisters as they are the ones who look after her daughter on a regular basis, she was rebuked by the staff of the organization and was asked to be more mindful of her daughter.

During the interviews with the women with disabilities, most of them said that both their parents had looked after them in their childhood, but it was their mothers who took the primary responsibility. Risha said that both her parents had looked after her since her birth, but it was her mother who had to do most of the work as she was the one available at home, after her father left for work. This made things especially difficult for her mother, who had to look after her and her brother who was not much younger to her in age, as well as the household responsibilities. In order to ease her difficulties, her parents had hired a domestic worker, but in spite of this, according to Risha, it was her mother who had to do most of the work.

In Risha's case it can be seen that her mother was overburdened with caring responsibilities because of having two young children at home. This difficulty was somewhat eased when they hired a domestic worker. It shows that Risha's family was well-off to be able to hire a paid caregiver, and this eased the overburdened mother's difficulties, albeit only marginally. It also points to a time when child labor was rampant and live-in domestic workers from the rural areas were easily available for a meager pay. In spite of this, not everyone could afford to hire domestic workers. Some of the women belonged to women-headed households, while others belonged to households in which both parents were forced to work for sustenance. Sobiha's mother's case has already been explained in Chapter 4. In the case of Nayana, as elaborated in Chapter 4, her parents had migrated to Guwahati and started living as live-in domestic workers for a very wealthy family. The only condition of this family was that her parents will have to work for them in exchange for food, shelter and some money. After Nayana fell sick, only her father worked for them as a cook, while her mother looked after her. When Nayana grew up and started going to school, the employers insisted that her mother should also work for them instead of sitting idle at home. In her words,

> *They did not leave my Ma alone. They saw that Ma was sitting idle, and they told her why you are wasting your time, you come and work at our home. We will give you some money for that. And you will also be occupied when your daughter is not at home. We only need you for that much time… They did not listen to her. Deuta was not happy with her working. Then Ma also insisted that instead of sitting idle, what will happen if I work a little. Deuta told her that if you want then you can work, I have no problems, but you will have to come back and look after her. Otherwise how can she manage on her own?*

In the above narrative it can be seen that Nayana's mother was not left with any choice when they started living with their employers. Even after repeated refusals, her mother was forced to work for their employers in order to keep herself 'occupied' when Nayana went to her school. Her father, however, was not very happy with this arrangement as her work had the potential of deviating her from her primary responsibility, that is, to care for their disabled daughter. From this narrative it can be understood that even in poorer households which needed the income of both the parents to run the household, it was the mother who was expected to take up the caregiving responsibilities, while the father fulfilled the role of the breadwinner, thus keeping intact the gendered division of labor in the family.

In one of the cases, the mother's expertise in handling the child was questioned by the father, which was read as love and care for the child by the mother. Suchismita had acquired her impairment at the age of one and half to two years (explained in Chapter 4). Suchismita's doctor was her mother's relative, who had attained training in polio management from Bombay (now Mumbai). After the initial management of her condition, the doctor gave them two different body massage oils which were to be rubbed softly on her limbs. When they were living in Guwahati, it was the doctor who massaged her regularly. But when they returned back to Shillong, Suchismita's father took this responsibility from his wife saying that she will not be able to do it properly. In the words of Suchismita's mother,

> *He was more worried about her than me. And he would not allow me to massage her. He thought maybe I would not do it properly. He was the one who massaged her from the hips down. Then he was the one who gave her bath. He took her charge. He said*

> *you do not have to do it, I will do it. You will find difficulties. When she was young he looked after her, I looked after the other children.*

The above narrative shows how Suchismita's father belittled her mother's role in taking care of their daughter by insisting that she would not be able to do it properly like him. In spite of this, Suchismita's mother praised him for his loving and caring nature towards Suchismita, primarily because this work was not expected of him. In Ghosh's study (2016) also it was found that due to the gendered division of labor, when fathers participate in caregiving, they are praised and looked up to for engaging in work which does not fall in their domain.

The gendered division of labor was also seen in the quest for cure for the disabled child, where the mother was seen to be completely dependent on the father for the child's treatment. Nayana's narrative shows this vividly. Nayana had very high fever at the age of two and half to three years of age. After three days, her mother urged her father to take her to a doctor, but he was so busy with their employers that he was unable to take out time. They tried different medicines at home, but they did not work on her. After one week, they noticed that she had an abscess in her belly button, and immediately took her to a doctor, who gave her medicines for malaria. According to Nayana, this further aggravated her condition. After a few days, her parents consulted another doctor, who gave her a tablet after much insistence. According to Nayana, it is this doctor and his 'good hands' that saved her life. In my interview with her, she mentioned that one of the few things that she remembers from that period was the constant fights between her parents. Her mother kept repeating one thing every day and night, that her husband did not listen to her and take Nayana for treatment early. This infuriated her helpless father who would often burst out in rage. He asked her mother, *"Can't you see? Am I not working? Am I not looking after you both? I have got the medicines, if the doctor is not able to recognize the illness, how is it my fault?"* Nayana explained that during that period her father was the only working member of the family, and he was unable to skip work to take her to a doctor. She further explained that her father was from the village, and he thought that children in the village often suffer from fevers, and get better in no time. He thought the same about her fever and did not take it seriously until it was too late.

From the above one can see a gendered division of caring responsibilities between the two parents. While the mother takes care of her child within the household, the father's presence is required in order to take the child out for treatment. This kind of division of labor was also seen in Mehrotra's (2004; 2006; 2013) study in rural Haryana where the women in the family helped in taking care of the disabled girl child, while the men possess the decision making powers regarding where to take the child for treatment. While most studies usually revolve around mother-blaming for the disability in the child (Chakravarti, 2002; Ghai, 2003; Vaidya, 2015), Nayana's mother puts the blame on her father because of his inability to do the work which was in his domain. The study also shows that people from the rural areas often take fevers very lightly, and neglect the early symptoms of a disease, which in several cases lead to aggravation of the condition. According to Dr. Alok Kalita, fever induced impairments are very common in the rural areas of Assam and one of the primary reasons for this is that of ignorance and delay in accessing healthcare.

In the literature on the families of persons with disabilities, most of the studies have focused on the roles of the mothers in the process of care-giving, and the way it is burdensome for them (Chakravarti, 2002; Ghosh, 2016; Vaidya, 2010; 2015; Mehrotra, 2006). Some of these studies have acknowledged the lack of studies being done on the fathers of children with disabilities, and have urged future scholars to deal with this aspect (Ryan & Runswick-Cole, 2008; Koydemir & Tosun, 2009). For the participants of this study, it is very unfortunate that several of them had lost their fathers at a very early age, while some had lost their fathers in their adolescence. The deaths of their fathers have affected the lives of these women in myriad ways. For some of the participants, the loss of their fathers exposed them to their disability. Dolly, for instance, acquired her disability when she started working at a printing press despite the opposition of her mother, after her father's death. She was 13-14 years old at that time, and she started working because her family was in a miserable financial situation with nothing to eat. During this short period of time, a machine fell on her right hand, and it had to be amputated. Few years before this incident, the thumb of her right hand was fractured. During this period, it was her father who had taken care of her. Dolly said,

> *...Later the same hand got amputated. Then when I joined for work, then this* [right] *hand got amputated. I was working in the press. At that time I missed Deuta. The kind of support that he had given me, Deuta has helped me a lot. Deuta got so tensed when only a thumb was broken, and now I do not have the whole hand. If he was there, he would have cried a lot.*

In the above narrative, it can be seen that Dolly terribly missed her father when her hand was amputated thinking about an earlier incident when her thumb in the same hand was fractured. She remembers how concerned her father was at that time. She feels that her father would have been very sad if he had seen her in this condition.

For other participants, the death of their fathers has meant an end to their treatment. Pronoti, 26, had acquired her disability at the age of 11 after a bout of fever. Her right hand and right leg are paralyzed from that period. The doctor had suggested that she must undergo physiotherapy for a period of one year, in order to regain strength in her affected limbs. During that period, they lived in Guwahati, where her father was posted. She continued her physiotherapy in the Composite Rehabilitation Centre (CRC), and it was her father who took her there for treatment. After about 6-7 months, her father met with an accident that led to his death. As a result of this, her treatment had to be stopped abruptly, and her family returned back to their village in the Joonaki Block.

The above narrative again shows the gendered division of caring responsibilities, where the father was the person who was responsible for taking her for physiotherapy. After his death, since he was the only working member in the family with five children, their family found it very difficult to sustain in Guwahati, and decided to return back to their native village. From the village, CRC was about two and a half hours away, and it was absolutely impossible for her to continue her treatment.

Several mothers also talked about the important ways their husbands had looked after their children when they were alive. Earlier it has been shown how Suchismita's mother talked about the ways that Suchismita's father looked after her. Similarly, Sobiha's mother also said that Sobiha was the apple of her father's eyes. It is by considering his love for his daughter that she did not put Sobiha in a hostel for children with disabilities (this will be elaborated in the next section).

From the above narratives it can be seen that most of the women and their mothers looked up to their fathers who took care of them in different ways in their childhood. It was only in the case of a few women who had ambivalent feelings towards their fathers. For Jeuti, one of the earliest memories of her life was that of her father taking care of her. She said that after she had acquired her impairment, sometimes she suffered from excruciating pain in her hand. In such moments, she screamed and cried for help. Jeuti said that her father found it unbearable to see her in so much pain. He tried to reduce her pain by tying her hand with a kerchief full of salt and warm rice. She agreed that her father was a good man, but she was also very bitter about his alcoholism.

> *Deuta was a good man, I would not say bad things about him, he was good. But he used to drink. After drinking he did not know how to run the house. When he worked, he contributed to the family expenses. But when he used to drink, he did not even have money to buy rice. In such a situation, Ma has brought us up with much hardship. In all weather conditions like sunny or rainy days she went out for work and she has brought the three of us up like this. Deuta has just given birth to us, but he was not able to bring us up. We respect him as it is because of him that we are able to see how the world is today. We have seen this green planet because of Ma and Deuta. That is why we do not disregard him. But after giving us birth the kind of care that people should receive we did not get that. We have undergone a lot of hardships since childhood.*

Jeuti's mother also talked about the difficulties she had faced because of her husband's alcoholism. When they got married, they lived in Nagaon. Even though he drank at that time, he was not an alcoholic. A few years after their marriage, they shifted to Guwahati. It was here that he met his drinking companions. Her mother said,

> *When he got friends here* [Guwahati], *the person drank so much that even if there is no rice at home, he would keep the money for his drinks. He did not bring me rice. They* [her daughters] *were young at that time. I told him bring them a packet of biscuit, he never bought them a biscuit packet. He just bought rice, he never bought anything else. Sometimes, I used to work, so I would bring the biscuit packet in my armpit, so that he does not see it. I see here and there, I look for their father, if he is not there, he is outside, I throw the packet under the bed. It would stay there. I give her* [Jeuti] *the signal. It is there. She understood my signals. The packet is there, you just keep it inside. I will go for work. The younger one was young, the middle one was also young. But she was able to look after them. We stayed like that.*

In the above narrative, it can be seen that Jeuti and her family underwent a lot of hardships because of her alcoholic father. In a few instances he had also beaten up Jeuti's mother when he did not get the money to drink. As a result, Jeuti and her mother did not have much respect for him. The narrative also shows that her father did not fulfill his gender expectations of being the provider for the family, which is what made Jeuti angry.

In another instance, Hema also talked about her ambivalent feelings about her father. On the one hand, she was grateful to him, for taking her for treatment to Bombay, and doing everything in his capacity to make her better. However, she has seen a complete change in his behavior in the last two-three years. She said that there is a property dispute in her family, where her elder brother and his wife want her and her mother out of the house. According to Hema, instead of considering her disability and taking her side and securing her future, her father has taken the side of her brother and sister-in-law. Hema was disappointed with her father that he did not fulfill the expectations she had from him as the head of the household, but instead it was her mother who was doing it for her.

This section tried to elaborate on the gendered division of caring responsibilities in the household, where the mother took care of the needs of the disabled child, while the father was expected to take the child for treatment and was expected to secure her future. As shown in Chapter 3, women of Assam, regardless of which social class they belong to, have historically been brought up in such a way that they prioritize their domestic and childcare duties over anything else. In case of having a disabled child in the family, it is but obvious that their mother are expected to take care of all the needs of the child, while the father may choose to take care of the child if he wishes. Dalley's (1988) distinction of caring functions as 'caring for' and 'caring about' becomes useful in this context. 'Caring for' refers to tending to another person, while 'caring about' refers to the feelings for another person. In the case of women, these two functions are considered to be an integral part of their nature. Thus, when a child is chronically dependent due to some sickness or disability, the mother is expected to extend her 'caring for' function. The same interweaving of caring functions is not seen in the case of fathers, who are expected to care about without being expected to care for (Dalley, 1988, as cited in Chakravarti, 2002). In the case of men, their success is measured in terms of the achievements they make in the public sphere, while women's work both inside the home and outside tends to be dominated by physically demanding and unrewarding activities. In such a context, the costs that women pay are high. But despite this, women get engaged in such work because both men and women have internalized the view that it is women who have a special relationship to the function of caring, through their capacities for self-sacrifice and sense of altruism (Dalley, 1988, as cited in Chakravarti, 2002).

Thoughts about giving up the child

Having a disabled child in a family which has limited access to resources makes life extremely difficult for the parents. In the available literature one can clearly see how disability is a cause and consequence of poverty for not only the individual but also other members of the family (Klasing, 2007; Grut, Olenja & Ingstad, 2011). As a result of this, parents sometimes think about giving away their disabled children, so that their problems would be reduced somewhat. In this study, this is seen in the case of Sobiha's mother. After the death of her husband, Sobiha's mother had to take the responsibility of caring for her two very young daughters along with the responsibility of earning a livelihood for sustenance. In the absence of any support from others, she was finding it very difficult to manage all these responsibilities alone. During this period, several people gave her the suggestion of leaving Sobiha in a hostel for children with disabilities.

> *Many people told me you have so many problems, send her* [Sobiha] *to an orphanage. I said if I send her to an orphanage, their Deuta had loved her so much. Now their Deuta is no more, if I send her to an orphanage, if she dies I would have to be completely alone. Let her be, she will be with me. Even if she is Lengeri or Khori* [physically disabled] *I will take care of her. Even now people say for how long will you be alive? Then what will she do? Once, when she was about ten years old, I had taken her to an 'orphanage' near Bhangagarh Medical* [GMCH]. *There is a hostel. They keep 'such children' there. Dada* [elder brother, here referring to Suchismita's husband] *was there* [alive] *at that time. Dada found out about the place and told us to keep her there. After taking her there I could not do it. I could not keep her there. After going there I saw that the children who were lying down in their beds, they were just staring into space. The ones who were sitting in the wheelchair, they were just sitting down. People had dropped the children there. I saw many such children. The bais* [cleaning women] *who were there they asked me if I have come to drop her there. I said yes. One person told me that you take her admission. After seeing all this I thought if I keep her there, she would also be under the same condition. She will keep shouting. One child was shouting to be taken to the toilet, after a long time they took the child to the toilet. I saw all that. After this I could not do it. The bais who were working there they told me that you will have to give a certain amount of money every month, and on top of that you need to give her good things to eat every week. After hearing all this I thought that if I have to give her good things to eat, and pay the money for the hostel also, if I give this here, it is better if I give her good things to eat at home. How can I give so much? I cannot give so much. They also do not take care of the children properly. She will also die on one side, I will also die here. So I said no. I took her there to take admission. They said take her admission here. I told them that I am not carrying so much money for the purpose. The admission fee was Rs. 2000. I lied to them that I am not carrying money for the admission. I thought if I give them the money, I would be trapped. That is why I thought I would not take her admission, and I would not send her to stay there. What will happen when she would get her periods? She had not attained her puberty at that time. When the children get their periods, they do not clean it. They do not keep girls there. The way the bais talked to me, I understood that they do not keep the girls when they start*

> *menstruating. That is why I thought no need. The person who was sitting there to assist in the admission process, he said you take her admission. You can bring her anytime you want. But you can admit her today. I told him I do not have money, saying this I brought her back. I did not go back there.*

In the above narrative, it can be seen that Sobiha's mother was influenced by others when they gave her the advice that putting her daughter away would ease her difficulties. However, when she went to see the hostel herself, she realized that it is impossible for her to leave her daughter under such circumstances. She lied to the management and brought her back home. In disability studies literature from the West, institutions have been decried for taking the person away from the community and bringing him or her up in a condescending environment where they do not get the right opportunities to grow and later compete with the mainstream society (Hunt, 1966; Brisenden, 1986). In countries such as India, as the above narrative shows, parents of children with disabilities from the poorer socio-economic backgrounds are often in a desperate condition where they have to make a choice between their work and their disabled child. In such a context, where institutions should have catered to the felt needs of the people, what we have instead are the institutions like the ones that Sobiha's mother described where parents would not want to keep their children. Her narrative also showed that such spaces are built keeping male children in mind, as no one would be available to help a young girl once she starts menstruating. One can draw a parallel of this with what happened in Sassoon General Hospital in Pune in February 1994. Girls with developmental disabilities who received care in an institution situated in a large rural community were prevented from wearing pajamas with drawstrings or sanitary napkins with belts because it was claimed that these might be used by the girls to commit suicide! (Ghai, 2002). The General Hospital forced 14 of these girls to undergo hysterectomies. Nineteen days later a major newspaper reported this incident after which women's groups intervened and the operations were stopped after these 14 girls (Ibid).

This narrative also noted the mixed feelings of Sobiha's mother towards lifelong caring for her daughter. Dalley (1988) had argued that such mixed feelings of caring functions (for and about) have serious repercussions for both the caregivers and the care-recipients. As long as the son or the daughter with disabilities is still a child, even though caring is an arduous task, it still falls under normal parameters. However, as the child grows, tensions may arise in the caring relationship for various reasons, due to which feelings of love become distorted by feelings of obligations, burden and frustration (as cited in Chakravarti, 2002). Such ambivalent feelings become more problematic when the public discourse insists that there is no separation between caring for and caring about in the case of mothers (Ibid). Sobiha's mother's mixed feelings, however, were clarified once she visited the hostel and saw the conditions under which children with disabilities were forced to live.

Support from Members of the Extended Family: Differences in Rural and Urban Milieu

The above themes have shown that in a nuclear family, parents are often under a lot of pressure when they have to look after a disabled child. During such periods, they require support from their extended families, friends and neighbors. Chakravarti's study (2002; 2012), conducted in urban areas of Delhi and Chennai, has shown that the support from the extended family has tremendously helped the parents of the disabled child in tiding over difficult times. This support usually comes from the disabled person's mother's side. Chakavarti (2002) argued that the reason for this could be that very often it is the mother who is stigmatized for bearing a disabled child, and due to this reason the husband's family usually abandons them to their fate. From her case studies she is also able to cite that it is usually the women from the maternal side like mother's mother or mother's sister who came to help the family (Ibid). Similar findings were also observed in the case of the women in the present study.

Suchismita was diagnosed with polio when she and her mother were visiting her mother's natal family in Guwahati. Due to her sickness, they extended their stay for a period of three months. During this period her mother was undergoing a lot of psychological stress thinking about the future of her daughter. As a result of this, she had lost a lot of weight. In my interview with her, Suchismita's mother said that her condition was even worse than her daughter's. She had never heard of a disease by the name of polio, and this made her all the more apprehensive about the outcome. At that time, it was her mother who took care of all their needs. She made Suchismita's food, and gave her the medicines and this helped them in staying isolated from everyone else for three whole months.

The above narrative shows that the support from the natal family is of great significance for the mother of the disabled child. This is seen more prominently when similar support is unavailable from the mother's affinal kins.

When Korobi was taken for treatment outside of Guwahati by her father and *Aita*, her mother was not able to think about anything else during that period. She cried day and night thinking about her daughter's condition and felt guilty about not being there by her side in her hour of need. She was so shocked and grief-stricken that she was not able to talk to anyone about her worries. At that time, one of her *Nonod* (husband's sister) asked her to cook in the kitchen to keep her occupied, while the other members of the family attended to the guests who came to ask about Korobi's condition. Her mother said that at that time, the other family members felt that leaving her alone in the kitchen would act as a form of catharsis that would help her in coming to terms with her grief. She also said that everyone in the family understood the kind of trauma that she was undergoing during that period because of which no one told her anything if the food did not taste well or if she had added more salt to the food.

From the above narrative it can be see that even though Korobi's mother was given the space to come to terms with her grief, she was not excused from doing the household chores as their domestic worker at that time was accompanying Korobi and her caregivers in their journey for seeking treatment. Unlike Suchismita's mother who was well looked after by her own mother and other kins from her natal family, Korobi's mother did not have that option as she had lost her mother at a very early age. Moreover, Korobi's mother did not receive any emotional support from anyone in her hour of need, thus highlighting the lack of acknowledgement of mental health issues in stressful situations. According to Chakravarti (2002), the lack of support from extended family members has a devastating effect in the mother of the disabled child. This can be seen in the case of Korobi's mother, as well as in the cases of other mothers as will be shown below.

In the case of some of the parents, they had migrated to Guwahati from their natal villages after marriage for better economic prospects. Due to this reason, they were completely cut off from their kins when they discovered their children's disabilities.

Risha’s father had moved to Guwahati for his higher studies, and later stayed on for his job at the Secretariat. After his marriage, he and his wife set up home in Guwahati, away from both their relatives. According to Risha, it is due to this reason, that they did not receive any help from their respective families to look after their children. However, because of their relative economic affluence, they were able to hire the services of a domestic worker, who helped Risha’s mother to take care of the children. Similar prospects, however, were not available to everyone because of lack of economic resources. Nayana was only one month old, when her parents had shifted to Guwahati from their native village in search of better opportunities. According to her, her parents had not received any help from the extended family for her upbringing. She said that it is only now, after her father’s death, that one of her *Khura* (father’s brother) started giving some money for their day-to-day needs.

These narratives show that when parents leave behind their parental homes and villages for a better life in the city, they also leave behind the kinship network, as a result of which in times of crisis there is no one else they can depend on, but each other. However, economic prosperity enables some to hire domestic workers to reduce at least some amount of work for the primary caregiver, as can be seen in the case of Risha’s mother.

In the case of other women, it can be seen that even though the economic resources available to the family is limited, the presence of mother’s natal kins can be of enormous support for the mother. After the death of Sobiha’s father, her mother took her daughters and tried to live with her different sisters. But wherever she went, there were a lot of disputes between her sisters and their husbands about feeding three more mouths. None of her sisters were married to well-off men; it was only Sobiha’s father who had a good income. After his death, her brothers-in-law did not find it necessary to look after them. She could not depend on her only brother during this period because he did not have a stable source of livelihood. As a result, Sobiha’s mother decided to start working herself instead of being dependent on others and hearing their taunts all the time. Her sisters, however, continued to support her emotionally, despite opposition from their husbands. All of them also helped her in finding ‘cure’ for Sobiha. During the interview, her *Mahi* (mother’s younger sister) said,

> *If someone told us something, it is about the life of a girl. We feel bad. The mother is going through so many difficulties. That is why we did whatever possible.*

In the above narrative it can be seen that even though Sobiha's mother's sisters were not able to help them financially, they were very concerned about the well-being of Sobiha's mother. That is why they did their best in seeking cure for their niece as they felt that this would lessen the hardships in all their lives.

Other women with disabilities also talked about the kind of emotional and financial support they have received from their mother's natal families, while similar support was almost negligible from the father's side. Bandana, 34, talked about the financial and emotional support that she had received from one of her *Mama* (maternal uncle), while they received no such help from her father's family. She said,

> *My Mama* (mother's younger brother) *had given a lot of support. From my Deuta's family we did not get any support. They did not have time to give support to us. They did not even have the time to ask about us. They are very mean, if we give things to them, we are good, if we do not, then we are bad. They are like that.*

This Mama, however, passed away a couple of years before the interview was conducted with her. During the interview she lamented his death, as with him she has lost a very important source of support.

In contrast to the urban areas, in the rural areas, the women and their mothers received a lot of support from the female members of the father's family. This is facilitated by the fact that in the rural and semi-urban areas, patrilineal kins tend to live contiguously, because of which a certain amount of relationship is expected and there is sharing of responsibilities (Dube, 1998, as cited in Mehrotra, 2013). Mehrotra's study (2006; 2013) conducted in rural Haryana has shown that in a joint family setup, paternal grandmothers and other female relatives have helped in bringing up the child with disabilities. However, links maintained with the mother's natal family is a source of support for the mother especially while seeking treatment (Ibid).

In the case of the present study, it was found that the women's connection with the mother's maternal family is weak, possibly because they live far away. In spite of this, the women cherished the relationship with their maternal kins and talked about them with utmost fondness. Their relationship with the father's family is comparatively stronger because most of them have either grown up in a joint family setup, or they live very close to their father's relatives. Due to this, a lot support was available for the women with disabilities across different phases of their lives from their grandparents, uncles, aunts and cousins. However, in spite of the presence of several family members, the mothers were most likely the primary caregivers. At the most, the childcare responsibilities were shared with the child's *Aita* [paternal grandmother], but not with any other female relatives.

As mentioned earlier, Gargi, her mother and her younger sister live with the families of her paternal uncles. Although they did not say it explicitly, it was evident that their position was marginal in the family after the death of her father. Gargi's impairment is comparatively severe in comparison to the other participants. The only place she goes out to outside her home is her school. For this she needs to be carried to the main road by her mother. But now that she has grown up, this process has led to a lot of physical difficulties for both Gargi and her mother. During the interview Gargi's mother mentioned that she does not receive any help in carrying her daughter to the school from other members of the family. She said,

> *They cannot carry her. I have carried her all the time, so I am habituated to it. No one else can carry her.*

She, however, said that when Gargi was young, her *Aita* had taken care of her if her mother had to go somewhere else.

In the above narrative it can be seen that the family dynamics is such that Gargi and her mother are at a marginal position in comparison to the other members of the family. Even though they have received financial support from Gargi's father's brothers, no one had supported her mother in physically taking care of her daughter, except her *Aita* under very specific circumstances.

In the case of Surabhi, she said that when she was young, other than her parents, she was taken care of by her *Aita*, *Khura* and *Pehi*. She said that they all loved her immensely. While her father dropped her at school in the morning, either her Aita or her Khura picked her up from the school in the afternoon. During the interview Surabhi said that her father was the oldest in the family and could be considered as the functional head of the household. All other family members including her *Khura* and *Pehi* were dependent on him at that time. It can be said that it is because of this reason that they showered Surabhi with utmost love and care during her childhood days, before the family disintegrated and they all setup their own homes in the neighborhood.

In contrast, Lata was partially brought up by her paternal *Aita*, who lived with them. Lata's father was her *Aita*'s only son, and she is her parent's only child. As a result, she received a lot of love and care from both of her parents and her *Aita.* During the interview, she fondly remembered that her *Aita* was very keen to see her study and pass her matriculation examination as early as possible, as she considered it to be a big deal. She gave utmost importance to Lata's education. In spite of the dire financial circumstances in which they lived, Lata's grandmother never allowed her to work in the agricultural fields, unlike other children of the neighborhood. Her Aita also dropped her at school every day and never tolerated anyone saying anything mean to her.

From the above narrative it can be seen that Lata's relationship with her *Aita* was completely different from that of Gargi's as there was no sense of competition with other family members.

It was also found that at the event of the death of the mother, it is not the father but a female relative who brings up the child. Anamika had lost her mother when she was only three years old, while her younger sister was only one and half years old. Her father was an alcoholic who spent much of his time drinking with his friends at that time. As a result, she and her sister were brought up by her *Burhi Aita* [father's paternal grandmother]. As she was herself very old at that time, Anamika and her sister had to learn to do the household chores from a very young age, which left them with very little time to concentrate on their lessons. Even though they lived in a joint family at that time, their responsibilities were not lessened by their aunts.

From this section it can be seen that the kind of support that the parents receive from the extended family varies according to a host of factors. These include rural/ urban residence, the economic position of the family, whether or not other kin members stay in the vicinity, presence of the mother's maternal family, the father's position in the family and the mother's presence in the household. Regardless of these dynamics, it can be seen that caregiving is a gendered task, as it is women who usually replace one another in caring for the disabled child in the family. Similar findings have also been reported in other studies conducted in other parts of the country (Chakravarty, 2002; Mehrotra, 2004).

The Family’s Vision regarding the Future of their Daughters with Disabilities

According to Klasing (2007), social integration of persons with disabilities begins and ends in the family. It is within the family that a child first acquires an attitude towards herself and the world. If the parents consider disability to be an overwhelming calamity, the child would also come to think so (Ibid). Likewise, if the parents consider disability as a challenge and channelize the available resources to overcome it, this can help the child tremendously in the long run. In order for this to be successful, however, the parents of the child with disabilities will need to have accurate information about the nature of the child’s disability and what could be done in order to ameliorate his/ her condition. As mentioned earlier, Suchismita’s mother was given accurate and appropriate information about her daughter’s impairment because of which she was able to overcome her worries about her child’s future. During the interview with Suchismita’a mother, she said that initially she was very depressed thinking about her daughter’s future, but her *Pehadeu* consoled her by saying that ‘such children’ are very intelligent and are able to surpass all kinds of hardships. She said, *“He told me that Suchismita will be very hardworking and self-sufficient”*, which ultimately helped her in overcoming her grief. Her mother said that it is because of what he had said about Suchismita that she was allowed to do anything that she wanted to do in her life. She or her husband never had any misgivings that Suchismita will not be able to do something because of her impairment. It is because of that confidence that Suchismita has been able to do so much for the disabled community in the two Blocks where her organization is functioning. It is, however, important to point out that her *Pehadeu* actually created a stereotype about children with paralytic polio as intelligent, hardworking and self-sufficient, that is, he reinforced the SuperCrip image (Crow, 1996). While it is true that all these qualities hold true about Suchismita who has touched many lives of the disabled community through her organization, it must not be forgotten that it was her family background that facilitated her access to different kinds of resources that helped in alleviating her problems. Her family background stands out starkly in comparison to the other women of this study who had to struggle for achieving even the bare minimum in their lives.

Unfortunately many parents are not adequately informed about their child's condition and what they would be capable of doing in the future. As a result, parents, especially in the urban areas restrict the movements of their children between their homes and their schools. This was found to be exceptionally true in the case of the women who had studied in Senehi. According to Rekha, a special educator at Senehi who has taught all of the four women who were interviewed from the organization, the social world of the women is limited to their schools. After passing out from the school at the age of 18 years, even though the school tried their best to ensure that they are able to earn a livelihood, parents did not show adequate interest. According to Rekha, the parents always required some kind of support from the school and were not able to think about ways to enable them to live an independent life. She cited the example of Risha, who had started working at the Disability Law Unit of the organization after passing out from the school. During that period, she had got the opportunity to go to Delhi for a workshop where she had to be accompanied by one family member. Rekha said that unfortunately neither of her parents showed enough interest on this prospect, as a result of which Risha had to let this opportunity slip from her hands. Rekha further said that this is a form of discrimination because Risha's younger brothers have not been restricted from achieving their dreams. One of her brothers was pursuing his Ph. D while her other brother was a Civil Engineer. She said that Risha's parents unfortunately did not have the vision to enable her to live independently. Rekha further said that this was not an individual case, as she has observed that many parents of women with disabilities do not expect their daughters to earn a livelihood and to live independently.

This lack of expectation from a disabled daughter was also seen in Ananya's narrative. Ananya had joined the ICT programme at Senehi a few months before the interview. During the interview, she expressed her frustration with her parents for not buying her a computer. She said,

> *Now I am learning computer here. So I told my parents that I want a* [desktop] *computer. But Papa said there is no need. I do not know why he said so. Ma asked what I would do with a computer. Earlier when I touched Baa's (elder sister) laptop, she asked me not to touch it. But now when I have asked them to buy me a computer, Baa says you can work in the laptop. This is the reason I do not work in her laptop.*

She further said that she does find it comfortable to work in the laptop computer and prefers to work on a desktop computer, but her parents have refused to comply with her request. She said that this is in sharp contrast to how her parents treat her older sister. She said that her father bought her older sister a laptop and even an exercise cycle to reduce weight in just one request, but he would not comply with her request. Ananya's narrative shows that she feels discriminated at home because of which she has stopped asking her parents for anything. She also mentioned that there is no point in talking to her parents as they will never understand her problems.

Rekha also said that in the case of financially well-off parents, they say things like *"We have property, and she would be able to live off that"*. In extreme cases they arrange their daughter's wedding by giving a huge sum as dowry to the man. She said that unfortunately parents do not think about the kind of future their daughter would have with such a man. In other cases, where parents are not well off, they give the entire responsibility of their child to the school. This was seen in the case of Nayana whose father gave her responsibility to the school principle on the day of her admission at the age of 8-9 years. Thereafter all the decisions of her life were taken by her teachers.

Rekha further said that since the parents of the women do not have much expectation from their children, the women themselves also did not have any confidence upon what they would do in the future. This reality is further complicated by the severity of the impairment in the case of many of the women which impeded them from venturing out of their homes alone. During the interview Risha had said that in all her life, she had only gone out once with her school friends to attend a wedding. She thoroughly enjoyed this outing but is not sure if she would be able to go out again with them. Amongst all the participants, according to Rekha, it is only Nayana who is now able to handle things on her own due to the support she has received from the organization. It was felt that since Nayana came from an extremely poor financial background, she needed adequate support from the organization, especially after her father's demise. In the case of the other women it was found that since they came from relatively well-off backgrounds, their families would be able to support them somehow. For aged parents, regardless of their financial condition, however, it is very difficult to find ways to engage their adult children who have all along been taken care of by the organization. This was also seen in the case of Chakravarti's study (2002) among children with cerebral palsy.

Similar to the women above, Bandana had also lived a very cossetted life until she met Kishore Kamal Bora, the founder of Moromi, an organization that provides economic rehabilitation to persons with disabilities which was situated very close to the staff quarters where she lived with her family. Kishore convinced Bandana's mother to send her to the organization for work. During the interview Bandana said that her Sir, as she referred to him, often took her and other workers of the organization for field visits to different places like the GMCH, orphanages, the blind school, school for the hearing and speech impaired, etc. in order to introduce them to the world outside. Bandana said that her mother did not like this and often scolded Kishore for taking liberties with her daughter. Bandana said,

> [Kishore] *Sir opened the world for me. He took me to different places with him. But Ma did not like it. She used to tell him, I have only given you permission to teach my daughter within the four walls of the office. Why do you take her everywhere? Ma used to come to the office at 5.30 pm to pick me up. Sir would say that is the gate of the hospital* [they stayed within the staff quarters of a government hospital] *and this is my gate, there is just this road in between. She would be able to go home by herself. But Ma would not allow me. Then Sir once told her that you would watch her go everywhere one day. And you would be the one sitting at home. In this way Sir teased Ma. She would again repeat her request to not take me out of the office. But Sir would say, "Today you are alive and I am alive, so she would get to eat. But tomorrow, after us, she would have to learn to live on her own. Everyone's mind is not the same. Some would love her, some won't. What will you do then? She should be able to live by her own means. We should see to that. She should have the courage in her own mind."*

From the above narrative it can be seen that even though Bandana's mother allowed her to work at the organization, she was not very happy about Bandana going out of the organization for the field visits, as she felt that this might harm her. Bandana, however, credits her ability to maneuver around the city today because of the confidence that she had gained through her association with Kishore and the disability organization, Moromi.

Studies on persons with disabilities have also tried to show how parents try to engage their non-disabled children into taking care of their disabled children from a very early age in order to prepare them to take care of their siblings after the parents have passed on (Vaidya, 2015; Chakravarti, 2002; 2012). The studies have shown that parents create differences between their disabled and non-disabled children from a very early age by indulging their disabled child, which is sometimes resented by the other children (Vaidya, 2015; Chakravarti, 2002; 2012; Ghosh, 2016). In this study it is seen that some of the mothers expected their younger children to study well and have a settled life in the future so that they would be able to look after their severely disabled children. This was seen in the case of both Gargi and Sobiha whose mothers expected their younger daughters to look after them in the future. In the case of Korobi also it was seen that her parents expected her younger sisters to look after her in school. Due to this reason, they stopped her younger sisters from taking admission in school. Her mother said that none of the Assamese medium schools in Guwahati were ready to accept Korobi because of her impairment. They later found a prestigious convent school that was ready to accept her. She was placed in the same class as her second sister who was four years younger than her as it was felt that she would be able to help Korobi in case of any emergencies.

While some of the siblings graciously took up the role of the caregiver, others complained about it. It was found that Korobi's second sister was very cautious about Korobi in the school. The teachers in the school often praised her for the care she provided to her sister. Even though the school had an *Ayah,* her services were never necessary as Korobi's sister was able to take care of her needs adequately. In the case of other siblings, however, it was found that the younger siblings sometimes complained about the lack of attention of their mothers towards them. Gargi's mother and Sobiha's mother both said that their younger daughters sometimes complained that they never received any attention from their mother. In such situations, the mothers have to explain to them that they are *bhaal* (non-disabled) and so they are capable of taking care of themselves, which is not the case for their disabled siblings. The mothers said that after such explanations, their other children did not complain anymore.

In certain other cases, parents themselves came to realize that they are not treating their children equally and tried to make amends. Nayana said that when her younger sister grew up, her father observed that she was always upset and did not talk to anyone. It was then that he realized that it is perhaps because he and everyone else gave more attention to Nayana than to her. He tried to rectify this by making her favorite dishes, and asking her to select what she wants to eat before Nayana and so on. This, according to Nayana, changed her sister's behavior somewhat.

On the other hand, women with comparatively milder disabilities were brought up like any other sibling without much special privileges. This was found to be particularly true in the case of the women in the rural areas. These women are trained and socialized in traditional gender roles from their early ages in order to prepare them for their adult roles of being a wife and a mother. They were expected to work like any other girl of their age and most of them have not got any special privileges because of their impairments. Minakkhi, Anamika, Surabhi and Uma emphasized that they have been helping with household chores since the time they had gained consciousness. Although they faced certain limitations sometimes, this did not deter them from engaging in household chores. Even though all of these women were enrolled in schools, their education was not given much priority by their parents. This, however, did not have anything to do with their impairments, as education was not considered to be a priority for even their non-disabled siblings of both genders. Their ability to learn the household chores was considered to be of utmost priority as most of the parents expected their daughters to marry and leave their natal homes one day.

It is only in the cases of some of the very young women whose parents considered education to be of significance for their daughters. After the death of her father at a very early age, Gargi’s mother placed tremendous effort to educate both her daughters. Although Gargi had initially faced rejection from a government school, members of Sanjeeboni had fought for her right to education. At the time of the interview, Gargi was studying in the ninth grade. She uses a wheelchair for mobility but faces several accessibility problems in going out of her home which is connected to the main road with the help of a narrow and fragile bamboo bridge which is impossible to cross in a wheelchair. In order to enable her to go to school, every morning her mother takes the wheelchair out first, carries Gargi to the wheelchair, and then pushes it to her school. This same routine is again repeated in the afternoon when she returns back from school. With age, Gargi has grown heavier which has created new hurdles for both of them. She and her mother both suffer from severe body ache due to this routine. In spite of these difficulties, neither of them talked about discontinuing education, as they understand that it is only her education that would enable her to become self-reliant in the future. At the same time, her mother expects her second daughter who was studying in college, to get a good job and look after Gargi in the future.

From the above narrative it can be seen that Gargi’s mother is determined to educate her daughter and for this she is ready to undergo any kind of hardships. Similar findings were also observed in Addlakha's (2007) study on women and men with visual disabilities. According to her, because impairment seriously marred the marketability of women as suitable partners, very often compensation is sought through employment. This not only enhances the chances of a woman with disabilities to get married, but also offers them a way of economic self-sufficiency in case they have to fend for themselves in the future (Ibid). This has also been facilitated by recent government policies such as the Right to Education Act 2009 which provide free and compulsory education to all children below the age of 14 years, regardless of their impairments. The Persons with Disabilities Act, 1995 and the more recent Rights of Persons with Disabilities Act, 2016 also provides reservation to persons with disabilities in government educational institutions and government jobs. These developments have improved the prospects of persons with disabilities, albeit marginally.

To sum up this section, it is seen that the kind of vision parents have for their daughters with impairments has a tremendous impact on their life chances. But for this parents often require an alternative image about persons with disabilities. As seen from the narratives above, in cases where parents have received this support from another individual or a disability organization or due to the changes in the policies, they have provided tremendous support to their daughters. It is also seen that parents often indulge more with their disabled children at the expense of their non-disabled children which sometimes lead to resentment among the latter.

Family Support for Daily Activities in Adulthood

The above themes have looked at the support that the women have received during their formative years after they had just acquired their disabilities. In this theme we would look at the support that the women require from their family members in their adulthood. As noted earlier, when parents look after the needs of a young disabled child, even though it can be arduous, it still falls under normal parameters and does not cause them as much distress as when they have to look after their grownup children (Dalley, 1988, as cited in Chakravarti, 2002). In her study on children and young adults with cerebral palsy in Delhi and Chennai, Chakravarti (2002) has shown that families of such children undergo the grief cycle process twice: first when they initially discover about the child's disability, and the other time when the child reaches the age of 20 years or more, when different types of anxieties like the parent's age, their own ill health, their death anxiety and the fact that the future of the child has to be secured, takes over the parents and consumes them. In her study it was found that one of the morbid fears among the parents was the possibility of the child outliving them. They were worried about what would happen to their child and who would look after them after their deaths. Most of the parents wanted their children to die before them and also felt guilty about thinking in such a way (Ibid). In this study since not all the parents of the women with disabilities were interviewed, it cannot be said whether they also suffered from similar anxieties. Nonetheless, since the nature of the disability is different many of the women were able to manage the activities of daily living on their own with only minor support from their families. This support was usually provided by their mothers, elder sisters, sisters-in-law or other female relatives. It was also found that the women who have difficulties with their hands face different kinds of problems in comparison to those who face difficulties with their legs. The following narratives give a glimpse of this.

Ananya said that she is able to do all the work in her daily life except for putting the hook of her brassier and tying her hair. For these activities she needs to depend on her Ma or Baa. Similarly, Minakkhi is also able to do most of her work, except sometimes when she needs to depend on her *Bou* for helping her in pinning her clothes or in wearing a stylish hairstyle. Surabhi also needs help from her *Ma, Baideu* or *Khuri* (father's younger brother's wife) for combing her hair and wearing her clothes.

Most of these women had acquired their impairments at a very early age and have been helped by their family members in doing these tasks. It is probably due to this reason that they never felt bad about asking for help from others. This, however, was not the case for Dolly who had acquired her impairment at the age of 13-14 years. She finds it extremely difficult to depend on others for her daily activities. She said,

> *After my hand was amputated, I used to ask my friends from the neighborhood to tie my hair for me. One day none of my friends were around, Ma was not well, to whom can I go every day for tying my hair? I threw the comb. I was very angry that I was not able to do it by myself. Now I have to ask for help from everyone. That day I closed the door and I tied my hair and left it open, I tried it multiple times. After doing it for many times, I got used to it. I can tie it on my own now. Whatever it is, I*

> *have to try to. My Xoru Bhonti* [younger sister] *also helps me with this. But now I do it by myself.*

From the above narrative it can be seen that for Dolly who had acquired her impairment later in her life, for her depending on others for day-to-day activities was a humiliating task. As a non-disabled person she had imbibed the virtues of independence all her life. When all of a sudden this independence was taken away from her after her amputation, it came as a big shock for her. In her interview she narrated multiple times that she had never known any other person without a hand, because of which she had never known that a person can even survive without a hand. It took her a great deal of time to adjust with her disabled self. In my interviews with the doctors, it came out clearly that persons who acquire their impairments later in life respond better to treatment, because they are more motivated to be cured. However, in terms of their mental health, such persons are usually depressed because all of a sudden they cease to be a non-disabled person.

The women who had difficulties with their legs faced other kind of problems in their everyday lives. Bandana, who is of short stature, said that before she joined Moromi, she had faced numerous difficulties in her life. She considered herself to be a disabled person and as a result of this she considered herself to be incapable of doing several tasks. However, after she met Kishore, the founder of Moromi, who introduced her to other persons with disabilities of the organization and took her out for field visits, she realized that there is no work that she and other persons with disabilities cannot do. Working at the organization gave her the confidence to face the world with a brave face.

> *I do not feel that I have any problems. But still I face the difficulty that I cannot reach objects that are placed at a height. I cannot draw water from the well which is a problem. I cannot climb a steep road instantly. But I can do all my work on my own. I used to face difficulties earlier. But not anymore.*

Thus, other than the constraints that are imposed directly by her impairment, Bandana does not feel that she has any other problem. The women who use a wheelchair for mobility face numerous difficulties, mostly related to accessibility. Nayana, who lives in a small rented room in Guwahati with her mother and younger sister, narrated the difficulties of living in a rented home, where the space cannot be adapted as per her needs. She finds it especially difficult to use the toilet, and it is her mother who helps her by taking her there. She said,

> *At home I have certain difficulties in using the toilet. We stay at a rented place. So there are difficulties at such places. I face problems in using the toilet. Ma helps me there. She takes me to the toilet. I can do rest of the things. She again brings me back from there and takes me to the bathroom… I do not have difficulties in taking bath. I can take bath on my own. If we had good toilet facilities at home, then I would not have needed any help from anyone. I have been to places like Delhi by myself, and I have been able to manage there on my own.*

The above narrative shows the problems that Nayana faces at her rented home because it cannot be adapted as per her needs. Ironically, she has never faced such kinds of difficulties while staying in hotels in other cities. During my interview with Rekha, the special educator at Senehi, she had mentioned that Nayana belongs to a very poor family who live in a one room apartment where they cook, eat and sleep. It is perhaps due to this reason that they are not able to find a place where their needs will be accommodated. This narrative shows how poor persons with disabilities are left with no choices but to adjust with the existing disabling infrastructure by being dependent on their family members.

Unlike Nayana who is able to do much of the work by herself, Gargi, who also uses a wheelchair, is highly dependent on her mother for her daily actitivities. Her mother said,

> [Gargi] *has difficulty in going to the toilet. I have to help her with that. I need to take her to the bathroom. I need to help her take bath. She is not even able to wear her clothes. I have to help her with that. She is able to eat by herself. With her left hand.*

Her mother said that even during her periods, she is the one who helps her with the sanitary napkins.

> *I do everything for her. I make her use the pads. I throw it away. With her I also need to take bath. We are Bengalis, we have a lot of taboos. I also need to take bath with her.*

In addition to attending to her physical needs, as mentioned above, her mother also helps her in going to school. This is significant because of the physical difficulties that both mother and daughter face due to this.

Even though the women with comparatively severe impairments had to depend on their families for minor things, some of them sought to be independent and expressed happiness in even their minor achievements. During the interview with Sobiha, it was found that she was very dependent on her family members for her every day activities until very recently, but at the time of the interview she said, with a hint of pride, that she is now capable of managing things by herself. She was, however, still very dependent on her family to take her to the bus stop to board her school bus in the morning or to go to her mother's shop right across the street, which was very busy most times of the day, in the evenings. Sobiha seemed to be very frustrated about depending on her family in this way. It was also found that the family used her school as a strategy to manage their daily lives. A few weeks after the interview, I heard from Suchismita that Sobiha was no longer permitted to go to school as she had passed the age of 18 years. As I did not get the opportunity to meet her later, I do not know how she or her family members were coping with this change.

In Risha's case, her doctor had informed her family in her childhood that her disability has bent her spinal cord, because of which she tilts sideways while walking. He had told her family that because of this, she is likely to have back ache when she grows up. Risha said that earlier, even though her backache was always there, she found it bearable. However, a few years earlier, she had a severe fall in the backyard of her home which increased her backache tremendously. As a result of this, she is not able to do many things now that were not very difficult earlier. She said that earlier she did not find it very difficult to walk to the main road and take the school bus from there to her disability organization. But after her fall, she needs to depend on her younger brother to drop her at the bus stop in the morning, while in the afternoons it is her father who picks her up from the bus stop and then they both return back home in a rickshaw. Despite these difficulties, her family has not stopped her from going to the school, as they realize that this is her only source of social contact. Furthermore, since the time of her fall Risha is unable to move much in the mornings because her body ache is at its peak at that time. It is her father who helps her in doing simple activities such as putting toothpaste in her toothbrush and so on.

The above narrative shows the type of help that family members provide to persons with disabilities. It shows us the accessibility issues that persons with disabilities face, and how their families cope with these problems, and do not make the person with disability feel like a burden to them. In Risha's case, in addition to accessibility issues, aggravation of her physical condition has also caused her new problems that restricted her mobility significantly.

Apart from the daily living activities, the study found that the mothers provide lifelong support to their daughters regardless of the daughter's marital status and their own age-related health problems. This is somewhat surprising because in Indian society a married woman is no longer considered to be a part of the natal family. However, the presence of impairment relaxes some of the gender norms for women with disabilities.

After Jeuti's marriage, she and her husband lived with her natal family for a while. Out of the fear of society's scorn, Jeuti's mother then suggested them to rent a place nearby. She said that this was her strategy to ensure that Jeuti does not face any difficulty in her new home. She further said that she is very concerned about Jeuti's well-being and feels that she might be hurt in her mind if she has to do a lot of work. This is the reason that she never allowed Jeuti to do any kind of difficult work when she was unmarried. Even after her marriage, Jeuti's mother sometimes sneaks in to their home, after Jeuti and her husband had left for work, and washes the dirty utensils and clothes for her. She said that even though Jeuti and her second sister often scold her for this, in her mind she is not able to accept that Jeuti would be able to do all the difficult household chores by herself. Her second daughter, however, tries to reason with her by saying that today she is living nearby, which is why they have been able to help her. But in a few years if they move away Jeuti will find it even more difficult to deal with these chores. Jeuti's mother said that thinking about this she sometimes resists herself from helping her daughter.

Korobi lives with her husband in her mother's ground floor apartment, while her 17 years old son is brought up by her mother. Her husband is Korobi's primary caregiver, because of which he is not able to do anything else to earn a livelihood. As mentioned earlier, they depend on her mother's family pension for their sustenance. Apart from her physical condition, Korobi had developed monophobia, because of which she cannot stay alone in a room even for a short duration. Both her mother and her husband said that it is this condition that they find to be more problematic as they are not able to go about their work because of this [this will be elaborated in Chapters 6 and 7]. Korobi sometimes worries about what would happen to them after their mother is no more.

The two narratives above show that women with disabilities receive lifelong support from their mothers even after their marriage. This is seen to ease out some of their difficulties. However, not all the women were able to ask for help from their natal families. Bandana, who had eloped with her husband, had hurt her mother and siblings immensely with this act. Even though now her family has accepted the marriage, she finds it very difficult to discuss about her marital problems with her family, as after all marrying him was her choice. For the same reason, Bandana also does not ask for money from her family during severe financial crisis.

From the above narrative it can be seen that sometimes, going against the family can result in hesitation to discuss about their personal problems, or to seek financial help. Such instances were also notice in Daruwalla et al.'s (2013) study in Mumbai.

To sum up, this section has tried to show the kind of support that women with locomotor disabilities require from their family members for their daily activities in adulthood. It is evident that the support needed differs according to the type of the disability and the body parts affected by it. Majority of the women are able to manage most of the activities on their own with minor help from their family members. The study also shows that the women receive lifelong support from their mothers even after their marriage and after having children. However, those women who go against their families to marry the person of their choice hesitate to discuss their problems with their family members out of the fear of being rebuked.

Support from Siblings

The study has also found that siblings, usually sisters and sometimes also brothers, provide a lot of support to the women. Mehrotra (2013) has used the term 'sorority' to invoke relationships between women (sisters and sisters-in-law) to analyze relationships that are linked through kinship and affinity. These relationships, according to her, are beyond negotiations within patrilineal kinship structures, where their relations are not necessarily built on competition and conflict but on mutual support, especially in crisis situations like that of disability or illness (Ibid). Her study in rural Haryana has found that the maternal kins provide moral and physical support throughout the life course of women with disabilities, especially through sorority. She also observed very little sibling rivalry among her study participants as the siblings often assume the role of the caretaker (Ibid). In this study also it was found that usually female siblings assume the role of the caretaker for women with disabilities.

In the case of Surabhi, it is seen that her older sister refused to marry so that she can be with Surabhi as they age. During the interview, her sister said that Surabhi has a terrible temper because of which it is very difficult for another person to live with her. So she decided to assume this responsibility. She, however, allowed her younger brother and younger sister to marry. Similarly, in the case of Korobi, her second sister told their parents that she will not marry as she wanted to take on Korobi’s responsibility for the lifetime. While Korobi’s parents were at a fix to respond to such a proposition, Korobi herself rejected it and expressed her desire to get married. During the interview, Korobi said that she did not want to be a burden on her sister and wanted her to live her life. Korobi was the first among the three sisters to get married, and this is a matter of great pride for the family. Her other sisters also got married soon afterwards. Her second sister now lives in Calgary, Canada, with her husband and children. Korobi is still very close to her second sister, and she is the one who takes Korobi for outings whenever she visits India.

Korobi’s narrative shows how marriage is perceived to change the equation between the sisters. Even though Korobi feels very happy that she did not stand on the way of her sister’s happiness, her marriage has not ended her dependence on the family as she, her husband and her son still depend on her mother’s family pension for sustenance.

Some of the siblings have shared the work responsibilities of the women, so that they do not have to work as much. Jeuti talked about the kind of support she has received from her second sister. She said that when she was unmarried and lived in her natal family, her sister never allowed her to do any of the heavy household chores. Her sister completed these chores before leaving for work. Even when she decided to go for the surgery of her hand, it was her sister who sponsored her treatment, and took care of her during the recovery period.

In the case of a few women, brothers have also played a significant role in their lives. Dolly said that after her amputation, when she was no longer able to work, it was her younger brother who decided to drop out of school in order to earn for the family. At the time of the interview, Dolly and her brother were the two working members in the family. She said that her brother often told her that it is okay if she does not contribute to the expenses of the family. She, however, helps in whatever way possible. She is very grateful to her brother that he took up the role of the provider of the family so graciously after her accident. At the same time, it is also one of her biggest regrets that her brother was not able to complete his school education because of her.

In the case of Uma, after her childbirth through Cesarean Section, she was finding it very difficult to manage her baby as well her home as she and her husband both were disabled. During this period, she did not receive any support from her mother-in-law and sisters-in-law even though they lived contiguously to one another. Instead, it was one of her *Dada* (older brothers), who came to live with them for a month. Her brother took care of all the household chores so that Uma can devote her time to her newborn baby. She said that even though her *Dada* is slightly *ojola* (has mild mental disability), he was able to understand her hardships and so he helped her with everything. Her husband's family, on the other hand, did not have any empathy towards her predicament.

From the above narratives it can be seen that although brothers do not always help in the daily activities of their disabled sisters, in times of need, they also provide the necessary support, sometimes going beyond their gender roles.

In patrilineal societies, unmarried women with disabilities usually do not have any friends left in their neighborhood as they grow older as their sisters and childhood friends get married and leave for their affinal families. With the marriage of their brothers, however, they have newer members in the family. According to Ghosh (2016: 111-112),

> …coexistence with the *baudi* [elder brother's wife] is dependent both on the girl's own position in the family as well as the *baudi's* ability to accept and adjust to an unmarried disabled *nanad* [husband's sister]. Disabled girls accept the socio-cultural ideologies regarding their status in the natal home and negotiate with their *baudis* to establish a cordial relationship with their married brothers and their wives.

Ghosh (2016) further said that it is especially true in the case of women who are able to contribute to the family either by sharing the household chores or financially. According to her, this gives the women a stronger position to negotiate the relationship with the new women in the family (Ghosh, 2016). In the case of

Minakkhi, after the marriage of her sisters, she said that her *Bou-s* (sisters-in-law) and their children are her new companions. She talks to her *Bou-s* whenever she has any difficulties. She said that they also help her out with day-to-day activities which she is unable to do like pinning her clothes or wearing a different hairstyle for a special occasion. During my interaction with Minakkhi's *Bou* she said that Minakkhi is a very likeable person who does not interfere with anyone else's lives. One of the reasons for the amicable relationship between Minakkhi and her *Bou-s* could be that she often helps them with the household chores and in caring for their children. Moreover, since she is working she does not have to depend a lot on her brothers for her upkeep.

Not all the women, however, had cordial relationships with their brother's wives. Chitra said that after her mother's death she was brought up by her older brother and his wife. She said that although she did not have to starve at her natal home as food was in abundance, she had to listen to a lot of taunts and abuses from her *Bou* (sister-in-law) that made it very difficult for her to live there. Chitra was sometimes also beaten by her. This is the reason why even though after her marriage she is living in extreme poverty with her husband, she feels happy that she at least has a peaceful life. Chitra's narrative shows that after the death of parents, women with disabilities who are vulnerable as a result of severity of their condition and lack of education, are at the receiving end of abuses of the spouses of their siblings who do not share the same feelings about the person with disability as their parents. This makes women with disabilities all the more vulnerable to both physical and verbal abuse.

Similarly, Hema also does not share a very good relationship with her older brother and *Bou*, who often make fun of her for being a *lengeri* (physically disabled). Hema said that what has made the matter worse for her is that instead of supporting her, her father has now taken the side of her brother. This often leads to quarrels between the family members, which in turn has disturbed her mental peace.

To sum up, this section has tried to show the kind of support that the women have received from their siblings and their spouses. The study shows that while most of the women have received adequate support from their siblings in their childhood, sometimes the equation changes after their marriage. Due to this reason most of the women were concerned about whether their siblings would look after them in the future, after their parents have passed on (this will be elaborated in Chapter 7).

Conclusion

The aim of this chapter was to show the kind of support that the women have received from their family members across different phases of their lives. The chapter was divided into different sections corresponding to different phases of the life course. It was found that different family members of the women have provided support to them across these different phases. Mothers of the women were found to be their strongest and most consistent source of support throughout their lives. It is due to this reason that the loss of the mother was viewed as the most catastrophic event that could happen to anyone (Anamika). While their fathers have also been supportive, it was found that most of them had passed away when the women were very young. The deaths of the fathers had affected the women both emotionally as well as financially. The way the death of either parent is experienced points towards the gendered division of labor prevalent in the society of Assam.

Other than mothers it was found that sisters and sometimes grandmothers also took care of the women. In the long run, however, the women are generally not able to look up to their sisters for support, as they get married and leave their natal homes. It was only in the case of Surabhi, whose sister said that she remained unmarried in order to be with her in later life. The women also received considerable support from their brothers, but they were unsure if this support would persist in the future. Thus the changing nature of the family setup plays a big role in undermining the life chances of the women. What complicated the situation even more was that unlike their siblings, it is not very easy for the women to find a marriage partner because of their impairments. Due to this reason they have to remain in their natal families throughout their entire life course. It was also found that the women were skeptical about their futures because unlike their brothers, they were not considered to be the legal heirs of parental property. Unfortunately, these women were left with no other option but to depend on their families because most of them were not very qualified for a government job. All of these factors lead to a cycle of dependency on the family. It was because of such factors that the concept of '*disabled household*' was found to be appropriate in order to understand the situation of the family with a disabled member. This point would be further elaborated in Chapter 9.

Chapter 6

Corporeal Experience of Disability

In the previous chapter, we have discussed the important role that family support plays in the lives of women with locomotor disabilities. The current chapter focuses on their corporeal experience of living with locomotor disabilities over the life-course. It uses the narratives of the women to describe the experiences of seeking treatment for their health conditions at different phases of their lives starting from their parents' quest for seeking cure for their impairments up until their most recent contact with the health system. The chapter elaborates on Grech's (2009) argument that in countries of the majority world, the sharp distinction between impairment and disability as espoused by the social model is contextually and culturally inappropriate. For many, impairment is a pivotal concern that cannot be negated, even for organizing a collective movement against oppression (Ibid). In the Indian context, as has been explained in Chapter 1, lack of access to healthcare is a major problem for the poor, which in turn makes them more susceptible to disabilities. Significantly, rehabilitation is mostly unavailable for this population either due to their lack of awareness or because of the economic hardships of the family that leaves little time for the family members to take the person with disabilities to a rehabilitation centre (Klasing, 2007). In any case, these centres are located far away from the rural areas where a majority of persons with disabilities reside (Ibid).

The chapter attempts at understanding the different barriers the study participants disabilities and their family members have faced in seeking cure and rehabilitation for their impairment-specific conditions, as well as for conditions that are not related to their impairments. It is important to note here that women with disabilities engage with the health services system in two different ways, first, for their impairment-specific services, and second for health conditions that are unrelated to their impairments (Thomas, 2001). This chapter follows this schema in understanding the women's life experiences of dealing with their corporeal experiences. The chapter is divided into four sections: the first section looks at the parents' quest for seeking cure at the time of onset of the impairment, the second section looks at the experiences of visiting doctors, going for corrective surgeries and physiotherapy sessions in their growing up years; the third section looks at the secondary conditions and experiences of bodily discomfort in their adulthood; and the fourth section looks at health conditions that are unrelated to their impairments. The chapter also gives the background information of the social location of each research participant in order to better understand their corporeal experiences.

It was found that while many of the women talked extensively about their impairment-specific difficulties, they almost overlooked their other health conditions, and reported that their general health was reasonably good. One of the reasons for this could be that since persons with disabilities are commonly perceived to be 'sick' or 'unwell', the research participants made a subconscious attempt not to identify themselves with the 'sick role' and to portray themselves to be as healthy as other 'normal' people. Similar finding was also reported by Begum (1996) in her study on the role of General Practitioners in shaping the lives of women with disabilities in the UK. In this study it was only in the case of Korobi, whose mother extensively talked about her different health conditions primarily because she had undergone varied health experiences in her life. Due to this reason, her narrative has been elaborated in greater detail in the chapter. Her narrative alerts us to the problems that people with 'unhealthy' disabilities face over the life-course for which the social model provides inadequate understanding.

Parents' Quest for Cure of the Disability

After the parents come to know about the nature of their daughter's condition, they begin the quest for seeking cure. In Ghosh's study (2016), it was found that within a few weeks, parents overcome the initial shock and actively seek cure for their daughters' impairments or at least try to lessen the impact of the impairment so that the girls are able to lead as 'normal' lives as possible. She also found that parents try to legitimize the impairment and represent it as *asukh* (illness). This, according to Ghosh (2016), is a mechanism to justify the occurrence of the impairment to themselves as well as to the outside world. She found that in this way parents still hope for a miraculous cure to restore their daughters to normalcy (Ibid). Mehrotra's study (2004; 2006; 2013) in rural Haryana found that parents initially neglect the disabled girl child and eagerly anticipate her death. However, when they realize that the child is able to cope with the disability in spite of the neglect, the family comes together to support her. Her study also found that sometimes the parents and other family members are unable to understand the symptoms of abnormality because of which there is a delay in accessing healthcare for the child (Ibid). In this study, the women, from both rural and urban areas of the district, did not report being neglected by their parents for their impairments, even though in many occasions it has been found that the early symptoms of their conditions were neglected by them. This, however, was not due to any inherent bias towards their daughters because of their gender unlike in other studies (Ghai, 2003; Mehrotra, 2004), but because of their socio-economic difficulties or the busy schedules of the parents that did not allow them to take out time to take their child to a doctor for treatment. In certain cases it was also found that the parents of the women were in denial about their daughter's condition which made them delay seeking treatment for their child. However, once they acknowledged the child's condition the parents sought different pathways to cure their daughters. This included going to doctors and folk healers, and doing whatever other remedies that were suggested to them by their relatives, neighbors, well-wishers and sometimes even strangers. The major aim of the parents' actions was to cure the women's impairments so that they can lead 'normal lives. The narratives below give a picture of the parents' quest for seeking cure for their daughters.

Few days after Minakkhi's birth, her parents realized that she is not well as her face, hands and legs had become very small. Her parents consulted an *ojha* (folk healer) for her treatment. Her mother explained that at that time they did not take their children to doctors for such conditions. Instead they relied on *ojhas* who gave them medicines which were acquired from the jungle. Minakkhi's mother said that the *ojha* told them that their daughter was suffering from *poya* because someone had casted an evil eye on her. She elaborated that when a person gets *poya*, his / her face becomes very small, like that of a monkey. The medicine for this was to go to the jungle and to get monkey dung, which was later wrapped in a leaf and tied with a thread on the neck of the affected person. According to her mother, they did this with Minakkhi, who was cured of her *poya* in no time. They did not, however, go to a folk healer to cure her hands as, according to Minakkhi, a folk healer is incapable of curing such problems. They can only cure in the case of impairments caused by infectious causes. Similarly, in the case of Uma, when her parents realized that her condition cannot be treated at the hospital, they took her to an *ojha* for consultation. However, the *ojha* also disappointed them by saying that her condition cannot be treated because it is congenital, and not acquired through an injury later in life.

In the above narratives it can be seen that parents usually take their children to folk healers for the treatment of a number of conditions, including their impairments. However, these healers are found to have limited capacity to treat congenital impairments such as syndactyly or congenital weakness of limbs. While in the case of Minakkhi her parents took her to a folk healer for treatment of another illness, which was not related to her impairment, in Uma's case her parents took her to a folk healer when doctors at GMCH told her parents that her condition cannot be cured because it is congenital. While parents of these women seemed to have a lot of faith on these healers, because all they wanted was their daughters to be cured, it was not so for the women in question. For instance, when Surabhi's parents realized that modern medicine cannot treat their daughter, they took her to a folk healer for treatment who massaged her body. Surabhi, however, was not happy with this treatment as the massages hurt her body immensely. During the interview she also mentioned that she did not have any trust on the treatment of folk healers when the 'real' doctor could not do anything to cure her. Surabhi's narrative shows that parents and their daughters might have different opinions and outlook about the modality of treatment. In spite of this, her parents did not pay any attention to her concern because they felt that they are acting in the best interest of their child. Minakkhi, Uma and Surabhi are from the Joonaki Block of Kamrup Metropolitan District. One of the reasons why their parents took them to the folk healers could be due to the inaccessibility/ unavailability of healthcare facilities in their vicinity during the period (late 1970s and early 1980s) when they were growing up.

Similar behavior, however, was also observed among the parents of women who are from the urban areas. In the case of Risha it was seen that her parents tried their best to seek cure for their daughter from every possible direction. When she was very young, they had hired a physiotherapist for a few years in order to cure her condition. But when it did not show any definite results, they discontinued his services, and instead tried to continue her exercises at home. She said that her parents did everything that they were told in order to cure her. For instance, some people had advised her parents to dig her in their yard for some time, saying that this would make her walk straight. Her parents had tried this in their hope that Risha would be cured of her impairment. Another time, when she was about 10-11 years old, a folk healer came to their home and claimed that he can cure her. Risha said that her parents were very hopeful for her cure, while she on the other hand, had given up hope after a series of disappointments. This healer suggested that drinking the urine of a cow would cure her of her impairment. Hearing this, her parents got very angry and asked him to leave immediately. She said that her parents did not believe in another folk healer after this.

The above narratives show that regardless of the nature of impairments and their place of residence in rural or urban of the district, parents were usually desperate and they try whatever they were told by anyone who claimed to cure their daughters. Even though certain research participants such as Surabhi and Risha did not like such kind of interventions, they were at a marginal position to voice their concerns to their parents who believed that they are acting in the interest of their daughters. However, blaming individual parents for putting their children with disabilities through such ordeal completely negates the situation under which such parents seek cure for their daughters. The knowledge about disability was considerably limited in the 1970s and 1980s when these women were growing up. On the one hand, the health services system was not able to provide adequate explanations about their daughter's condition; while on the other hand, the parents of the women were often accused by the wider society for bringing about such a plight for their daughters. At the same time, there were no disability organizations during this period to provide adequate information or to show a positive image of persons with disabilities to the parents. There was a dormant hope of cure in the hearts of all the parents that became active every time someone mentioned some form of treatment that might cure their daughters' condition. In such a context, parents became easy prey of quacks who extracted money out of fooling the parents. As a consequence of all of this, it was the women with disabilities who underwent a lot of harassment in the name of treatment. Ghosh's study (2016) among women with locomotor disabilities in Bengal has also shown that parents explore the indigenous system in order to search for cure for their daughters. It is only after the failure of this system that parents opt for biomedical treatment in the hope of improving their condition and reducing the visible impact of their disability (Ibid). In this study, however, it was just the opposite. Parents went in search of alternate cures for their daughters only after they faced failure from the biomedical system.

Apart from quacks, in certain cases, the parents were also seen to believe in spiritual gurus in order to cure their daughters' condition. As elaborated in Chapter 5, Korobi's mother believed that her daughter's operation was stopped due to the divine intervention of [Sathya] Sai Baba. When Korobi, who was about 5 years old at that time, heard about this, she began to worship him, looking at his photo. Her mother said that after this incident, she also started to light an incense stick in his name. When Korobi's *Deuta* [father] and her *Aita* [paternal grandmother] had decided to go to Vellore from Calcutta for her further treatment, Korobi's mother insisted that they must also go to the Sai Baba Mandir as it is not very far from Vellore[132]. She said,

> *Her Deuta and Aita did not believe in all this. Yet her Deuta decided to go there first. He said if you are getting his visions, let us first take her to him. Maybe something good might happen to her. He just wanted to see what Sai Baba does as so many people kept talking about his miracles. They took Korobi along with them. After that they became bigger devotees of him than me! [she laughs]… They took Korobi to the Sai Baba Mandir. Her Deuta wrote me a letter narrating what all had happened there. I'm telling you what he wrote to me. Her Deuta wrote that Sai Baba saw Korobi and asked her Deuta to bring her to him. He then said that I have called her from Assam. Her Deuta and Aita were surprised that he knew where they had come from. Her Deuta did not believe in all this earlier, he, in fact, used to laugh at others. But after seeing him, he had a change of heart. After seeing Sai Baba, her Deuta felt like he has gone through an electric shock. Her Aita also felt the same way. Her Aita touched the feet of Sai Baba and said that his feet were very soft, as soft as cotton. Thereafter, her Deuta also touched his feet. Both of them also asked Korobi to touch his feet, but she refused. She did not like touching anyone's feet. Seeing this, Sai Baba asked them not to force her as she is a young girl. At that time he told Korobi, I would give you one thing, and he did some tricks with his hands, and gave her a gold locket. Her Deuta and Aita did not come to know from where he had taken out this locket. He gave Korobi this locket and asked them to make her wear it after three days. In the letter, her Deuta had written about that locket, that it had two sides, on one side was written Pita* [father] *and on the other side was written Mata* [mother]. *Sai Baba told him that this locket should be with Korobi always. Her Deuta took the locket and he was very happy. Sai Baba also asked them to attend the bhajans*[133] *every day and to bring her to the temple. There was a Ganesh temple there, and they asked Korobi to take a round around it. After the round was over, they gave her some Prasad* [offering made to God that is later shared among the devotees]. *Her Deuta took Korobi for the bhajans in the next morning and made her sit there. She also tried to sing along, but she was not able to. After staying there for two days, Korobi did not want to come back from there. But her Aita said that this won't do as I was alone at*

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[132] The Sai Baba Temple is located in Puttaparthi in Anantpur District of Andhra Pradesh. At present it takes about three hours to reach Vellore from Puttaparthi by road.

[133] *Bhajan* refers to any song with religious theme or spiritual ideas, in a regional language from the Indian subcontinent.

> *home with our newborn baby. They were already away for several months by that time, as they had gone there directly from Calcutta. At the end there was no other option for them but to come back. Sai Baba had asked them not to leave from the Mandir until he asked them to. But they left for Vellore the very next day without informing anyone. They felt we have come so far, we should also consult the specialists in Vellore. At the Mandir, Sai Baba had given her a tonic and told them that she would be cured by the age of 12 years. He told them that he has blessed the tonic. At Vellore, when the doctors took her for the investigation, her Deuta felt that she would face difficulty. So he made her wear the locket. This was because she had already faced a lot of difficulties during her operation in Calcutta, where the doctors took out some fluids from her spinal cord. It was not the third day yet, but he still made her wear the locket. When they took her inside for the investigation, at that time, Korobi lost the locket. They looked for it everywhere, but they could not find it. There was also a lot of fuss in the hospital that a gold locket has gone missing, but they could not find it. They could not find the locket, so they came back just like that. They did the investigation there, and she was given the same tonic from the hospital, that was given to her by Sai Baba. It was the same medicine! They were surprised to see this. Maybe she would have been cured if she still had the locket…*

As elaborated in Chapter 4, despite being from the urban area when Korobi's family did not receive an adequate medical explanation about her health condition, her parents decided to take her to Calcutta for treatment. When the doctors at Calcutta also could not cure her and referred her to Vellore, her mother was able to persuade her father and *Aita* to also go to Sathya Sai Baba Mandir. By this time, she was getting his visions and she felt that Sai Baba would be able to cure her daughter. As can be seen from the above narrative, even though her father and her *Aita* never believed in such spiritual gurus, they gave in to Korobi's mother's request because they were also desperate for her cure. After their interaction with Sai Baba, their belief on him as a divine entity was restored. The family seemed to have complete faith on the guru and his capability to cure any illnesses or disabilities. The narrative shows that her mother believes that Korobi too would have been cured if her father and *Aita* were not in a hurry to leave. However, she realizes that there is no point in thinking about this as it was necessary for them to return back home after being away for so many months. During the interview, Korobi was not very vocal about her responses. It seemed as if she liked to listen to her mother's narrations of her treatment trajectory. However, she did mention a word or two here and there. When her mother was narrating about her stay at the Sai Baba Mandir, Korobi added that she really liked it there, and sometimes when she thinks about those days, she feels very sad. In the next moment she said that instead of thinking about the many dreadful incidents of her life (which would be discussed in the subsequent sections), Korobi prefers to think about the good things or how she can manage to collect some money for the treatment of her different health conditions.

Her narrative shows that even parents from urban middle class backgrounds who have the money to seek treatment for their daughter from any part of the country were not immune from the hope that their daughter would be cured through some divine intervention. In the narrative it can be seen that Korobi's father and her Aita were very impressed by Sai Baba's tricks of producing a gold chain out of nowhere. In the later years of his life, Sathya Sai Baba has been accused of faking his miracles by doing amateurish magic tricks that even children can reproduce given adequate practice and also of sexual abuse (Lane, n.d.). In spite of such allegations, Korobi's and her mother have not reevaluated their belief on the guru. This must also be read in the light of the dissatisfaction of people with medical care which have forced them to look for cure from alternative sources (Dalal, 2002).

In a few cases it was also found that even though the women's parents were informed about the health condition of their daughters, the information was not very adequate due to which their physical management was neglected that led to further deterioration of their conditions. Due to this reason, sometimes they have been rebuked by the 'experts' who have very little understanding of the circumstances under which parents have had to stop seeking treatment. The following narrative gives a glimpse of this:

After Sobiha's birth, the doctor at GMCH informed her mother that Sobiha has some problem. The doctor recommended Sobiha's mother to take her to Senehi for her physical management and rehabilitation. The doctor also told her that Sobiha's condition would improve if her treatment is continued for three years at a stretch. However, her mother did not realize that her condition would get so severe if she discontinued Sobiha's treatment. Due to this reason, she did not give it much priority when she faced other familial and economic problems (as elaborated in Chapter 4). When things settled down a little bit, Sobiha's mother took her back to Senehi which had shifted to its permanent location by this time. Sobiha's mother said that they refused to accept her at the organization citing that now she is old enough and they will not be able to improve her condition. Sobiha's mother met Suchismita when

Sobiha was about two and half years old. According to Sobiha’s mother, this was a life changing event for her and her daughters. She said,

> *Actually, the thing is, what I have come to know now, if someone comes to me with such a child, I would be able to say to them whatever I have learnt through my difficulties. I would be able to explain these things to them. But at that time there was nobody to explain such things to me. There was no one who explained to me that she is like this. And I was also not able to understand these things. That is why I did not pay much attention. After that her Deuta also passed away when she was 2 years old. That is why I could not continue her treatment.*

Suchismita took Sobiha’s mother to different workshops for parents of children with disabilities. After attending many such sessions, Sobiha’s mother was able to understand the nature of her daughter’s impairment. Sobiha’s mother, with the help of her siblings, also took her to many folk healers (and quacks) in the hope of treating her daughter. In the process she had spent a lot of money. She went to these healers without informing Suchismita as Suchismita did not believe in such things and Sobiha’s mother was scared that she will be rebuked by her. During the interview, Sobiha said that she does not believe in folk healers. She sarcastically said, *“They are all liars. They said I would be able to walk in three months. Till now I have not been able to walk”* [she laughs]. However, her mother and other family members did not pay attention to her viewpoint, and continued doing what they thought was best for her. All these factors, however, have left a deep impact in Sobiha’s mind, who feels that her mother had neglected her in her childhood, and because of this reason her physical difficulties have aggravated:

> *I was taken for treatment. The doctor said take good care of her, your girl would be better. Ma did not do it. She was not able to do it. She did not get the time, what to do. That is why I am like this. I am slightly better than before. Now I can go out alone, I can eat by myself, I can take bath myself. I do everything by myself. But I am not able to walk out of here by myself. Bhonti needs to take me out. Or Ma needs to take me. I want to go out by myself. I cannot fulfill my aspirations, to work as I feel like, I cannot do that.*

As can be seen from the above narrative, Sobiha feels sorry about the fact that she is not able to go out on her own and has to depend either on her mother or her sister. Her mother also said that Sobiha gets angry very fast and in such situations sometimes she beats her mother or her *Bhonti*. It is probably due to her repressed anger that Sobiha gets very violent when her demands are not met by them.

As discussed in Chapter 4, Sobiha was born in the late 1990s and by this time Senehi had firmly established itself as an organization for children with cerebral palsy. Even though Sobiha's mother was informed about her condition and the kind of treatment she would require, the information was not adequate for her to understand what might happen if Sobiha's treatment is discontinued. As a result of this, her mother did not pay adequate attention to her physical rehabilitation. After she started her roadside shop, she met Suchismita who informed her about the importance of physical rehabilitation. In spite of this information, Sobiha's mother still had the hope in her heart that her daughter's condition is curable. This is the reason why she along with her sisters took her to different folk healers (and quacks) for her treatment, even though Sobiha herself was not in favor of such interventions. Cure, therefore, was given more importance than rehabilitation. Mehrotra's study (2006) also shows that family members of the women avail all kinds of possible resources to find cure for disability, while similar emphasis is not given to rehabilitation. As Sobiha's case has shown, very often parents do not receive sufficient information about how rehabilitation can improve the conditions of persons with disabilities. This point was also highlighted by Jonak Borgohain, rehabilitation personnel at a private hospital in Guwahati. According to him, physiotherapy has been ignored by people in Assam for the longest time. This is because people have very low awareness about this form of therapy, and they generally prefer to be cured by having medicines. He also said that people usually want a speedy recovery, and are not patient enough to wait for a few months or sometimes years for the outcome of the therapy. He said that it is only in the last few years after the introduction of physiotherapy degree courses at a private college in Guwahati that the awareness about physiotherapy is spreading in the community in both rural and urban areas of the state.

To sum up, this section has tried to show the different ways that parents, regardless of their class status, level of awareness and place of residence try to seek cure for their daughters in every way possible. This involves using the services of healthcare providers, traditional healers and sometimes even spiritual gurus. One of the primary reasons why parents sought such modalities of cure is because of the lack of any adequate form of explanation from doctors. Due to this reason, parents always had the hope of cure for the condition. The study also found that after a series of disappointments some of the women had lost hope about cure and did not believe that alternate forms of cure would treat their condition. In spite of this, they were in a marginal position to voice their concerns as the parents and other elders felt that they were acting in the best interest of their children. The study also found that while cure was foremost in the minds of the parents, there was very little knowledge about how physical rehabilitation would be able to help them. This is the reason why when parents realized that cure of the condition is not possible, they also stopped seeking rehabilitation of their condition. The narratives clearly indicate that parents of children with disabilities should receive proper information about their child's condition as only then they can make informed decisions about the appropriate mode of treatment for their child, so that they do not fall prey in the hands of quacks.

Experience of Growing up with Locomotor Disabilities: Visiting Doctors, Corrective Surgeries and Physiotherapy Sessions

The study found that the research participants had to undergo different modalities of treatment in the initial years of their lives in order to 'cure' their conditions. This section elaborates on these experiences. Ghosh's (2016) study found that parents in her study undertook many tiring and expensive trips to hospitals in Kolkata for curing the disabilities of their daughters. This included travelling far and for long hours, mobilizing funds and companions to escort them to the hospital and to arrange for someone to take care of their other children (Ibid). In this study also the research participants and their mothers talked about the myriad ways in which treatment was sought for them. This section is only relevant for the women from the urban areas. The women from the rural areas, on the other hand, did not talk about their experiences of seeking healthcare for their impairment in their growing up years. One of the reasons for this could be sample bias, that most of the women had comparatively less severe impairments; while another is the lack of such services in the rural areas which made visiting doctors, getting corrective surgeries or physical rehabilitation nearly impossible for the women (as shown earlier in Chapters 4 and 5 in the cases of Anamika, Minakkhi, Surabhi and Pronoti). Let us now look at the experiences of the women from the urban areas.

After Korobi returned back to Guwahati from Vellore, everyone in the family had heard about how she had responded to the *bhajans*. Eventually, people in the family and neighborhood started taking her to public *bhajans* and made her sit in the front row in the hope that this would have some positive affect on her. Her mother said that Korobi tried to sing along, but she had no voice at that time. Some people had also suggested that she should be taken to the circus. So every evening after work, her father took her to the circus. Some people also asked them to play western music for her. According to her mother, it was probably to make her 'nerves' active as she tried to dance in between listening to the music. Her mother said that Korobi used to dance Bihu before her head injury. But when she started going for the *bhajans* she also started dancing Bihu, but by sitting, as she was no longer able to stand up and dance. Her mother said that in this way, gradually she became better. Her mother also said that when she was about 5 years old, she had uttered the word *Deuta* for the first time after the injury. This made everyone very excited as for a long time she only uttered the word Ma. She also said that the doctor asked her to keep talking to Korobi. She said, "*The doctor told me just because she does not talk, do not keep crying and remain silent*". He had asked her mother to narrate stories to her. The doctor also asked her to make sure that she does not forget the alphabets. Her mother said that when she brought out the books in front of her, Korobi would not look at them. So her mother had to apply different strategies like spelling the word Horlicks while she was made to drink it. Korobi had difficulties pronouncing certain letters, but would make an effort nonetheless. Her mother said, "*I had passed those years in tears. We tried so many things, but nothing happened. She did not talk*". Then one day, her mother narrated *Tejimola*[134]'s *xadhu* (tale). Listening to it, Korobi started crying. Her mother said,

> *This meant that she was able to understand everything from within. When I tried to continue with the story, she shut my mouth with her hands. I sang the Tejimola song, and she started crying. When I said this to the doctor, he said that this is because she is alright from inside and is able to understand everything. However, she was not able to say anything.*

Her mother said that Korobi continued going for the *bhajans* and the circus. She liked singing, and she tried to sing, but was not able to. One day at the circus, she saw the lion, and screamed out. After this, her father continued to take her to the circus or wherever she wanted to go. She liked to eat food from outside, so he allowed her to

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[134] *Tejimola* is a heartrending folktale about a young girl being mercilessly tortured by her step-mother in different ways in the absence of her father. Even though it is a very violent and distressful story, it is narrated as a bedtime story to very young children.

eat outside. Eventually she started singing the *bhajans* in bits. She also started to talk one or two words at a time. Her mother said,

> *In spite of all her difficulties, her smile never stopped. When we took her to the doctor, he was surprised. I had taken her in my arms. The doctor looked at her and said she is so jolly. No disease can ever attack her. She will be alright one day.*

Her mother further said that from her childhood, Korobi liked to be happy. When guests came to their home, she liked to go out and greet them. But everyone in the family asked her not to go out. They thought people would ask her what has happened to her. But she wanted to go out. She wanted to sit with everybody and talk to them. Her mother said,

> *One day she was talking to someone in the drawing room. Her Aita asked me to go out and see who has come. When I went out I found that she was talking to herself. It was a bad thing that she was talking to herself. I did not move from there and overheard what she was talking about. I heard her saying how many children do you have? What are their names? How old are they? She was asking such kinds of questions. In between she was also laughing a lot. I wondered why she is laughing so much. Then I heard her saying that your youngest son is very naughty. I got very scared seeing all this. I went to the doctor and told him these things. He asked me to allow Korobi to say whatever was there in her heart. He said, listen to her, but do not laugh at her. Her Pehi, who is a doctor, also said that she is saying all these things by thinking about something. She also asked me to allow Korobi to say whatever was there in her heart. In this way, she was able to talk gradually. By talking to herself she had improved her speech considerably. The doctor said that she would become alright with time. There is no other treatment for her. He only asked her to reduce her weight as she had put on a lot during that time.*

Korobi’s mother said that in Calcutta, some fluid was taken out from her spinal cord because of which she had bent down a little. In order to cure this, the doctor had given her certain exercises. They had employed a physiotherapist for this purpose. After two months or so the family was no longer able to afford his costly services. The physiotherapist, however, recommended her to continue these exercises on her own. Her mother complained that she did not continue with these exercises. She said,

> *I had a small baby at that time. I had difficulties, so I was not able to make her do the exercises. So they made her something in order to make her leg straight (splint). We used to make her sleep by wearing it, but she used to scream so much. Her Aita used to sleep in the next room. She used to say, I have high blood pressure, please let me sleep well at night. So we had to remove it, which is why this treatment did not work for her. There was a very famous doctor in (Assam Medical College[135]) Dibrugarh[136]*

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[135] Assam Medical College, Dibrugarh is an educational institution in Dibrugarh, Assam. It was the first medical college in North Eastern India. It is the tertiary medical referral centre for upper Assam and other neighboring states.

[136] Dibrugarh is one of the two main cities of Assam (the other being Guwahati). It is located 439 km east of Guwahati.

> *by the name of Dr. Mohan Bora. We went there to show her feet. He asked us to leave her there. He said that he would look after her like his own child. We got her admitted there. But after the admission, everyone scolded us for keeping her in the hospital, so we brought her back. If she was allowed to stay there, with that thing tied over her leg… Her Deuta was so angry. He had got the splint after spending a lot of money, but she would not wear it and scream aloud. I feel that it was a big mistake on our part to remove it. Her Deuta tried a lot to make her understand, but she did not listen to anyone. Because she did not listen to anyone at that time, she is suffering now. Her leg has become very stiff now. At that time it was not like this. They did everything for her. She was not able to ride a cycle, so they bought her a cycle. But she did not use it out of fear. Later they bought her a stand cycle, to pedal on it. But she did not use it either. They also made a bar for her to walk on. She did not use that even. Everyone loved her so much that if she said no, they never forced her. This excessive love has finished her.*

The above narrative shows how Korobi's mother and other family members tried to help her in becoming 'normal' again by engaging her in different activities. While she happily engaged in some activities like participating in *bhajans* and going for the circus, she did not like to exert her body physically as she found those to be painful. The narrative shows that her mother completely negates her condition (mild cognitive disability[137]) and her age (barely six or seven years old) at that time, and blames her for being spoilt enough to not listen to what the elders were telling her. Her mother still feels that because she did not wear the splint and do those exercises in her childhood, she is facing the repercussions of it in her middle-age. In Ghosh's (2016) study also it was found that the love and concern of the parents sometimes acted as a deterrent in accessing services as well as in continuing with the rehabilitation process. In this study, particular attention must be given to Korobi's family's class status. They were able to engage in all those activities like going for *bhajans* and the circus every day because her family was considerably affluent. Additionally their social relationships were strong enough that people from their extended family also supported Korobi's parents in their effort of curing her. Unfortunately, not all the women had access such resources and relationships which hindered their cure considerably.

The study also found that several research participants had undergone corrective surgeries at different points in their lives to correct their physical deformities. The following narratives give a glimpse of their experiences.

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[137] It was very apparent during my interactions with Korobi that she had mild cognitive disability. This was also later confirmed by the Secretary and General Secretary of Helen Keller Charitable Trust, with whom she tried to have regular interactions. During the interviews, however, neither Korobi nor her mother talked about her cognitive disability and it is very much possible that her family considers it to be a mild problem in light of the other drastic problems Korobi has faced in her life.

Ananya's impairment (cerebral palsy) has affected the left side of her body, including her left eye, her left hand and her left leg. She said that she faces difficulty in seeing very small letters with her left eye, but her parents have not made an attempt to do anything about this problem. However, she had undergone two different surgeries for her impaired hand and leg. She said that she was very young at that time, because of which she does not remember the exact details about those surgeries. She has heard her parents saying that her leg was operated by a foreign doctor, which is why she believes that it has been cured. In contrast, the hand was operated by an Assamese doctor, which is why she feels that it remained impaired. She further said that when she got admitted to Senehi at the age of 7-8 years, she was given a splint to correct the deformity in her left hand from the school's physical rehabilitation unit. She said,

> *I was given a splint from the school to correct my hand. But I did not use it. I was very young at that time. That is why I did not understand anything about all this. I did not use it. Ma-Deuta told me to use it, but they never forced me… I did not face any difficulty while using it as such. Only sometimes, if the cotton inside it was taken out, it used to hurt. I did not face any other difficulty... Who knows, had I used the splint, my hand might have been better by now. Now I regret it. Now I regret it very much…*

The above narrative reiterates the bias that persons with disabilities and their family members have towards healthcare providers from Assam because of which they usually prefer to avail health services from outside the state, and in case they cannot afford it, then to get treated by a visiting foreign doctor. The narrative also shows that she did not use the splint as she was too young at that time to understand how it can correct her impairment. However, after growing up she understands that it was a big mistake on her part and regrets not using it because of which her hand could not be cured. Ananya's parents never explained to her about the need to wear the splint, as probably they were not convinced themselves. Ananya blames herself for her own ignorance, but does not blame her parents for it. She belongs to a middle class family. In the last few years her father had suffered from a severe business loss due to which their economic condition was not very good. It is quite probable that her parents did not pay any attention to her eye condition because they did not have the money to seek cure.

Like Ananya, several other research participants underwent surgeries in order to correct their deformities. Suchismita's family, as cited in Chapter 4, had shifted to Guwahati in 1972 after Shillong became the capital of the newly formed state of

Meghalaya, and the capital of Assam was shifted to Dispur. At that time, her parents got her admitted to a prestigious convent school in Guwahati. During the interview with her mother she said that she had requested Suchismita's teachers and classmates not to make fun of her leg as this might have a psychological impact on her. As a result of this, Suchismita did not face any difficulty in adjusting with her classmates. However, over time, Suchismita began to get tired of dragging her right leg while walking to and from the school. Her hopes for cure were suddenly raised by her father who, when Suchismita was about 13 years old, told her that an orthopedic surgeon from the UK was visiting Assam to conduct corrective surgeries on children affected by paralytic polio. In the book chapter on her life, Suchismita narrated to the author that when she met the doctor for the first time, she begged him to make her leg strong so that she would be able to walk for miles without tiring. The doctor reassured her that after the surgery she would be able to run around and even play lawn tennis if she wanted. It was a three phase surgery when she stayed at the hospital for six long months, but she did not complain even once because she was treated like a queen during that period. After the surgery, she was made to undergo physiotherapy. After her discharge from the hospital, even though she had a limp she felt that her leg was much stronger. However, few weeks later she fell down while walking over a plank of wood and twisted her operated knee because of which her surgery had come undone. As a result of this, although Suchismita was able to walk, she was not able to run as she had hoped. Suchismita, however, did not brood over it for long as by then she had learnt to accept whatever she got in her life (Raimedhi, 2015).

Suchismita's narrative shows that her family had sufficient resources to seek cure for her condition. But in spite of this, her condition could not be cured because of the unfortunate fall. Even though the incident crushed her hopes for the future, she had a very supportive family and network of friends who did not let her feel low for long.

Like Suchismita, Nayana also underwent a corrective surgery in her adolescence. During the interview, she said that after she was diagnosed with her condition (polio), the doctor taught her parents certain exercises. She said that her parents could not afford the services of a physiotherapist, so they continued these exercises at home. In spite of proper counseling from the doctor, her parents still hoped for a miraculous cure for her. That is why when someone informed them about a place in Siliguri[138] where she can be cured, her parents decided to give it a try. She said,

> *When I was about 15 or 16 years old, someone informed my parents about a place in Siliguri. They told my parents that if I am taken there I'd be able to walk. They also said that everything would be taken care of there. So my parents thought there is no harm in trying. Ma and Deuta had already known by that time that my condition cannot be cured. The first doctor had specifically mentioned this. So they told these people that we can go ahead with the surgery, but we do not have any hopes about the outcome.*

As expected, the surgery was not able to cure her condition. But in spite of their low expectations, her parents still had hopes in their heart about her cure. Nayana said that the only benefit from this entire episode is that after the surgery, her feet, that were earlier bent, had become straight. Due to this reason, even though nothing came out from the surgery, she did not have any hard feelings against it.

While seeking cure for their daughters was paramount in the minds of all the parents, sooner or later, some of them realized its futility as certain conditions were irreversible, and the treatment was actually causing their daughters more harm than good. Bandana's narrative brings this out clearly.

Bandana said that her parents tried their best to cure her. Although she has never spoken to her mother about her disability (short stature), she has overheard her mother's conversations with others that if she had more money, she would have taken Bandana to Patna for treatment. But the doctors at GMCH reassured her that they would provide the best treatment that is available in Guwahati to her daughter. From her birth till the age of 15 years, Bandana had undergone several surgeries and physical rehabilitation sessions, which did not bring about any changes to her impairment. She and her mother both were fed up of the medical treatment she received which caused her more pain and aggravated her condition than what should have been the case. Finally her mother decided that Bandana would no longer seek any treatment for her condition. In her words,

> *We stopped because, Ma* [mother] *and even I, we got fed up every time going to the doctor, going to the medical* [hospital]. *I found it so painful. They were only talking about this exercise, that surgery. After the surgery for about six months I was not able to get up from bed. I was not able to do anything. Even now, if I had not done the operation, I would not have faced any difficulties. Now I get tensed when I have to*

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[138] Siliguri is a city in the state of West Bengal. The distance between Guwahati to Siliguri is 472 km by train.

> *rush. It is because my main ankle has been removed and they have inserted an artificial ankle. Now I find it very hard to run out because I fear falling down. If I somehow fall down, because they have fit in screws, if something happens to me, that is what I am scared of. Earlier it* [healthcare] *was not very expensive. Now it is so expensive. That is why I am tensed.* [She weeps]

The above narrative shows that Bandana's condition was worsened by the medical intervention that she was undergoing. According to Dr. Yogesh Basumatary, if a person with short stature wants to increase his/ her height, then they can opt for a procedure called Ilizarov technique. This technique takes advantage of the body's remarkable ability to grow new bone tissue. It involves an initial surgery during which the bone is surgically fractured and a circular metal frame known as Ilizarov fixator is attached to it through pins and wires. Fixator rings hold each segment of the bone in place while new tissue is growing and maturing. As the patient recovers, the fractured bone begins to grow together (www.mainstreetfoot.com). According to Dr. Basumatary, Ilizarov technique is a very effective but also very cumbersome process as it takes a long period of time for the treatment. During this period, the patient has to wear the fixator rings which can be painful for them. This point has also been highlighted by Littlewood (2011) who had stated that even though Ilizarov can have dramatic benefits for the patient, it is not very easy for them as they have to wear the metal frame for many months, and the process itself is very slow and can be painful for them.

When Bandana's mother realized that her daughter's condition is getting worse because of the pain, she decided to stop seeking cure and making her suffer more. In disability studies and the disabled people's movement, mothers of children with disabilities occupy a very complex and yet marginal position. This is because of the (more likely) non-disabled status of mothers, whose actions are often interpreted as constraints within their children's lives, restricting their opportunities and aspirations (Ryan & Runswick-Cole, 2007). As non-disabled researchers, who are mothers of disabled children themselves, Ryan & Runswick-Cole (2007) argue that they occupy a position of liminality, where they are neither disabled nor non-disabled. In disability studies literature, parents have been described as wanting to normalize their children, which work to the detriment of the latter. In some of the literature, parents are allied with professionals, negating the loving, intimate and enduring relationship they share with their children, in contrast to the professional's payment for limited hours of contact and emotional attachment (Ibid). Ryan & Runswick-Cole (2007) argue that mothers are more than just allies to their disabled children, as they directly experience the discriminatory practices and attitudes that their children face, and also experience the psycho-emotional aspects of disabilism as they begin to ‘know their place’, moderate their behavior and learn to internalize oppression. In the above narrative, we found that even though Bandana’s mother wanted to normalize her condition, it was because of the hope she was given by the doctors, that her daughter’s condition is curable. Bandana’s mother was not given a clear picture about what would happen to her daughter after a particular surgery or a particular mode of treatment. It has been argued that the success of the Ilizarov technique is highly dependent on the attitude of the patient as they have to find ways to cope with discomfort, pain and frustration during the long process (www.mainstreetfoot.com). In a society where doctors are considered as supreme beings, questioning their expertise requires a lot of strength which unfortunately many of the mothers of this study lacked. Barbosa, Chaud & Gomes’s (2008) study, which was conducted in Brazil, has shown that parents are often disappointed by the lack of sensitivity from the health professionals regarding the disability of the child. The first author of the article, who is a nurse herself, concludes the paper by stating that it is very important for the health providers to bond with the family, as if they are indifferent to the needs of the family, this could have repercussions for the relationship of the child with the family (Ibid).

Unlike the other participants who had undergone their surgeries at the insistence of their parents, Jeuti decided to go for her surgery when she was about 22 years old. She said,

> *After I started working at Moromi, [Kishore] Sir asked me if I am interested in getting a surgery of my hand. At that time I was a little scared. This was not a minor, but a major surgery, that is why. I visit a temple called the Teeni Jhandi Mandir. The pujari of that temple, he was very kind to me and always gave me good advice. On a purnima (full moon night), he told me that if I go ahead and get a surgery done, then it would be beneficial for me. Actually a person had come to the temple who told the pujari about Dr. Alok Kalita. He also gave me Rs. 1000 for the visit. I think it was God’s way of letting me know. I went and met the doctor at his private clinic. He did not charge me anything for the visit after he heard my story. He asked me to go to GMCH. At GMCH, I consulted another doctor who told me that after the operation my condition might get worse and I may not be able to do anything at all. I got very confused at that time. What if my condition gets worse? I thought like that. But Dr. Kalita said that I must go ahead with the surgery as my hand would become better. I again spoke to the temple pujari about the versions of both the doctors. He said that I must only listen to Dr. Kalita. He told me that the outcome of the surgery would be good, and that I would be able to do everything nicely then. I moved ahead only by keeping faith on him, and my belief on God. I primarily pray to Shiba Baba, and*

> *whatever sufferings I have been through, He has helped me somehow. I have a lot of faith on God. People say that God is not there, that God does not open His eyes. But I believe that God opens His eyes, although it can be delayed sometimes. I spoke to [Kishore] Sir also. He said that he knows Dr. Kalita, that he is a good doctor. One of my colleagues at the office was also operated by him. In this way, I kept my faith on God and gathered my courage to go ahead with the surgery. I was very scared at that time as it was a major operation. I had cried before going to the operation room, thinking what if I do not come out of there alive. At that time no one was there with me to give me support. Ma and Mama [mother's brother] were there, but they were outside… My family had supported me a lot during that time. Ma and my Bhonti have cared for me after the surgery. I was in plaster for three months. The plaster went in a particular way around my body due to which I was not able to remove my clothes by myself. This is why I wore a skirt all the time during that period ... My condition has improved after the surgery. They have fit in some screws on the joints of my shoulders. I did not have any difficulties earlier as such. The way I work now, I was able to work like that earlier also. But at that time I was not able to lift certain objects with my hands, and I was not able to draw water from the well. I do not face these difficulties now. If this has happened to me, then it is because of the blessings of Sir and the pujari.*

As can be seen from above, Jeuti decided to go ahead with the surgery even though she had a lot of inhibitions. According to her mother, Jeuti has been teased so much in her childhood by the boys in the neighborhood, that probably she always wanted a cure for her condition, even though she never said it aloud. So when the opportunity presented itself, Jeuti did not want to let it go, even though there were many risks involved. This, however, would not have been possible without a boost from Dr. Alok Kalita, her employer, Kishore, the temple priest, her support from the family, and lastly, her belief on God.

This section tried to elaborate on the medical and rehabilitative interventions that the study participants had to go through in their initial years. It was found that parents try everything to cure the impairments of their daughters, even though sometimes they may not be so convinced about the outcome. It was also found that usually in their younger years the women found the physical management procedures to be very painful. But as they grew up, they expressed their regret about not paying more attention to their treatment. The family members also seemed to blame their daughters for not being mindful about their treatment, even though they were very young at that time and did not have the ability to understand what was right for them. It was probably due to this regret and also the negative self-image that Jeuti had imbibed through her interactions with other people in the society, that she decided to undergo a corrective surgery in her adulthood to correct the deformity of her hand, even though she was told that it was going to be a major surgery. The study also found that for certain disabilities, the doctors were treated their patients as mere experiments. As her narrative shows, Bandana's condition did not pose any difficulty in her daily living activities. But in spite of this in spite of providing her parents proper counseling about the lives of people with short stature, they made her undergo numerous surgeries and physiotherapy sessions that had a bad impact on her perception towards seeking health in her adulthood.

Secondary Conditions and Experiences of Bodily Discomfort

Persons with disabilities often suffer from the risk of developing secondary conditions. A secondary condition is defined as

> *…an additional condition that presupposes the existence of a primary condition. It is distinguished from other health conditions by the lapse in time from the acquisition of the primary condition to the occurrence of the secondary condition. Examples include pressure ulcers, urinary tract infections, and depression. Secondary conditions can reduce functioning, lower the quality of life, increase health care costs, and lead to premature mortality. Many such conditions are preventable and can be anticipated from primary health conditions (World Report on Disability, 2011: 58).*

In this study, several women reported having secondary conditions-like complaints. While some of these conditions are a result of their primary conditions, others are a result of social causes such as lack of infrastructural barriers or due to even using inappropriate aids and appliances. Many of them have never consulted a doctor about these conditions, due to which they may not be labeled as secondary conditions. Yet it cannot be denied that these conditions are connected to their primary conditions. The following narratives illustrate this point clearly.

As elaborated in Chapter 4, Sobiha was diagnosed with cerebral palsy at the time of birth, after her mother fell down from the stairs in the seventh month of her pregnancy and did not receive any medical support for a few many days. During the interview, her mother revealed that Sobiha also suffers from seizures[139]. She said that when Sobiha was young, a doctor had prescribed medicines for her seizures but did not inform this to her. When her mother started facing financial problems after the death of Sobiha's father, she stopped buying these medicines for her. She said, "*I could not*

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[139] It is very common for children with cerebral palsy to experience seizures (www.cerebralpalsyguidance.com).

even buy milk for her, from where could I buy her medicines?" When Sobiha grew up a little, she started getting seizures. Her mother said,

> *She started getting fits. She falls down whenever she got the fits. We think what has happened to her. She used to shake when she got them… Earlier she got fits in her sleep. When she behaves weirdly then I come to know that she has got fits. When I call her, she does not respond. She just stares at one direction*.

When Sobiha's mother consulted a doctor, he told her that it is because of the medication. He changed her medicines and prescribed her a less expensive one, which she was able to purchase. The doctor told her to give her these medicines regularly as otherwise Sobiha would not be cured. Her mother said that *"Since the last two-three years by the grace of Allah, she does not have fits anymore."* Sobiha's *Mahi* (mother's younger sister) who was present in the room at that time said that there are times when Sobiha does not take her medicines. Her mother said that she is supposed to take the medicines thrice a day, but sometimes she acts 'slightly over-smart' and refuses to take her medicines. To this Sobiha responded by saying, *"I have been having medicines since my birth. From my childhood. Every time it is very irritating. That is why I do not have the medicines.*"

At that time, her mother also shared that her younger daughter who was pursuing her Higher Secondary education from a prestigious government college at that time, sometimes also got seizures. Her mother said that when she was in class 8, one day she fell down at the junction on the way to her tuitions. Some of the passersby helped her during that time by sprinkling water on her face. When her mother and other relatives reached the spot, they immediately took her to an *ojha* who did some *zara-phoonka*[140] and gave her a *tabeez*[141] to wear. After a few days she had another fit. At this time the people from the neighborhood said that this could be because of lack of proper nutrition, and asked her to have nutritious food. Few days later she fell down again and this time Suchismita took her to GMCH and consulted a doctor. The doctor did a few tests and said that her younger daughter is physically weak and she is also 'not normal'. He also said that because the age gap between Sobiha and her sister is

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[140] *Zara-Phoonka* can be roughly translated to the English word 'incantation', that is, a series of words said as a magic spell or charm. Several research participants had noted that this practice relieved them of some of their conditions, such as pain.

[141] *Tabeez* (*ta'wiz* or *tawiz* in Urdu) is an amulet or locket that is worn by some Muslims to protect themselves from the evil. It usually contains a small paper with Quranic verses or other Islamic prayers and symbols written on it.

only one year, her sister is also suffering from seizures[142]. From that time, Sobiha's sister is also having the medicines. Her mother said that the medicines have several side effects. Sobiha's sister has gained a lot of weight since the time she started taking the medicines. She also feels very sleepy and is not able to concentrate on her lessons. It is because of these reasons that sometimes she does not take her medicines, and if she continuously skips it for three days or so then her condition deteriorates and she gets her seizures again. Her mother said that sometimes she gets so frustrated with her daughter that she ends up beating her.

> *Sometimes I cannot tolerate it. I hit her hard one day. She was getting her fit on one side and I was beating her on the other. How can I see all this? Have the medicine, whatever it is. I bring her the medicine after so much difficulty. She is supposed to have it. But she does not have it because she feels sleepy and is not able to concentrate on her studies. She says I get very sleepy that is why she does not have it. I tell her to think about her life.*

From the above narrative it can be seen that both Sobiha and her younger sister hate to take the medicines for their seizures. While Sobiha sometimes skips the medicines because she does not like to take them, her sister sometimes skips her medicines because she has gained a lot of weight on the one side, and because the medicines make her sleepy which makes it difficult for her to concentrate on her lessons. The narrative vividly shows how their mother is worried about both her daughters. She gets especially angry when her daughters refuse to take the medicines despite the struggle that she goes through to buy them.

Like Sobiha, for several of the research participants, visiting doctors had become a part of their lives from a very early age. This has had a deep influence on how these women treat their health conditions as they grew up. Some of them, for instance, have developed specific dislike towards hospitals, doctors and medicines, and prefer not to take medicines for minor and sometimes even for major conditions. As cited in Chapter 5, Gargi's parents came to know that she has a disability when she was not able to stand or walk till the age of two and half years. When they took her to a doctor in GMCH, he said that Gargi is 'like this' since her birth. He gave her certain medications, but according to her mother, she could not be cured. When biomedicine did not work on her, her mother and other family members took her to an *ojha*, who

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[142] Siblings of children with seizures have a slightly higher risk of developing seizures than others because there may be a genetic tendency in the family. It is more likely to occur if the sibling has generalized seizures and not partial seizures.

‘nicely’ massaged her body, but again she was not cured of her condition. Her mother said that the doctor at GMCH advised her to do a few exercises for improving her muscle control. When her mother did not see any improvement in Gargi’s condition, she gave it up completely. When she grew up a little, she constantly complained of pain under her arms. One of her school teachers told her mother about a neurology doctor in GMCH. Her mother took Gargi to his private clinic in Guwahati for consultation. He gave her medicines for a year and said that she would have to take these medicines till the time she gets better. Gargi said,

> *He gave so many medicines. Sooo many!* [With emphasis]. *The medicines were sooo big. Who would have them? My Aita said you do not have to have these medicines like a cow.* [She laughs]. *She also scolded Ma for giving me those medicines. The tablets were so big. I had them for a few days, but after that I threw them away.*

Her mother said that after a point when they realized that the medicines cannot cure her, they just stopped taking treatment. Gargi did acknowledge that having those medicines helped her in relieving her body ache. She realized it only after stopping the medicines because of which her body ache started again. As cited in Chapter 5, Gargi suffers from the body ache all the time because she has to be carried to the main road by her mother every day in order to enable her to go to school. In return, her mother also suffers from severe chest pain. But in spite of their difficulties, neither of them had talked about discontinuing education as they realize its value for her future. Her mother further said that sometimes when Gargi finds the pain to be unbearable, she gives her painkillers, but makes it a point to not give it every day, keeping in mind its side-effects.

This narrative shows the important role that architectural barriers play in heightening the problems faced by persons with disabilities and their family members. It is also important to note here that because Gargi and her mother occupy a marginal position in the family after the death of her father, they have not been able to do anything about this barrier, and consequently the discomfort that both mother and daughter face on a regular basis.

Many of the participants talked about suffering from pain especially during the winter season, or when they engage in strenuous activities, but at the same time they avoided taking painkillers as much as possible either because they hated having medicines, or by keeping in mind the side effects of these medicines. Surabhi said that in the winter season, when it is very cold, sometimes she suffers from excruciating pain in her impaired hand. During such periods, she does not prefer to go to a doctor because, "*Since childhood I have been taking medicines. Now I am scared to go to a doctor"*. Instead when she suffers from pain she takes bath with warm water, and feels better. Similarly, Anamika also complained about having pain in her impaired limb in the winter season. However, after her terrible experience at the hospital in her infancy, where a nerve was severed by an inexperienced doctor, she does not prefer to go to a doctor. She said,

> *I suffer from pain in my legs only in the winter season. When it is cold, and I use too much cold water, then it pains at night. I also had such pain in my childhood. At that time my Burhi Aita massaged my leg. After that it did not pain. As I grew up, I did not have this pain at all. But now it has started again because I have to walk so much to come to the office or while going for fieldwork. I need to walk for 4 km to the bus stand every day, and then another 4 km in the evening… There was this one time I had gone to an Ojha. Actually I had sprained my ankle while walking. The sandal was slippery. It got swollen after that. So I went to an Ojha. He did some zara-phoonka with rice and some other substances. After that I felt better. It did not swell anymore. Earlier my bone had swollen. I was not able to come for work during those days. It was paining a lot. If there is a fracture or a sprain, if you immediately go to the Ojha, then it gets better. I had gone to him just one. He is no more now… Everyone in our village used to go to him. I had heard a lot about him. That is why I had gone to him.*

From the above narrative it can be seen that Anamika's pain has aggravated because of the lack of public transport in her village. As a result, she has to walk for 8 km every day to reach the nearest shared-auto stand. In spite of her difficulties, Anamika prefers to go to an *Ojha* than to a doctor because of her earlier experiences at the hospital. She further said that now when she experiences pain in her leg, she does not massage it. She just presses it a bit and continues with her work. She also cannot use hot fomentations because, she said that she has high pressure and feels hot very soon. From both Surabhi and Anamika's narratives it is clear that they suffer from pain especially in the winter season. But despite their difficulties, both of them did not prefer to go to doctors and tried to find a solution in their own ways. When I asked Dr. Basumatary about this, he said many people especially from the villages, do not come to the hospitals for pain relief in the initial stages. He said,

> *In the initial phase when people suffer from pain, what they do is that, if it is a village area, they go to a local quack, then they do many things there. What happens there is that they get instant relief, but in the long run their pain increases. Their condition gets aggravated due to all this. In such a condition they come to us for treatment. One good thing about pain is that they feel uneasy because of this. Due to this reason they*

> *show us comparatively early. That is why treatment for pain is not so bad when we explain things to them.*

Dr. Basumatary's narrative shows that due to lack of awareness people do not generally prefer to come to the hospitals in the initial stages itself. However, from Surabhi and Anamika's narratives it is clear that it not always lack of awareness that hinders them from coming to the hospital, but sometimes their previous life experiences that force them to increase their threshold of enduring pain so as to not visit a hospital facility, a setup which they have grown to hate over their life-course.

Dolly also said that she experiences pain on her amputated hand, especially on very cold days during the winter season. She had consulted a doctor regarding this who told her that this is a side effect of amputation which would remain, and asked her to take painkillers when she finds the pain to be particularly unbearable. Dolly, however, refuses to take these painkillers, and instead ties her hand with a rope or sometimes hits it hard in anger and frustration. She said that if her hand pains more after this, she bears it. Sometimes she also sits in front of the fire, which brings slight relief to her hands, but most of the times she tries to bear her pain.

When I asked Dr. Satish Chaudhury about this, he told me about the *phantom limb pain* (PLP) that people with amputated limbs suffer from. PLP[143] refers to the ongoing sensations of pain that seem to be coming from that part of the limb that has been amputated. This pain often starts soon after the surgery and can feel like a variety of things such as burning, twisting, itching or pressure. It is assumed that nearly 80 percent of the amputee population worldwide has experienced this kind of pain (www.amputee-coalition.org). The length of time that a person suffers from PLP varies from individual to individual. It can last from a few seconds to a few hours, and even for a few days. For most people, the pain diminishes in both frequency and duration during the first six months, but many continue to experience some level of these sensations for years (Ibid). PLP is very difficult to treat, and most people who suffer from this kind of pain find relief by taking high-strength painkillers or other medications which unfortunately come with a host of side-effects (www.hortonsoandp.com).

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[143] The exact cause of PLP is unknown . However, it appears that the pain originates from the spinal cord and the brain. During imaging scans such as MRI and PET scar, it is seen that portions of the brain that had been neurologically connected to the nerves of the amputated limb show activity when the person feels this kind of pain (www.mayoclinic.org).

Like Dolly, Hema had also undergone an amputation of her leg after several years of suffering from the infections of a punctured wound. During the interview she mentioned that she suffers from a lot of pain in her arms and both her amputated leg and her *bhaal bhori* (good leg). She said that the pain in her arms is because she uses crutches for her mobility. She also suffers from pain in her *bhaal bhori* because it has to compensate for the amputated leg and in the process it works far more than it can. According to Dr. Chaudhury, persons with disabilities require more effort to do the same work that others do, due to which they suffer from muscle degeneration and muscle pain. This can also happen when they use mobility aids such as crutches as some muscles may get eroded in their underarms, which leads to pain. According to Dr. Chaudhury, "*no matter what is done to cure their disabilities, persons with disabilities remain handicapped in certain ways*". Hema also said that her amputated leg does not usually have any pains, but in winters it pains a lot. She feels a kind of sensitivity in that area when she feels cold during winters. She said that in such times she puts a bandage in that leg. When I asked Dr. Chaudhury about what can be done about PLP, he had mentioned that using prosthetic limbs can reduce the pain. This is because of their contact with the amputation site which improves blood circulation by stimulating the nerves. Additionally, strategic bandaging and using shrinker socks also helps in alleviating the pain as they apply even pressure on the remaining limb (www.hortonsoandp.com). During the interview, Dolly had mentioned that she uses a prosthetic hand sometimes to reduce the visibility of her impairment, but due to the pain she suffers from while using it, she does not use it for a long time. Similarly, Hema was also advised to wear a prosthetic leg by her doctor. But she found it very painful, because of which she stopped wearing it completely. According to Dr. Chaudhury, a good quality prosthetic limb would not cause pain for the person with amputation. Jibon Narzary from a renowned artificial (lower) limbs unit in the Kamrup (Rural) district also reiterated this. He said that people only complain about pain in the initial stages. At the unit they make it a point to explain to the beneficiaries about the benefits of wearing the artificial limb. He said that once they start using the artificial limb, they feel the happiness that they are able to walk on their own again, without being dependent on anyone. It is, however, important to note that many of the participants are not able to afford good quality aids and appliances and so get them for free from different meetings organized either by some government body or by disability organizations. Suchismita had said that initially her organization, Sanjeeboni, had distributed aids and appliances through the support of the ALIMCO[144]. But they soon realized that the quality of their products is very low and that is why they approached the corporate sector, which according to her has been providing good quality aids and appliances since the last few years. She further said that the people of the Block under the jurisdiction of Sanjeeboni have very good access to aids and appliances. This, however, is not the case for people who are not associated with such kinds of organizations as they have to depend on either the benevolence of someone to buy them good quality aids and appliances or have to rely on the ALIMCO manufactured aids and appliances.

Nayana also complained about problems that she faced while using aids and appliances. As mentioned in Chapter 5, Nayana uses a wheelchair for mobility. She said that earlier she had used a low quality wheelchair that her father had got from somewhere. She said that it was very hard for her to maneuver it and often experienced pain and swellings in her arms. She then requested the Executive Director of Senehi, Zohan Hussain, to buy her a good quality wheelchair. Nayana said that he then got her a new wheelchair from Russia, after which she does not face this difficulty anymore. However, she complained about another type of problem from using the wheelchair for long hours, which is that of pressure sores[145]. During the interview with her, she stopped for a while to speak to Rekha, the special educator at Senehi, who was passing by the hallway at that time. Nayana complained to her that she had two pressure sores at the same spot like earlier and this was making it very painful for her to sit down. Later she told me that her difficulties with these sores increase manifold in the summer season when she needs to sit in her wheelchair for long periods of time at the organization, while she is wet from sweat in the inside. According to Dr. Basumatary, this is a very common problem among wheelchair

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[144] Artificial Limbs Manufacturing Corporation of India (ALIMCO) was established by the Government of India in the year 1972 as a 'Not for Profit' company with the mission to empower persons with disabilities and restore their dignity by way of manufacturing and supplying good quality aids and appliances in order to promote the physical, psychological, socio-economic and vocational rehabilitation of persons with disabilities.

[145] Pressure sores, also known as bedsores, is a problem that many wheelchair users face. These sores are caused when the blood supply is cut off from a particular area of the skin. If the skin is under pressure for continuously sitting in a wheelchair in one specific position, it results into such sores. Pressure sores are also caused when the wheelchair seat is not comfortable or if the weight of the wheelchair user is not evenly distributed. Pressure sores are one of the most common ailments that result from mobility issues and can lead to severe consequences with respect to hygiene and health of the sufferers (www.myfrido.com).

users. He said that as doctors they advise their patients to use soft cushions to avoid this problem. In Nayana’s case it is seen that she did not pay attention to this advice because for her cushions are a luxury that she had to do without.

Appropriate aids and appliances play a very important role in the physical rehabilitation of persons with disabilities as they enable a them to perform tasks that would have been impossible otherwise (Klasing, 2007). From the above narratives, however, it is clear that using aids and appliances can also create certain physical difficulties for them. Similar difficulties were also seen in my study on women with locomotor disabilities in Delhi-NCR (Sarma, 2014).

Several research participants also complained about falls, which aggravated their physical conditions even further. The following narratives give a glimpse of this.

Risha said that when she was young, a doctor had warned her parents that she might suffer from backache in the future as due to her gait, her spinal cord has been twisted. Risha said that even though she remembers having backache every now and then, it was never very severe. However, two-three years before I had conducted the interview with her, she fell down in the backyard of her home. She said that she had gone down to see something. While climbing up the stairs she lost her balance and fell down. After her fall, her parents took her to a private hospital where the doctor told her parents that she would require a spinal cord surgery. Her parents then went for a second opinion. The second doctor said that she can be cured with the help of medicines and certain exercises, so they decided to stick to it. She said that she had also consulted a doctor in Kanpur while visiting her brother who lives there. This doctor also told them that surgery is not required. Risha reported feeling better after taking some medicines and did not consider it necessary to go for the surgery. She said that immediately after her fall, she used to take painkillers almost every day. But now she has reduced its intake considerably and only takes them when she finds the pain to be especially unbearable. She said that now she can live up to 15 days without taking these painkillers. Risha also mentioned that this fall has changed her life considerably. Before this incident, she had joined as a Junior Project Assistant in the Disability Law Unit of Senehi. She was not able to sustain her job after the backache started as she could not sit for long hours at a stretch. She stayed at home for a few years, and then joined the newly introduced ICT programme at Senehi. This is in spite of the fact that she knows the basics of computers which is taught in this programme, but prefers to go for these classes nonetheless, in order to avoid boredom at home.

Like Risha, Ananya also faces problems in balancing her body weight and talked about constant pain in her left leg and back. She said that this pain had started after she slipped and fell down in the bathroom a few years ago. Ananya had informed her parents about her difficulties, but they have not taken her complaints seriously. She said,

> *I have not consulted a doctor regarding my problems. I have spoken to Ma and Papa about the pain. They said that it is nothing. They told me that it is paining just like that. What can I say? That is why I slowly massage these areas with Volini. I am just living like this. The pain reduces when I use Volini. But it starts again when I stop using it… I apply Volini every night before going to sleep.*

From the above narratives it can be seen that even though both Risha and Ananya suffer from constant pain, their respective families have not done enough to alleviate their sufferings. One of the reasons for this could be that their parents probably realize the futility of visiting a doctor, as they have understood that the pain would remain no matter what. While Risha did not complain about her parents, Ananya seems to have a very dejected outlook towards her parents as they do not take her physical sufferings seriously.

In another case, during my first meeting with Suchismita I had asked her if her physical problems have aggravated with age. She said,

> *Yes my problems have increased. I came to know only much later, that polio affected people should wear calipers. As there is such a risk of falling. I have broken so many of my bones in my right leg, the polio affected leg. Due to polio, the bones become very brittle. I just had a fall recently and I had to be operated. Plates and screws are here now* [she shows me her calf muscles and upper outer thighs]. *It was a very light fall and yet I had to go through the operation. My bones are so brittle now.*

In the book chapter on her life, Suchismita had mentioned that she has undergone seven major surgeries on her polio affected limb. She also lamented not wearing calipers in her youth because of which, she feels that her bones have become very brittle. As mentioned in her narrative, even a light fall sometimes leads to broken bones and she has to go for a surgery in order to cure it. She also said that over time she had become so frustrated with her falls that she decided to consult a *gonok* with her horoscope to ask if everything was alright. She said that the *gonok* had told her that there is some *dux* (defect) in her horoscope and had recommended her certain ways to undo it.

From her narrative it can be seen that even among the more educated and successful women, the problems with regard to their bodies can sometimes be so frustrating that they begin to think that there must be some defect in their horoscope and feel that consulting a *gonok* would help them in lessening their physical problems. In the case of Suchismita particularly, this is problematic because she is no ordinary woman. She is the founder of a disability organization that is working in two different rural Blocks. In these Blocks she often gives lectures to distressed parents and young persons with disabilities against having superstitious beliefs. But if she herself does not practice what she preaches publicly, then surely it is very problematic.

In this section I have tried to show the secondary conditions that women with disabilities suffer from. It was found that most of the women had secondary conditions-like complaints, but since most of them had never consulted a doctor about these, it is problematic to label them as such. However, it cannot be denied that the women suffered from multiple physical problems. While some of these problems were related directly to their physical conditions, others were physical conditions that were aggravated due to the accessibility problems faced by them. In spite of their difficulties, most of the women were reluctant to consult doctors for their conditions, due to their past experiences of treatment. During the interviews with doctors, however, most of them talked very objectively about the conditions of their patients, as if their problems were only caused by the physical condition and not by the environmental barriers. Due to this reason it is imperative that, despite its flaws, healthcare providers must be aware about the social model of disability and the kinds of difficulties that persons with disabilities face due to the physical barriers present in the society.

Other Health Problems

As cited in the beginning of the chapter, apart from impairment-specific conditions, persons with disabilities also utilize the health services system for conditions that are not directly related to impairments. This section elaborates on the general health condition of the research participants. Most of the research participants mentioned that despite their impairments, they were relatively very ‘healthy’ in their childhood. The following narratives give a glimpse of this.

Surabhi said that she has never suffered from any major health issues since her childhood except for cold and mild fever. Her only problem at the time of the interview was that she has gained a lot of weight and has a very huge belly. She said that because of this reason she is not able to fit into her old clothes. Uma also said that she did not suffer from any sickness in her childhood. She said,

> *Ma used to say, whatever God has given you* [her impairment], *maybe because of your leg you do not have any other sickness. She used to say like this to me. I had no sickness when I was young.*

However, this has changed according to her, after the birth of her son through Cesarean Section.

> *After the birth of my son, I have been falling sick, one after another. I have toothache and I have very severe headache when I go out in the sun… I do not go to the doctor for these conditions. My husband gets me tablets, I have those and I feel better. I am scared of going to a doctor. I feel that if I go there, he will administer an injection. I feel like that. I have never taken an injection since my childhood. Before Babu*[146] [her son] *was born I had not even taken an injection. I had taken injection only at the time of my Cesarean.*

Similarly, Minakkhi’s mother also said that by the grace of God, her daughter has never faced any major illnesses in her childhood except for mild fevers and coughs. In a separate interview, Minakkhi, however, said that about 5 years before the interview, she had to visit GMCH due to stomach ache. She said that at that time she was not admitted at the hospital, but visited the hospital from her cousin’s home who lived nearby. She said,

> *I had severe stomach ache during that period. I had to do an ultrasound. I took medicines and stayed in Guwahati during that period. In that way I was cured. It took me a long time to get cured.*

She further said that the treatment cost her lot of money (about Rs. 2000-3000) but she did not face any difficulty in paying for it as she had saved up the amount for her treatment. She also said,

> *The doctors were very good to me. They told me that they would check my hand and operate it. I told them that I do not want to operate it anymore* [she laughs].

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[146] Babu is not the same of her son. All young boys are referred to as Babu in Assamese.

From the above narratives, it can be seen that most of the research participants were ‘healthy’ in their childhood days and suffered from only minor illnesses for which they had taken over-the-counter medicines. As noted earlier, some of these women also feared seeing a doctor because either they were reluctant to have medicines or were scared that they would have to take an injection. It was only in very severe cases, like Minakkhi, when they had no other option, that they gathered up the courage to visit a doctor.

Similarly, Dolly had also refused to visit a doctor for her abdominal pain. It was only when her pain got unbearable and her colleagues insisted her that she just visit a doctor, that she finally gave in. She said,

> *I had gas and fever. Everyone told me that it is jaundice. When we showed to the doctor, he also said that it is jaundice. Simultaneously, I had also gone for zara-phoonka. There is a woman near my house who does zara phoonka. My family took me there for treatment. She used mango leaves for the zara. I felt very relieved after that. I was cured of this problem. Later when I went to the hospital, they said that I have gas problem. Actually it was a tumor, it was very small at that time. We only came to know about it when it got bigger… One day I had severe stomach ache. Usually if it pains, I do not tell anyone. I keep quiet about it. When I have the pain I do not tell anybody. It is only when I cannot control it, that I tell others about it. That day I was sitting with my coworkers, when my stomach started aching. I was not able to do any work on that day. I told my colleagues please weigh the packets for me. Then one of them told me, you have stomach ache for a long time. Why don’t you do something about it? I said no what is there to go to a doctor for such a small pain. She said no you will have to go. There was another boy, both of them took me to a* [private] *hospital in Aathgaon after work. The doctor asked me to come back the next day without eating anything. When I went there the next day, they checked me and said that I have a tumor in my uterus. They told me that I have to do an operation for that. I was very nervous. The doctor had not told me anything, he was hesitant to talk to me. I told him, Sir I have the strength in me. Please tell me what is wrong. He then told me that this is the thing. He helped me during that time. Thankfully I have the ESI card that is why I was saved. I was admitted at the Beltola hospital immediately.*

Dolly said that she had gone through the operation about 3-4 months before the interview. She further said that the behavior of the doctors in the ESI Model hospital towards her was very good. All of them gave her a lot of attention. She also liked the fact that they sympathized with her for not having a hand. She said,

> *All the doctors gave me a lot of attention. They said you are such a young girl and you do not have a hand. And in such a young age you also got this tumor. They behaved really well with me. I have been to many places before this, but I have never found such good behavior.*

The above narrative shows that in certain cases even though the women are suffering from excruciating pain, they do not want to acknowledge it and consult a doctor. Even though Dolly was suffering from severe pain, she trivialized her suffering and was reluctant to go to a hospital for consultation. It was only because of the insistence of her colleagues that she went to the hospital where it was found that she had a tumor. The narrative also shows how having the ESI card saved her from the financial burden of her treatment. She was also very grateful to the doctors for behaving nicely with her because of which even for once she did not feel as if she should not have come for the treatment.

In certain cases, however, it seemed as if some doctors were reluctant to speak to the women about their health problems. In the previous section we had discussed about the aggravation of Risha's condition after her fall. During the interview with her she said that in the initial days, the doctor never spoke to her directly, but instead spoke to her parents. She said,

> *Doctors mostly spoke to my parents. They do not usually know if I would be able to understand or not. Some doctors do not have such kind of knowledge, whether I would be able to understand them or not. That is why, they sometimes do not talk to me directly. But there are some doctors who talk to me directly. Like my present doctor, who is looking after my back pain, he talks to me directly. He speaks to Ma also, but he also speaks to me directly.*

During the interview, Risha seemed to be so used to being talked-about, than being talked-to, that she did not seem to care whether the doctor was talking to her or her parents.

Some of the women said that they face certain physical difficulties because of the kind of work they have to do. Like most of the other research participants, Anamika also said that she has never fallen sick in her childhood. However, she said that she has started facing certain health problems after she began to work for Sanjeeboni. She said,

> *I have gastric and headache. Few days back I had a severe gas and headache. I had to buy tablets for it. When I come to the office or go to the field* [for the organization's work], *I cannot have proper food. That is when I have severe abdomen pains. Even if it pains a little, it feels like it is paining a lot. I need to roam around in the sun. When I stay at home, I do not take medicines. I drink only water and try to subdue my gastric. When I have gas, my head also starts to ache. These are my only problems, I do not have any other problems.*

Similarly, Minakkhi also talked about her occupation related health problem. Minakkhi has been working as a weaver at Sanjeeboni from 2015. During the interview she said that, since the past one year, she has suffered from a persistent headache and body ache. She has also started having problems with her eyesight. She thinks that her problems have started because of sitting in the handloom for too long, as these problems have only begun since the time she had started working for the organization. Few weeks before the interview, she had consulted an ophthalmologist in a private clinic near her home in the Joonaki Block and she has been prescribed to wear eyeglasses. Since the time she has started wearing the glasses, she said that she does not suffer from headaches anymore.

The above narratives outline the kind of problems women with disabilities face as a result of their work. Bandana had discussed about her gynecological problems because of which she was consulting a folk healer. She said,

> *I have abdomen ache related to my periods. I have been taking medicines for it, but I did not get cured. According to the doctor some nerve has been blocked. She had asked me to go for a surgery. But he* [husband] *does not want me to get an operation. He said no need to go for an operation, let's see if it gets better with gaoliya dorob* [folk medicine]. *Now I am taking gaoliya dorob. The ojha told me that I will get better with his medicine. I have had the medicine for one whole month. It is like small tablets. But I have not been better. The ojha has asked me to come again. He said that he will do some zara-phoonka with river water. But I have not been able to go. Actually it is so far from here. It is in Haju*[147]*. That is why I feel lazy about going there. In order to go there, I will have to close my shop. It is very hard. It is also so hot these days. I find it very hard to go there in this climate… If it does not get better with the gaoliya dorob, then I will have to go for an operation.*

From the above narrative it can be seen that Bandana's husband was not keen about having a surgery, and because of this he suggested that she must try folk medicine instead. During the interview, it seemed clear that she was not much convinced about this modality of treatment. Yet she did not say anything because perhaps she herself was also reluctant to go for the surgery keeping her past history of surgeries into consideration.

The above narratives have discussed about the physical problems that the women were facing. Some of the research participants also complained about psychological issues. When I asked Nayana if she has any other health conditions, she said that she had not slept for two weeks, and has the problem of sleeplessness. In her words,

> *Since childhood, I sleep less. But since the last few years, five years to be exact, my sleep has lessened a lot. I haven't slept since the last two weeks. I have kept my eyes*

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[147] Haju is an ancient pilgrimage centre for three religions, Hindus, Muslims and Buddhists. It lies on the banks of the River Brahmaputra, and is located about 24 km from the city of Guwahati in the Kamrup (Rural) District.

> *open. Today I have slept a bit. I did not feel like waking up and coming here today. But then I remembered that I have to meet you* [she laughs]. *I thought that if I do not come it would be a bad thing, since I had already told you. That is why I came here today. My eyes are burning now.*

When I asked her if she had consulted a doctor about her insomnia, she said,

> *I have, but they are not able to diagnose anything. They gave me sleeping tablets. But if I take sleeping tablets, I face a lot of difficulty. I feel like sleeping all the time. How many days can I sleep like that? And the medicines are so powerful that my head starts to spin. I had medicines for a few days, but after that I just left it. I am scared of having the medicines now. My hemoglobin level is also less, which is another difficulty.*

Nayana then narrated about what had triggered her sleeplessness.

> *When I was young I had a very big sickness. Actually Deuta had gone to a different place to work. I did not see him for about a month. When so many days passed like that, I got very tensed. Why is Deuta not there with me? I had this tension. I did not eat anything for some 3 or 4 days. Then I fell sick. I had to take drips. I only cried during that period. I kept on asking Ma, when Deuta would be back. At the end our landlord, he went and brought back Deuta. He said that your daughter is in this condition. When Deuta finally came back, my eyes had swelled up so much. It was raining heavily on that day. Deuta took me to the hospital. There were no beds available there. Then somehow I got the drips and I became alright. This happened because I had not eaten anything. I used to think what would happen now that Deuta is no more with us… I loved Deuta so much. Ma tried to explain to me, but I was not able to understand anything. This was the biggest problem for me. Deuta passed away 5 years ago, and since that time I have not been able to sleep properly.*

When I probed further, she said,

> *I have mainly lost my sleep after the death of my father. Now even if there is a big storm, I feel scared. Earlier I was not like this. I was not scared of anything. I was not scared of anyone. I was like that. If someone said something to me on my face, or even behind my back, that person cannot be rescued from me. I was like that. But now why I have changed I do not know. Since Deuta passed away, there is some kind of worry within me. I have not been able to bear his loss. I have sleeplessness because of this. Actually I was very close to Deuta.*

When I asked her if she had gone for counseling for her problem, she replied,

> *What will happen if I go to a counselor? I loved Deuta, what can others do about it? That is what. I cannot express these things at home. If I say, Ma is very emotional. If I am emotional, it means everyone else at home would be emotional. So I have not consulted anyone… I share my thoughts and feeling with everyone. But the fact that I am missing Deuta, I have not said this to anyone. Neither to Bhonti nor to Ma. If I talk about him, I generally laugh and say. I cannot show that I am emotional. If I show it, others will break down more than me. I know this. Everyone is very weak emotionally. I was the only one who was strong, but this strength has now decreased within me. Others are not aware of this.*

The above narrative shows that even though Nayana suffers from insomnia and knows the exact reason behind its cause, she has not been able to do anything about it. During the interview, it was clear that her father was her biggest source of support, and after his death, she has a kind of fear that the others close to her would also move away from her, leaving her alone. As cited above, she has not been able to talk about her problems either with her mother or her sister because of the fear that they will be crushed by this news. Although Nayana had taken sleeping pills for a few days, she does not consider them to be a good option to solve her problem. She also complained about having physical difficulties after taking those pills. In spite of these difficulties, she has not considered going to a counselor as she feels that s/he would be incapable of handling such an issue as no one else can understand her love for her father.

In contrast to all the other research participants, Korobi's life history is very different as she had suffered not one, but two different disabilities, at different points in her life. During the interview with her mother, she said that by the age of 15-16 years, Korobi was completely cured of her previous health problems. She was able to walk straight without any difficulties. But when she was about 18 years old, she suffered from a burn injury that caused severe pain and anguish for Korobi and her entire family. She said,

> *When Korobi was about 15 or 16 years old, she was able to walk like earlier. Dr. Mohan Bora from* [Assam Medical College] *Dibrugarh had completely cured her leg. Gradually she was able to walk straight. And when she was getting better, one day suddenly she suffered from a burn injury. It was in the evening of 31st December, 1982. Everyone was watching some programme on TV. Everyone was making a lot of noise. Every now and then she was coming inside to her room. I told her do not come inside, sit with everyone and watch TV with them. She was very restless and was not able to sit down. I wondered what happened to her. It was my Baideu's* [elder sister] *daughter's wedding in a few weeks. She had given me some clothes to stitch. I was inside, stitching those clothes. She went to the kitchen and tried to light up the dhuna*[148]*. There were a lot of mosquitoes at that time. She had asked the kaam-kora-suwali* (live-in domestic worker) *to light it for her. She told Korobi that she had done it already, and there is no need for doing it again. She was also watching TV. This made Korobi very angry. So she went inside the kitchen and tried to light up the dhunar mola*[149]*. It was our bhagyo* [destiny] *that she tried to light up the dhuna near the gas cylinder but it did not burst. She had used many narikol bakoli* [coconut skin] *for the purpose. She used a lot of dhuna also in it. While lighting it some of the narikol bakoli got stuck to her clothes. She was wearing a polyester skirt without*

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[148] *Dhuna* (resin) is an organic extract which is believed to have medicinal value as its fragrant smoke is extensively used to get rid of mosquitoes. Unfortunately, its use is rather limited now, due to the availability of different mosquito repellents in the market.

[149] *Dhunar mola* or *Dhunadani* is an earthen vessel to burn resin. *Dhunar mola* has been an integral part of Assamese (and Bengali) culture till about a generation ago.

letting anyone know about it. That skirt was given to her by one of her Pehi, who brought it from London. It was a very beautiful skirt. I told her do not wear it at home, you can wear it when you go out. Anyways people are not supposed to wear clothes made of polyester at home. So she used to wear it like a petticoat under her other clothes. Because of that material, the burning skirt got stuck to her skin. We were not able to remove her clothes… There was a corridor. The windows were open. It was very windy that night. She came running out of that corridor. I saw that someone was burning. I saw her and I felt something. I saw that a woman is running; she was wearing something long. She also had a shawl wrapped around her. The fire was coming up and she was standing amidst the fire. I saw her from a distance and I fell down. There was a mat near me. When she came closer to me, I covered her with that mat. I was not able to find a blanket to cover her at that time. I covered her with the mat and due to this she had an infection. It was covered with dust… The neighbors saw the fire and they started shouting. It was at the time of the Andulon [Assam Movement]. *Everyone thought that the fire is related to the Andulon. Many homes were set ablaze during that time. So our neighbors went out to see what has happened. As a result, there was nobody to help us. At home everyone was watching TV, and there was a lot of noise because of that. So no one heard anything. We were a joint family at that time. We were a lot of people. One of our neighbor's sons saw the fire and informed their Deuta when he was coming back from the market. He was not ready to believe that it was our home. In the meantime I pulled her from the corridor to the verandah so that someone could see her. I pulled her and made her lie down on the floor. By that time the fire had almost burnt out. I was working with a pair of scissors; I could have cut her clothes with it. But I was not able to think at that time. I was not even able to find a blanket. I had taught them these things, but at that moment I forgot everything. If I would have cut out her clothes from below, the fire would not have gone up. At that moment I did not have the sense to do all that. I also fell down. My hand was burnt a bit. After sometime everyone came running towards us and saw her in that state. They removed their shoes and with their socks they tried to burn out the remaining fire. There was one relative, he was a doctor, he poured water all over her and took her out in his arms. Her skin had come out from her body and was hanging like clothes. No one allowed me to go anywhere near her. They all pushed me aside. The neighbors had come to our home by that time, the women had also come. They all pulled me aside and made me lie down on the bed. Her Bordeuta* [father's elder brother] *saw her in that state and developed a heart disease. She was taken to GMCH, her Bordeuta was also admitted there in the next room. Both of them were shouting each other's names. Few days later he even passed away… At the hospital, we were not able to put clothes on her body. Her Deuta had made an iron frame for her. We covered it with a piece of cloth. We kept her like that. She was burnt so much. The outer skin was completely burnt. We could see her insides. Then one new doctor, she was a girl, she said do not leave your legs open. Fold your legs or else your inners will not get dried. When Korobi folded her legs, her thigh muscle and her calf muscle got attached to one another as it was all raw flesh. Korobi was not able to straighten her leg after that. Then they were not able to do anything, and it led to a lot of fuss. Actually she was a new doctor and she felt that folding the legs would help her in healing faster. After this incident they asked us to take her away from GMCH. That doctor was very sad. Whatever it is, she did not do it knowingly. There was no point in being angry with her at that time. We just had to think about curing her… Gradually her condition started to deteriorate. The doctors at GMCH asked us to take Korobi to Safdarjung Hospital in Delhi for treatment. They said that we cannot do it here, and the chance of her survival is less. Then one doctor saw her and said that she is not in a condition to be taken to Delhi. Then they asked us to go to* [Assam Medical College] *Dibrugarh. They said that the doctors there would be able to deal with her case. She also required skin grafting, which the doctors at GMCH said they would not be able to do. So we took her to Dibrugarh for this. Their*

> *father was in the police force. The DIG gave us a car and said that take her to Dibrugarh immediately. She was not in a condition to travel by train or flight at that time. We went by that car at night. The doctor was in the car with us. He gave her oxygen and drips all along the way. They drove the vehicle very slowly. If they drive fast, then her flesh would have come out from her body. It took us several hours to reach Dibrugarh. I held her hand throughout the journey. We also faced some difficulties because it was during the peak of the Assam Andulon. But since her father was in the police force, we were a bit relieved. If he was not in the police maybe the protesters would have troubled us also. And the DIG had asked him to travel in his uniform. I think because of this they did not trouble us at all… In Dibrugarh, they pulled out the muscles that had got attached together. She was screaming with pain. They were not able to give her anesthesia. They had to cut her leg when she was still conscious. They had laid a bucket below her, within few minutes one whole bucket of blood had come out. I cried so much seeing all this. I held on to a pillar and cried.*
>
> *Korobi: There was blood everywhere* [she gasps]. *There were about 8 buckets of blood. I fell unconscious beholding that sight. I was very scared.*
>
> *She had to face all these hardships because of that doctor's mistakes at GMCH. She suffered from so many infections. Actually so many people had come to see her there. All her Deuta's colleagues and our relatives were there. Then the hospital gave it in writing not to bring in so many people. Then the doctors went inside her room and gave her injections, not one, but many of them. The infection was spreading, and they were not able to stop it. That is when they asked us to take her away from Guwahati. Whenever I think about these days, I cannot stop my tears from falling* [she said while wiping her tears].

The above narrative shows the kind of turmoil Korobi's family went through during that period seeking cure for her burn injury. Korobi's ordeal with the health personnel did not stop even after reaching Dibrugarh. There also she received 'wrong medicines' from a doctor who was not able to see her in so much pain.

> *Korobi: After I got burnt, I was unconscious for a few days. It took me about 5 days to come back to my senses. I was not able to walk for several months after that. They had to do skin grafting. They had to cut the skin from my hands to put in my legs. There was full plaster in both my legs. They also had to give me blood. Ma gave two bottles of blood, my Pehi's daughter also gave me blood. I needed about 8-9 bottles of blood. And then one of the doctors gave me morphine[150], because of which my condition had aggravated again.*
>
> *Korobi's mother: Actually we had known that doctor. He was Dr. Bora's assistant. When he saw Korobi, he got scared that she has been burnt by fire. He was a doctor from a different department. He was not from the burns department. He got very scared and gave her morphine thinking that she will get better. He saw her screaming with pain. But actually one should never give morphine in burn cases. I did not know about this. After this incident there was a lot of conflict at the hospital. He was not supposed to give morphine without the permission of the doctor from the concerned department.*

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[150] Morphine is a medication that is used for pain relief. It acts directly on the central nervous system to decrease the feeling of pain.

From the above narrative it can be seen that both Korobi and her mother consider the drug morphine to be dangerous in the case of burn injuries. However, in the literature on pain management for burn injuries, it is seen that morphine must be quickly and aggressively administered to a patient with burns injury, intravenously (www.nursingcentre.com). There was probably some other complication in her case, that they forgot to throw light on during the interview.

Korobi's mother further said that for one whole year they had to live in Dibrugarh for her treatment:

> *Korobi and I stayed in Dibrugarh for one whole year. During that time, I took care of everything. The doctor had asked me to give her baths for 4-5 times in a day. But she did not like taking baths. I used to take her to the bathroom in a stretcher and poured water all over her. I gave her baths in the stretcher itself. I could do it only 2-3 times in a day. I could not do it for 4-5 times. She used to scream a lot and it used to be very exhausting for me.*
>
> *Korobi: I was very scared when she took me for the baths. Whenever she did this, my heart started to beat fast. I was 89 percent burned.*
>
> *Korobi's mother: I was in Dibrugarh alone. I had left my other two daughters behind. I felt very bad for them, I was also very worried for them. But they used to say do not worry about us; we would be able to manage… Her Deuta was with them. He was busy with his work. We had a kaam-kora-suwali* [live-in domestic worker]. *She was very good. She was the one who did most of the work at that time.*

All these incidents, however, did not dampen Korobi's spirit. After she got a little better, she was again back to her usual self. Her mother said,

> *Gradually, she started talking a bit. She wanted to listen to music, and asked for a radio. So we gave her a transistor radio. She used to listen to songs in it… From her childhood she was like her Aita, she liked to get ready in the evening by combing her hair, putting powder on her face. She liked to look nice. At the hospital also she started doing the same. She asked for lipstick. By looking at her people would not be able to say what has happened to her. Only her upper part was visible, her lower part was not visible during that time because of the iron frame. Everyone who went to see her was surprised. They all said she would get better soon as she had so much willpower. She was in the hospital for a long period of time after this… After she became okay from her earlier problems, she was able to do everything on her own. She was able to make her own bed, she was able to cook food, and she was able to do everything on her own. She was also able to walk on her own. And then one day she also burnt herself.*

The above narrative shows that after Korobi got a little better, she came back to her usual self. During the interview, she also said that after the burns injury she faces a number of health problems. She said,

> *Korobi: I suffer from body ache since the time of my burn injury. The doctor said all the nerves in my legs got contracted due to which my blood circulation is less. My legs also feel very itchy and uneasy. If I apply some oil I feel better… With age my difficulties have increased further. My hands and legs have pain all the time now. Even now I have body ache. And my body and mind feels bad. I have a feeling of depression. I also get scared*

After her burn injury, Korobi suffered from a number of physical problems. When I asked her if she also had any other health problems, she replied,

> *Korobi: I have to complete my dental treatment* [she had several decayed teeth], *and I have to cure my leg. I am not able to bend my knee, and my ankle lifts up when I try to walk. There is also a big gap in my spinal cord. When I was young they did wrong treatment in Calcutta. There is a big gap now. That is why I am not able to walk straight. I need to cure that. I am not able to walk without the walker. I have fallen down in the bathroom many times. I had kept the walker outside that is why. I also have a severe ache in my abdomen. I had cysts. It weighed 2 kilos. But I was cured after having medicines. I have also been coughing a lot lately. I need to go for a checkup for that. And I should not be scared. If I get help for all this, it would be enough ... My treatment continued till about 1998. After that we did not continue with the treatment. There has been a big gap now. That is why I feel that if I get the support from the* [Helen Keller Charitable Trust], *I will go for all the treatment at a go. I will go to GMCH. I haven't consulted a doctor for these conditions yet. After I get the financial help, I would go to a bhaal* [good] *doctor. I had gone to a doctor recently for my backache. He gave me wrong medicines. It all went in vain. Now I have thought that I will not go to him again. I will consult a bhaal doctor from orthopedics department of GMCH…*

From the above narrative it can be seen that Korobi suffers from a number of conditions, and she wants to be cured of them all. Korobi's husband who was present at that time said that she likes to think that she is unwell, even though in reality nothing is wrong with her. He said that they have conducted several medical tests to check her problems, but none of them have shown any cause to worry. Korobi, however, said that she liked to talk about her health conditions. The reason she gave for this is that since her childhood she has been exposed to the health services system. This also makes Korobi different from the other research participants, who usually brushed aside their conditions as not important, unless they suffered from a condition that was difficult for them to ignore. The above narrative also shows that Korobi wants a cure for all her conditions, but she does not have sufficient money for the same. She has applied to the Helen Keller Charitable Trust for financial assistance, but she considers the money she has received from there to be inadequate for her treatment (this would be elaborated in Chapter 8). It is her mother who has paid for all her expenses since the death of her father in the year 2000. Korobi realizes that she cannot depend on her mother for her further treatment and so had applied for financial assistance from the organization. As can be seen from her husband's narrative, her family members feel that sometimes she is over-exaggerating her problems, while in reality she has no health problems as per the medical reports.

During my interactions with Korobi and her family it was also found that she, her mother, her youngest sister, and her husband seem to have a lot of disagreements about her treatments. During the interview, Korobi mentioned several times that now she is completely dependent on her walker and is not able to move without it. She said that it was given to her by her second sister during her last visit from Canada. Her mother and her youngest sister, however, feel that this is her laziness and she must try to walk on her own and also try to reduce her weight as a result of which the difficulties with her legs have increased manifold. They also consider her husband to be incapable of handling her tantrums regarding this and consider him responsible for promoting her lazy behavior. They also seem to have a difference of opinion regarding her psychiatric treatment. The following argument gives a glimpse of this:

> *Me to mother: Do you all face any kind of problems because of her disabilities?*
>
> *Mother: Yes! She is scared all the time. She runs behind everyone* [she laughs]. *That is the foremost difficulty that I am facing. Even if she is not able to walk, she can hold us or she can at least take the support of the walker. But because of her fears, we are not able to leave her and move an inch. Suppose both of us are sleeping together, if I get up from the bed, she would also get up immediately.*
>
> *Husband: If she hears a loud noise, then she wakes up all shocked.*
>
> *Korobi: My heart beats very fast. I feel that my hands and legs are not there. I feel that something would happen to me right at that moment. I feel that I won't be there anymore.*
>
> *Me: Has she been to a psychiatrist?*
>
> *Mother: She had gone. She was taking treatment also, but she left it in between.*
>
> *Husband: She was taken to a psychiatrist. But after taking the medicines she was not able to get up from bed. She was not able to move at all.*
>
> *Korobi: When I took those medicines, I was not able to go to the bathroom. I felt as if my bladder would just burst.*
>
> *Husband: After taking those medicines, she was not able to walk. She was not even able to put her feet on the ground.*
>
> *Mother: She should have been taken to the hospital after about a month. The other woman, she got treated.*
>
> *Husband: Her case is different. She did not have a disability. Korobi, on the other hand, finds it difficult to walk after having those medicines.*

> *Korobi: I was not able to open my eyes, and I was not able to eat anything. I used to vomit everything.*
>
> *Husband: Food was another matter. She could have had juice. But she was not able to walk at all. If a bhaal manuh* [non-disabled person] *is not able to walk, we can hold them and take them. But it is difficult to hold her and take her anywhere.*

The above narrative shows the difference of opinion of all the members of the family regarding her psychiatric treatment. It shows that Korobi's mother is quite resentful of Korobi's husband for readily agreeing with her when she wanted to discontinue her medicines. She feels that Korobi should have been taken to the hospital and these problems should have been discussed with the psychiatrist. Her husband, on the other hand, felt that she was facing so many side-effects of these medicines that it was alright if she wanted to discontinue them. Although they did not have a heated argument, they were both not ready to understand the others' perspective. It also seemed as if Korobi's mother partially held Korobi responsible for aggravating her physical conditions as she never continued with her treatment procedures and never listened to the advice of her elders. As she had said earlier, she feels that excessive love from her family members has completely ruined her life.

Other than these physical and psychological/psychiatric problems, some of the research participants talked about their dental health problems. It was found that dental health was given the lowest priority and dental care was sought only when the women suffered from excruciating pain that made seeking cure inevitable. The following narrative illustrates this clearly.

During the interviews with Ananya, I observed that two of her incisor teeth in the upper jaw, and one incisor tooth in her low jaw were missing. I asked her what happened to her. She said that she had toothache because of which those teeth had to be extracted. She said that she had gone to GMCH for this treatment. I asked her why she did not wear caps for the missing teeth. To this she replied that the dentist had told her that they would call her back for replacing the missing teeth, but they never called her back. Since I never got the opportunity to meet her parents, I do not know if she was never called back from the hospital, or her parents thought that she does not need caps. I also observed that several of the other members of the women with disabilities network of Senehi [some of whom were not my research participants] also had missing teeth. It was quite strange because usually women of this age group [18-35] would not have missing teeth, because it would lessen their 'beauty' from the conventional feminine norm. Not replacing the missing teeth with caps perhaps reflected that they have been desexed because of their impairments, and due to this reason they did not require to conform to the conventional norms of feminine beauty.

Other research participants also talked about their dental health problems. Lata fell down in the year 2008 but went for a dental checkup only in the year 2016. She said that because of their poverty, she was not able to seek care for her problems earlier. She said,

> *After my 12th, I started working in a private insurance company. During that time, I had gone to someone's home. They gave me mutton to eat. At that time I did not know that I'm allergic to mutton. They gave me mutton to eat, and I had it. On the way back, I boarded a shared auto. By that time I had become completely red because of the allergy. All my blood had risen up to my head. I did not know about it. After coming back home, I took a bath. Then I went to sleep. After waking up, I felt like going to the bathroom. When I came out, my head started to spin and I fell down. When I fell down, my entire weight fell on my tooth* [incisors in her lower jaw]. *When this happened, I started to bleed. The teeth started to move. I fell down in such a way that three of my teeth started to have problems. I did not understand that I fell down. Ma and Pita* [father] *were both outside. They saw me and brought me to my bed. Again I tried to get up and my head started to spin. It was only on that day that I came to know how it feels when the head spins. Otherwise, I have never had this problem. On that day this happened because I had this allergy. After the tooth injury, I did not go to a dentist. We did not have money for it. We had so many problems with money at that time. I stayed like this, and since I stayed like this that is why this happened to me today… I had an infection. Few days back, while eating one of the impaired teeth came out partially from the gums, while the gums went on another side. At that time I was in so much pain. It was unbearable. Still I did not go to a doctor. If I would have had money, I would have gone immediately. But I did not have any. So what to do? Even though I went later, it was of no use. If I wait for 1 or 2 years, what is the use? They cannot cure my illness. Now they cannot cure it at all. It is like that. In my life, I have never had anything good, everything is bad in my life…*

From the above narrative it can be seen that Lata blames her poverty for not being able to seek treatment on time. It was only when the pain aggravated 8 years later that she went to a private clinic for her treatment. She said that she did not have to spend a lot of money on her treatment because her teeth were already moving. It cost her Rs. 1600 inclusive of the consultation, medicines and the cap. It was not very difficult for her to pay the amount as she had got her salary by that time. She further said that during the procedure, the doctor gave her one medicine that made her tongue very heavy.

> *The medicine made my tongue very heavy. I was not able to talk. At that moment I though how I would ever work again. If I am not able to talk, what will happen to me? I thought I would only have to work with the HI* [hearing impaired children] *ones now [She laughs].*

From the above narrative it can be seen that during her teeth extraction procedure, when her dentist used local anesthesia, she was concerned that she will not be able to talk again. She was worried that if this was the case, she may not be able to do her work again, and may have to only work with only children with hearing impairment in the future. This was a big concern for her as her work was the only source of livelihood for her entire family.

Similarly, Hema also talked about her dental problem. During the interview, she mentioned that one of the orthopedics she had consulted in the past has now become like a family doctor. She consults him for all her problems including her dental problems.

> *I go to Saikia Sir if I have any difficulties. He is very affectionate towards me. He even treats me for the pain in my ear. He treats me like his own. If I do not go to him for a few days, he asks me where were you for so long? What has happened to you? If I am sick, he says, nothing is wrong, everything is fine. He says like that. I had gone there for my ears. Sir has helped me a lot over the years.*

When I probed further, Hema said,

> *I have some pain in my ears. Do you see this tooth* [incisor in her upper jaw]*?* The *dentist has asked me to remove it. He said that it is because of the tooth that I have pain in my ears. But I have not gone to the dentist as yet. I have to show it to a good dentist and get it removed… I will remove it. I have a lot of pain. Because of my toothache, there is pain till my ears. But the thing is, my heart is a bit weak. The dentist has told me that it would not be a problem. I can remove the tooth. I will have to ask Saikia Sir once. The thing is I have had so many tablets in my life, that now I'm scared. I have some kind of fear for extracting my tooth. That something might happen to me. Now it is fine, I do not have any ache. But I cannot bite with it. The gums have been damaged.*

From the above narrative it can be seen that due to her past experiences of having medicines, Hema does not want to extract her tooth, despite all the pains, as she was scared that something might happen to her. It also shows that Hema is dependent on the opinion of her orthopedic for nearly all her health problems including her toothache.

This section elaborated on the other health problems of the research participants. It was found that during childhood most of the participants were 'healthy' in comparison to their peers. However, with age they have faced different kinds of physical, mental and dental health problems. During the interviews it was found that most of the women went for a checkup for their health conditions only during extreme situations, while at other times, they tried to trivialize it. Due to this delay in treatment seeking the health conditions of most of the women had deteriorated with time. Poverty was also found to be another factor that created hindrances for the women in seeking healthcare.

Conclusion

The aim of this chapter was to understand the corporeal experience of locomotor disability among the study participants. As mentioned earlier in the chapter, it is important to study this aspect because disability studies literature, following the social model distinction between impairment and disability, has completely negated it. Majority world theorists have argued that such a distinction makes no sense in the case of persons with disabilities in the majority world because healthcare itself is inaccessible to a large section of the population in this context which makes people more susceptible to disability (Grech, 2009). It was found that this framework was very apt for the current chapter. The chapter was divided into four sections. In the first section I elaborated on the parents' quest for cure for their daughters. It was found that unlike other studies (Mehrotra, 2004; 2006; 2013), none of the research participants were neglected by their parents after they came to know about their impairments, even though due to their busy schedules or their lack of awareness the parents have delayed seeking treatment for their daughter's conditions. After they acknowledged their daughter's condition, the parents were found to seek treatment from every possible way to cure including modern medicine, traditional healers and spiritual gurus. This was found to be true for all the almost all the parents, regardless of their class status, level of awareness about the condition and their place of residence. At a superficial level one can argue that belief in traditional healers or the miracles of spiritual gurus is a result of the superstitious beliefs of the community, but as I had argued in Chapter 4, it is necessary that we look at the broader context in which the experiences of the women and the parents are embedded. Even though I haven't found any research to support my argument that healthcare facilities in Assam were in tatters in the latter half of the 20th century due to years of insurgency, ethnic violence and neglect from the central government, the narratives of the women and the mothers where they often repeated that they wanted to seek healthcare from outside of the state is quite telling of the healthcare scenario of that period.

Unfortunately, the parents did not emphasize as much on the physical rehabilitation of the women because they were not aware about the benefits of such forms of therapy. In one case where the mother did receive information about physical rehabilitation, it was observed that the information was not adequate for her to understand what would happen if she does not continue with the treatment. The findings of the chapter suggest that the health services system needs to be more mindful about the information that is passed on to the parents as this information determines the entire life-course of a person with disabilities. The study also found that the parents of the women did not give much attention to their daughters' opinions about their treatments if they were convinced about the outcome of the treatment. In cases where they were not convinced themselves, they did not put much pressure on their daughters.

In the second section, I elaborated on the women's experiences of growing up with locomotor disabilities, with a special focus on visiting doctors, corrective surgeries and physiotherapy sessions. This section was relevant only for the women from the urban areas. It was found that many of the women from the urban areas spent their early lives seeking cure for their conditions. Depending on the nature of their impairments, a few among them also underwent corrective surgeries and physiotherapy sessions at the insistence of their parents although it may not have led to desirable results. It is noteworthy that none of the research participants had a successful corrective surgery or were able to continue their physiotherapy sessions for long. This points towards the skewed nature of services for persons with disabilities, even though available data has shown that the majority of persons with disabilities reside in rural areas. This suggests that more effort needs to be put from the State to ensure that persons with disabilities have access to healthcare services. At present it is the disability organization, Sanjeeboni, that is providing services to the persons with disabilities in the Joonaki Block. As will be shown in Chapter 8, their services focus on only a few activities as has been directed by their funding agency. Besides, their services are only provided to persons with disabilities who live within the jurisdiction of the Block, which excludes a large section of the population.

Third section elaborated on the secondary conditions of the women. It was noted in the beginning of the section that none of the research participants went for a checkup for these conditions, due to which these conditions cannot be labeled as secondary conditions as such. Nonetheless, their complaints were a result of their primary conditions and so require greater attention. In certain cases the women also complained about their health problems due to accessibility problems, use of aids and appliances, their occupation related problems or falls. The women and their family members complained about seizures, body ache, pressure sores, In spite of these difficulties many of the women refused to seek healthcare for their conditions due to their terrible experiences in the past or because they were tired of having medicines and visiting doctors. In contrast some of the women preferred to go to folk healers for *zara-phoonka* to relieve their pain.

In the final section I had elaborated on the other health condition of the women. It was found that most of the women considered their general health to better. This could be one of their ways to assert that they are not different from nondisabled people. It was also found that the women did not pay much attention to their health unless they experienced some kind of discomfort, for which treatment was more readily sought. It was also found that mental and dental health was much ignored by the research participants.

These findings clearly indicated the necessity of engaging with the corporeality of persons with disabilities.

Chapter 7

The Psycho-Emotional Dimensions of Living a Life with Disabilities

In the previous chapter we have looked at the physical experience of living with impairments that are acquired in early age. This chapter deals with the fourth objective of the study, that is, understanding the significant events in the lives of women with disabilities, and its impact upon their mental well-being. It focuses on what Thomas (2004a; 2004b) had termed the *psycho-emotional dimensions of disability*, that is, the experiences that persons with disabilities have to endure along psychological and emotional pathways as a consequence of living with impairment in a society that does not easily accommodate people who are different, or who have different needs (Ferrie & Watson, 2015). The key argument of the chapter is that having a visible physical disability may invoke certain kinds of reactions from the society, which in turn may distress the mental wellbeing of women with disabilities. It is important to study this aspect in-depth as much of the work in disability studies has focused on the social model of disability that has talked explicitly about the 'public' experience of oppression but have avoided discussing the more 'personal' experience of oppression, that operate at the emotional level (Thomas, 1999, as cited in Reeve, 2006). Disability scholars have taken such a stance in order to avoid invoking the much prevalent personal tragedy theory (Reeve, 2006). Feminist disability scholars such as Morris (2004) and Thomas (2004a; 2004b), however, have critiqued such a viewpoint and have argued that it is very essential to understand the intimate and experiential aspects of disability. Thomas (2004a; 2004b) has argued that those who relegate these experiences to the realm of the private life actually ignore key dimensions of the experience of disability, while Morris (2004) has appealed for more research to be conducted on how the experience of disabling attitudes and environments affect the emotional well-being of persons with disabilities (as cited in Reeve, 2006).

The chapter traces the women's entire life trajectory from the time they became aware about their impairments, to the challenges they had faced in attaining education, the reactions they faced from the society when they became adults, their relationships with non-disabled peers, their experiences in public spaces, their concerns as unmarried or married women with disabilities, their experiences of childbearing and childrearing, their abilities to do household chores and their concerns for the future. In each of these phases the women's psycho-emotional dimensions of living with disabilities is explored.

Becoming aware about the impairment

In her study on women with disabilities in Bengal, Ghosh (2016) had stated that girls with disabilities live a protected and pampered life within their families, where all the family members, including parents, siblings and other extended family members treat her with a lot of affection and care. Differences between them and their siblings are only subtly created that usually reinforce their special status within the family (Ibid). Ghosh (2016) has argued that although such kind of parental cosseting is done out of love and concern for their child, it actually reveals the underlying socio-cultural ideologies that construct girls with disabilities as weak and in need of protection. In the current study also it was found that most of the women, usually with milder forms of disabilities, were protected and pampered by their parents, so much so that they never realized that they have any 'defect' in them. During the interviews, they said that they came to know about their impairments in their pre-teen years, not through their health conditions, but through the ways other children of their age made fun of them. The following narratives give a glimpse of this.

Jeuti never realized that she is different from others in her childhood because her family never treated her any differently from her two younger siblings. She realized that she is different from others only when she began to notice that some boys of her age from her neighborhood made fun of her.

> *When I was young, even though I had the disability, I did not pay much attention to it. At that time I did not understand so many things. But when I went out, sometimes there were some boys that we know, they used to tease me. I must have been 12-13 years old at that time. When they teased me, slowly I started feeling bad that they tease me or do such things with me.*

Jeuti said that in such situations her *Maju Bhonti* (second sister) chased those boys away. After a few such incidents, slowly she began to realize that the boys made fun of her because she walked differently from the other people around her. During the interview with her mother, she said, *"Many people laughed at Jeuti. They said she is a lengeri* (physically disabled)*, who would marry her? A lot of people had made fun of her."* Perhaps such comments had a deep impact on Jeuti's mind because of which she decided to undergo a major surgery to correct the deformity of her hand as cited in the previous chapter. After the surgery her deformity has been corrected to quite an extent, and she no longer feels inferior to others. This boost in her confidence has also been facilitated by her association with the disability organization, Moromi, for over five years during the time of the interview.

Similarly, Nayana also talked about the taunts and jeers that she had to endure from the children of her neighborhood when she was young.

> *I have too many experiences where people have made fun of me. When I grew up and was able to understand things, then I realized this. I got so angry. The children of the neighborhood where I grew up made fun of me. They were mostly of my age. I had only one friend amongst them; she was bhaal* (non-disabled). *She was a very good girl. But the rest of them, they made fun of me. They used bad words such as lengeri to refer to me. When I grew up a little more, they made fun of me in a different way. There was a song at one point called "Bhagra Pale". They had changed the word for that. They said "Lengera Pale" or something. Things like that. Oh God! I fought so much with them. I still remember that I felt like beating them up.*

The above narrative shows that Nayana also became aware of her impairment not because of her physical condition, but because of the way the children of her neighborhood made fun of her for being physically disabled. Unlike Jeuti, she never remained quiet, and went ahead to fight with her bullies. The primary reason for this could be the support that she had received from her teachers at Senehi who made her feel confident about herself. In spite of their experiences, it is intriguing that neither Jeuti nor Nayana complained about their problems to their parents. Both of them said that they were afraid that if they share these problems with their parents, they would be very hurt. Moreover, it is important to keep in mind that both of them belonged to economically poorer households and their parents were more concerned about their livelihood and sustenance in Guwahati than to ensure that their children are not bullied by other children in the neighborhood. This point stands out clearly when we contrast their experiences with the experience of Suchismita who belonged to a middle class household. In her case, her mother made sure that she is not harassed by her classmates in school because of her physical impairment (post-polio residual paralysis).

After Suchismita's family moved back to Guwahati from Shillong, they got her admitted to a prestigious convent school for girls (and her brothers were admitted to a prestigious convent school for boys). At the time of the admissions, her mother specifically requested the Principal of the school as well as her class teacher to ensure that she is never teased by her classmates for her physical impairment. She also spoke to some of her classmates and requested them to not tease her for the same. During the interview with her mother, she said that she felt it was necessary as otherwise this would have left a lasting impact on her mental health.

The above narrative shows that parents' understanding and involvement in their daughters' social world makes a huge difference in their lives, as without such support many women felt vulnerable in the outer world. This must be understood by taking into consideration Suchismita's sound socio-economic background and the explanation that her mother and other family members had received from her mother's *Pehadeu* about her physical condition (as shown in Chapter 4).

In other cases, it was found that the women became aware about their differences from others only after moving away from their familiar environment. In the following narratives I illustrate this point.

Anamika had grown up in a Nepali village in the Joonaki Block. During her childhood, she never realized that she is different from the other children. She said that in her small village, since everyone knew each other, her classmates in the primary school were aware about her condition from a very young age and so never made fun of her gait. However, after her primary education, when she went to the high school in a different village 7 km away from her home, she realized that the other children from her new school made fun of her.

> *When I moved to the high school, it was 7 km away from my home. We had to walk 14 km every day to and fro. Only at that time I came to know that there is some difference between me and others… Other students, they made fun of me. About the way I walked. They did that every day. Before that I never realized that I am different from others… The primary school was in my village. All the students were from my village. So no one said anything. We went to school together.*

From the above narrative it can be seen that Anamika became aware about her impairment at the age of 11-12 years when she moved to her high school. When the teasing continued for a long time, she, with the encouragement of a friend, decided to complain to the school authorities.

> *Me and my friend, who lived near my home, we complained to the teacher and the headmaster. I did not have the courage to go alone. So we both wrote their names, that these boys said such things to me. We wrote to the headmaster. The headmaster's son was also involved in teasing me. The headmaster beat them up very bad. Why would you tease her like that? The headmaster told them, she is like this. She hasn't done it on her own. What is the need of you all to say such things to her? The headmaster beat them so hard that their hands had cracked. After that time nobody teased me.*

From the above narrative it can be seen that it is due to her friend's encouragement that Anamika wrote the names of her classmates who were involved in teasing her and gave it to the headmaster of her school to teach them a lesson. The headmaster beat up her bullies that acted as a lesson for other children to never tease her again. It is, however, a matter of speculation if beating the boys so mercilessly was the right solution for the problem. Such forms of disciplining mechanisms do not make young children understand the diversity that exists among human beings and, in my belief, deepens the differences among people. What was needed was an encouragement for a dialogue among the students to understand her difficulties and why she walked differently from others.

Like Anamika, Lata also started feeling that she is different from other children only after she moved out of her primary school. She fondly narrated that she had a very intimate bond with her school friends from her primary school. She studied with these friends from her 1st to 6th grade. She said,

> *I really liked the atmosphere of that school. All my friends treated me as an equal. I liked my friends very much. They never treated me differently because of my impairment. During our lunch breaks, all of us stayed together. We used to talk to each other. Sometimes we used to draw flowers together. It was really nice. We were all of the same age. They had known that I have some problem, but they never let me experience that I am different from them.*

From the above narrative it can be seen that Lata liked spending time with her friends from the primary school because they never made her feel any different. As noted in Chapter 4, her parents came to understand that she is different from other children only when people in the streets started making fun of her when she was about 10 years old. She said that when she was younger, her *Aita* often accompanied her to the school, and it is probably due to this reason that no one dared to say anything about her looks. However, when she moved to her high school which w0as a bit far from her home, and later to her higher secondary school, people often passed nasty comments about her looks that made her feel miserable about herself.

> *I have known that I am different since childhood. Earlier also people used to say some things but I was not able to understand. When I reached High School, by that time I knew about it slightly. When I reached Higher Secondary, from that time I started feeling even more. From that time I also began to worry more.*

When I probed why it was so, Lata replied,

> *People used to say this and that about me. When I hear those things, I used to feel sad. There are some people who said that it is nothing, that it is a very small thing. Then I felt better. But most of the people said negative things. There are some who said, "Why should such people even take birth? What is their use in this world?" ... Some people even said that this is a result of my sins. Have I committed so many sins? Mostly I used to lie down on my bed and cried. I have cried a lot. After crying for a long time sometimes I even got a headache. I was not able to talk to anyone during that period. If I talk to Ma, she will be sad. After passing my Higher Secondary, I became even more alone. I was not able to talk to Ma or Deuta. Even if I meet some friends, they are not able to understand these things. Everyone's perceptions are not the same. Even when I talked to some of my friends, they took the matter very lightly. That is why I was not able to talk to anyone. I did not have a best friend to talk to so that s/he would understand my feelings. I had friends but they were not able to understand my feelings. That is why I used to cry as much as I could, for about 2-3 hours, as long as I was sad. Till that time I would keep on crying. I wrote in my diary about all my sorrows, and it would be wet with my tears. I still have those diaries.*

Lata's narrative shows that she had to hear a lot of taunts from passersby when she moved out of her home due to the visual nature of her impairment (short stature). Unlike Anamika who had the support of her friend, Lata had no one to share her sorrows with. She also refrained from talking to her mother about these problems out of the fear that she would be hurt. During such times her diary was her only companion where she would vent out her problems.

From all the above narratives it can be seen that women with milder impairments became aware about their health conditions through the taunts and jeers of other people, especially children, around them. The narratives have shown that usually the teasing starts in their pre-teen years and goes on for a few years till they gradually learn to deal with their bullies. Such instances have left almost all of them shocked, angry and sad. The women, however, maintained that they do not hold any grudges against the children who made fun of them in their childhood. They said that they were all young at that time and so lacked the knowledge to understand the repercussions of their actions. The narratives have also shown that during such times an understanding parent or friend is very necessary for emotional support and to act as a shield against harassers and bullies. The women with severe impairments, however, said that they have never been ridiculed for their impairments. Their experiences, in fact, are vastly different from the other women mentioned above. The following narratives give a glimpse of this.

Gargi said that she has always known about her impairment and that there has been no single incident in her life that made her realize that she is different from others. She narrated that in her class everyone talks to her nicely and helps her with the class notes. However, during the lunch break she mostly sits alone in the class as all her classmates go out for their midday meal.

> *Gargi's Mother: She prefers to sit in the classroom during the lunch break. All the other students go out of the class to eat their meals, but she keeps sitting in the classroom. I give her food at home. She eats that. They get midday meals in the school, but she cannot go and eat by herself. That is why she does not want to eat.*
>
> *Gargi: If I eat who would help me wash up? Who would bring me back to the class?*
>
> *Mother: They would help if we say so. But she does not like to eat outside. In the LP [lower primary] school also they used to serve khichidi. Even then she did not eat it. She eats at home before going to school, and later she would come back and eat.*
>
> *Gargi: If I eat and drink water I may have to go to the bathroom, who would take me there?*
>
> *Mother: Who would take her to the bathroom if she wants to go, she has that fear. Before going to school she would go to the bathroom, and again she gets off at 2.30-3 in the afternoon, then she comes back and goes to the bathroom. She does not even have rice[151] before going to school. She does not have rice in the morning. She has roti and goes to school.*

When I asked her what if she is thirsty during the school hours, she replied,

> *Gargi: I do not drink any water when I'm at school.*
>
> *Mother: She does not even drink water. After coming from school, she would have water, rice, everything that she wants. But she has the fear…*
>
> *Gargi: Who would help me there?*
>
> *Mother: Who would help her? Now she is older, even when she was young she did not like to rely on other people. When she was young her friends could have helped her.*
>
> *Gargi: Who would help me there?*

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[151] In Assam, rice is the staple food, and people usually have rice three times a day. Due to this reason, not having rice in the morning before going to school, was a big deal for Gargi's mother.

> *Mother: Now she is old. No one can take her there. That is why. She might want to go to the bathroom that is why out of fear she does not eat or drink anything.*

The above narrative shows the accessibility issues that Gargi faces in the school premises because of which she prefers to isolate herself from her other classmates. It also shows her intense fear of eating or drinking anything in the school during the lunch break as she was scared that she might have to depend on someone for washing up after eating, or worse, that she might need to use the bathroom. It is due to this fear that she kept repeating *"Who would help me there?"* in case she chose to eat or drink water in the school. Gargi's narrative clearly shows that even though she has been included in the school, it is only at a superficial level as she has not been integrated into the activities of the school because of the very basic problems like using the wheelchair within the school premises and the difficulty of using the bathroom as and when she needs to. This point also becomes clear when her mother said that she reaches 10-15 minutes before the school gets over, as if she is late, all the students leave Gargi alone in the class and go back home. Gargi said that she feels very scared to sit alone in the class and that is why expects her mother to reach the school a few minutes early.

Unlike Gargi, whose mother couldn't do anything to ease her problems at school, Korobi's parents devised a full-proof plan to help her with her bathroom and other emergencies. After they moved from Shillong to Guwahati, her parents looked for an Assamese medium school for Korobi's admission. Her parents' plan was to admit all their daughters in the same school so that Korobi's younger sisters would be able to look after her. However, none of the Assamese medium schools were willing to accept her because of her physical impairment. These schools felt that Korobi will not be able to take care of herself and would require an *Ayah* for the same. Finally they approached the same convent school where Suchismita had studied and was accepted there without any fuss. During the interview, Korobi's mother said that Korobi was admitted to the same class as her second sister, who took care of all her difficulties.

> *Korobi was put in the same section, with the middle one. The school authorities said that she would be able to look after Korobi a bit. Both of them went to school in this way. So when her sister went to play, every time she would make Korobi hug a pillar. She told her to hug the pillar so that she does not fall down if in case someone pushes her while playing. Even while playing with her friends, her attention was always on Korobi. So her teachers used to say that we do not need an Ayah. We felt that she would require an Ayah in the school and that is why we were very careful in choosing the school for her. But they said that they did not require an Ayah to look after her.*

> *When they entered the school, her sister would hold Korobi's books, she would hold her and take her to the class, she would also ask her to hold a pillar in the verandah so that she does not fall down. She took a lot of care from a very young age. She loved her a lot, now when I think about it I feel very sad.*

In the above narrative it can be seen that Korobi's parents made a conscious effort to ensure that Korobi is well looked after in the school by her younger sisters. However, it should be noted that her parents as well as her school authorities were only concerned about her physical problems, and not about the subtle social exclusion that she faced in the school. For this reason, they never tried to ensure that she is fully integrated in the 'normal' school where she studied. Like Gargi, Korobi also said that her classmates never made fun of her, but cooperated with her difficulties by sharing their class notes with her. In spite of their reassurances, it cannot be overlooked that while they were never teased in their schools, their classmates never looked at them as an equal. The findings of the study support what Mehrotra's had stated in the case of women with disabilities in rural Haryana that "*The severity of the disability plays a significant role in the manner it is reacted to. The more severe forms of disability are treated somberly, but the less severe forms are treated jocularly"* (2013: 162).

All the above narratives were about women who had acquired their impairments either at birth or in their infancy or childhood. The narratives clearly show that women with milder forms of locomotor impairments have never really considered themselves to be inferior to others, as their impairments were 'normal' for them. It was only when other people made fun of them that they realized that they are different from others. On the other hand, women with severe forms of impairments could not recall a single incident when they were singled out and made fun of because of their health conditions. However, their narratives had subtle hints that they were isolated by their peers because of their impairments, even though they have otherwise referred to them as kind and friendly. The narratives have also shown the importance of support from family members and friends in overcoming the emotional problems women with disabilities face when they become aware about their impairments.

Unlike the other participants, Hema and Dolly had acquired their impairments due to amputations in their teens. This means that they had lived their early lives as non-disabled people and had internalized some of the prejudices that able-bodied people have about people with impairments. This made it very difficult for them to mentally adapt to their 'newer identities' as persons/women with disabilities. In spite of the similarities in the nature of their impairments, their experiences are considerably different from one another. This is because while Hema had agreed for her amputation after prolonged suffering for several years, Dolly was given no other option but to go her amputation due to the severity of her injury. This difference in the time between their physical suffering and the amputation made a huge difference on how they accepted their newly impaired selves.

Challenges faced in Attaining Education

Education plays a crucial role in the lives of persons with disabilities, especially those from the poorer socio-economic background because it is the only hope that is likely to provide them with livelihood opportunities in the future (Pal, 2011). Although a few existing studies have shown that parents consider education to be more of a priority for men with disabilities than for women with disabilities (Addlakha, 2007), in this study, it was found that several parents, especially from the urban areas, were very keen to educate their daughters. Due to this reason, it was a big disappointment for them when 'mainstream' government schools discriminated against their daughters by refusing to give them admission. Apart from a few women who were not able to study because of the nature of their impairments, most of the women would not have faced any trouble in studying in 'mainstream' schools. However, as Ghosh (2016) has shown, a number of factors influenced the extent to which the women were able to access the education system. These factors included the degree of their impairment, construction of their disabilities, family and cultural ideologies and physical barriers. In her study, it was found that the women with mild to moderate impairments who were living mainly in the urban areas were able to take good advantage of the educational opportunities available to them. In contrast, girls with severe impairments who were living in the rural areas have either never been to school or had dropped out of school after receiving some primary education (Ghosh, 2016). In the current study it was found that a clear cut rural-urban divide in the access to educational opportunities could not be established. The following narratives highlight this aspect.

When Nayana was growing up, her parents had very high hopes for her bright future. With this hope they had approached several government schools for her admission.

However, in all the places she was denied admission citing her disability (post-polio residual paralysis) and her wheelchair as the problem. She said,

> *After I grew up a little, my parents started worrying about my education. When other children from the neighborhood went to school, I used to ask my parents, "When will I go to school?" I still remember this thing. Ma told me to grow up a bit. But they were not aware that I will not be admitted in a 'normal' school. Deuta had gone to many schools for my admission. Ma used to lie to me. "Grow up a bit more", she used to say. There was a school nearby, she used to take me there to watch other children go inside in the morning, and come out of there in the afternoon. After a point my parents started worrying about where I will be admitted to a school or not. They felt that maybe I will have to stay at home. Then there was an uncle, who knew my Deuta very well. This uncle informed Deuta that there are special schools for 'children like me' and that I can be admitted to such a school. He had good contacts with the ex-Principal of Senehi, and it is through him that I got admission here. Since that time, my life has been going on like this.*

From the above narrative it can be seen that Nayana's admission was denied in the 'mainstream' government schools due to the socio-cultural assumptions about her capabilities, in spite of the fact that her disability was only physical in nature, and had not affected her intellectual abilities in any way. It is also noteworthy that she was able to get admission at Senehi only because of her father's contacts. As mentioned in Chapter 2, Senehi mainly worked with children with cerebral palsy and other developmental disabilities. Nayana, in fact, was the only student with post-polio residual paralysis in her school. After getting admission to the school, Nayana was very happy. She said,

> *When I came to know that I am joining a school, oh God! I was so thrilled! I will be going to school like everyone else. I thought that I would study a lot. I was about 8-9 years old at that time.*

When I asked her if there was something specific that she liked about the school, Nayana replied,

> *There was nothing that I disliked about the school. I liked everything about it at that time. I do not know why. I met friends here. I met the Aunties here* [the special educators]. *All the Aunties were very affectionate towards me, from the Principal Aunty to everyone else. I liked seeing these things. I did not have to sit at home that was the main attraction for me. Slowly I got busy with the activities in the school. The school organized different kinds of functions and I participated in those. I also discovered that I can sing well. I liked it very much.*

From the above narrative it is clear that Nayana was very bored at home. The school enabled her to come out of her home and interact with the world outside. She also liked the fact that besides her parents there were other adults who were affectionate towards her and gave her the encouragement to sing. Reflecting back on her first day in school, Nayana said,

> *When I entered the school for the first time, I thought are there such kinds of schools? And the students in the school had so many difficulties. I used to think like that. And then I thought, we cannot walk, maybe that is why we have to study in such kinds of schools. Later I also realized that for children with other kinds of disabilities, there are other disability schools, like there are schools for the kola-buba* [hearing and speech impaired]. *I came to know about these things later, and after this my feelings deepened.*

From the above narrative it can be seen with time Nayana began to realize that as a person with a disability she and others like her have been segregated from the mainstream society because of their perceived inabilities. She said that she does not know in what way her life would have shaped if she had studied in a ‘normal’ school. However, the experience of being excluded from the mainstream school did make her feel that she does not belong in the places where non-disabled people spend their lives.

Like Nayana, her friend Risha was also denied admission in several ‘mainstream’ government schools because of her impairment. During the interview, she said,

> *When I was small, my mother once took me to a school for admission. The school did not take me in there because of my problem ... I do not remember the name of the school. I was very young at that time. The school was not far from our home. They said that other children may have problems and their parents might complain about having ‘such a child’ in the school. That is why they did not take me in that school.*

When asked if she felt bad about being rejected from the school, she said that she was too young to understand what was going on. Later when she was about 8-9 years old, one of her father’s friends told them about a school for children with mental disabilities. Risha was admitted to that school, and she remained there for a year. Towards the end of that year, one of her teachers informed her parents that they can take her to Senehi for admission, where she is likely to receive better attention. At Senehi, after several assessments it was found that even though Risha had several physical difficulties like inability to balance herself and speech difficulties, her cognitive abilities were not impaired (Athetoid cerebral palsy). Due to this it was decided that she would be able to study like other ‘normal’ children. Keeping this in mind, her teachers gave her sufficient attention in the school so that she was able to write her matriculation exam from the Open School.

Both Nayana and Risha had received a lot of support from the special educators of Senehi to write their matriculation examination from the Open School. In spite of this, attaining the minimum educational qualification of a high school diploma was an uphill task for them. This is because both of them required a scribe during their examinations. According to Rekha, special educator at Senehi, their parents were not at all proactive about their education and wanted the school to do everything for them. According to her, it was not possible for the school to arrange the scribes for them. In Nayana and Risha's narratives they said that they had somehow managed to find their respective scribes. But due to one particular incident, they both decided to quit their studies. Nayana said that during the time when they were students, the medium of instruction at Senehi was Assamese, due to which they had difficulty in understanding both spoken and written English. They had written their examinations from the Open School, which only published question papers in English at that time. During one of their board exams, they were not able to understand a question in the paper. They asked each other but when neither was able to understand the question they decided to ask the invigilator to explain the question to them. Risha said,

> *I had English, English or some other paper, I think it was English, I asked the Sir* [invigilator] *there, I was not able to understand the question, I did not ask the answer. I asked him to explain the question. He talked to me very badly.* [She cries, rubs her tears with her stole, and apologizes for crying]. *He said, "She does not know anything, why has she come to write her exam?"* [Still crying]. *[...] But my family had never said anything like this. That is why I got very emotional.*

During the interview, Risha had mentioned that her family has never treated her any differently because of her impairment, due to which it came as a shock when the invigilator spoke to her so rudely. While narrating this incident, she broke down several times, implying that the memory of that day was still very fresh in her mind. She said that she decided to quit her studies after this incident. She had informed her parents about this incident at that time, who in turn approached the school to take necessary action against the teacher. Risha had not followed up on the matter and so does not know what happened to him.

Although Nayana did not mention it, Rekha said that Nayana had failed in her examinations due to which she decided not to rewrite her exams. Rekha also said that the financial condition at her home was not very conducive to her education because of which her parents were not able to give her the requisite support. Both Nayana and

Risha also said that the school syllabus during their initial years of schooling was not at par with that of the 'mainstream' schools due to which they found it very difficult to adjust with the syllabus in their senior years at the school. Risha had received support from her father and her younger brothers for her education, but similar support was not available for Nayana due to her parents' illiteracy.

The above narratives show how the life trajectories of the two women have been shaped due to the perception that they would be unable to cope within the 'mainstream' education system. Although they received a lot of attention from their teachers in the special school, yet it is noteworthy that the system itself has very less expectations from them. This is reflected in the inferior curriculum in these schools in comparison to the mainstream schools (Armstrong & Barton, 1999, as cited in Barnes & Mercer, 2003). Additionally, prejudice and attitudinal barriers on the part of the invigilator, who humiliated them on being asked a simple question, also obstructed them from attaining education in the future. The narratives also show the psychological consequences of being denied education in mainstream schools that have caused serious damage to self-worth, confidence and acceptance by oneself and others (Klasing, 2007).

Such kind of discrimination was seen to be less prevalent among the women from the rural areas in getting admission to government schools. One of the reasons for this could be sampling bias, that is, most of these women had comparatively milder forms of disabilities. However, the women had faced other kinds of difficulties that made it very difficult to continue their education. This point is clearly evident in the narratives of Anamika and Lata. Anamika said,

> *Our economic situation was very poor. When we used to go to school, nowadays children get so many facilities, but we had nothing. We did not have a cycle. My father was not in a position to buy me a cycle. There was no money. We registered our names in the school, but the school did not give us the books. We had to buy our own books. After walking for 3 km when we reached Kolongpaar, even the buses would not take us. They would ask us to get down from the bus. Not many vehicles ran through that route at that time. Nowadays there are shared auto-rickshaws, but at that time there were only line buses. These buses followed a set time schedule. 7 am, 8 am, 9 am, 10 am, like that. For the 10 am bus, we had to reach the bus stop at 9.30 am. If we reach by 9.45 am, the buses would not take us. The bus would be full of people by that time. They do not want to stop after that. They would just ask us to get down. So from Kolongpaar again we had to walk to the school for another 4 km. Even from home, we used to get 1 rupee for a week as pocket money. Just one rupee! The bus fare was 50 paisa. Only sometimes we took the bus, most of the times the bus would not let us in. It was very difficult for us.*

Apart from the distance to her school and the lack of transportation facilities during that period, Anamika also talked about her family problems that made studying very difficult for her and her sister.

> *Earlier we lived as a joint family. It has only been 5-6 years since our separation. We faced a lot of difficulty in studying. If I start narrating it would be longer than the Mahabharata* [she laughs]. *We had a total of 30 cows in two cowsheds. Deuta would leave us in the morning. Borma* (father's elder brother's wife) *and Bordeuta* (father's elder brother) *would be there. They had small children. They did not work. I was 10 years old at that time. Bhonti and I both were there. In the morning we would free the cows and throw away the cow dung. Then after having rice we would leave for school. After coming back from school, we had to tie the cows. We had to bring back the cows which did not returned on their own. All such difficulties were there. I did not get any support for my education. Now Deuta says why did you not study? I had allowed you to study. But it is not sufficient to just allow us to study. We need the support from home. In the morning we had to go to school by walking, we did not have a cycle. Even those who knew to ride a cycle at that time did not have a cycle. It was like that. Just allowing us to study by giving us money, books and submitting the school fees is not sufficient. We also needed some rest. Our minds had to be fresh. In the morning we had to cook and eat, make tea, mop the floor. During floods, I had to wash the house and then mop it with fresh mud. We need to do that. Then at the time of* [Durga] *Puja, we had exams. Then we had to go to the fields to cut the grains. We had to go very far to cut the grains. During the half yearly exams we had to sow the grains. From where will we get the time to study? We did not get any support to study.*

Anamika said that due to the difficulties in concentrating in her lessons, she had failed in her matriculation examination. The next year her sister also met with the same fate. She also said that the pattern of examination under the state board was very difficult in their times, when they had to study the syllabus of class 9 and 10 together. She said that due to all the difficulties in the family it was very hard for them to concentrate on their lessons. Towards the end, Anamika said,

> *It was very difficult for us to study, especially because we did not have our Ma. We did not get any time. They did not give us time. Who else would give us time? Everyone wants the work to do done, that's all.*

From the above narrative it can be seen that a number of factors hindered Anamika's access to education. This included the distance from her home to the High School, lack of transportation facilities as a result of which she had to walk for a distance of 7 km one way to attend her classes, and the absence of any adult female member in the family which made it mandatory for her and her younger sister to do all the household and agricultural chores before and after school. All these factors made it very difficult for her to concentrate on her lessons that led to her failure in her board exams. Next year her sister also met with the same fate. However, it is interesting to note that the life trajectories of both the sisters are very different. After her failure in the exams Anamika lived with her Pehi in Lakhimpur[152], while her sister was married off within a couple of years. Although she did not say it explicitly, but Anamika's father probably never thought of her marriage because of her impairment.

Similarly, Lata, who had passed her higher secondary examination from a government school, talked about the multiple problems she had faced during her student days. She said,

> *Since childhood, I liked to study. All my family members wanted me to study. They never pressurized me to do any household or agricultural chores. But I have not studied much. I have only studied till my higher secondary… When I was in class 9, I had failed in my exams. At that time I felt very sad. What happened was that, I used to get good marks in Hindi, Assamese and Social Studies like about 60-70, but I used to get very low marks, sometimes not even the passing marks, in Math, Science and English. Hindi was my favorite subject in school. I used to get the highest marks in the subject. I found Science very difficult. I did not understand the subject. I also found Math very tough. There was no one to explain it to me. There was no one in the family or in the neighborhood who could teach me. I also felt very shy to ask questions in the class. There were so many students in the high school. I was scared to ask questions to Sir. I have very less courage. If there was someone to teach me I would have got more marks… After my tenth exams, I took admission in higher secondary. There also I found difficulty in understanding Economics. We hardly had any classes. The book was so huge. We were not able to finish the syllabus in the class. I did not have difficulty in understanding the other subjects as much. I was also a bit lazy. I should have studied more, but I was always so sleepy… After passing my higher secondary, I wanted to pursue my* (graduation) *degree, but there were a lot of problems at home. We did not have the money to take admission in the degree course. Rs. 3000-4000. How can we arrange so much money? I also faced a lot of difficulty while travelling. There were few* (public) *buses at that time. Everyone wanted to get in first. Who would allow me to board the bus? They might push me. So Ma and Deuta did not want me to go to college … Due to all these reasons, I could not take admission in college. But I was very interested in studying further. I feel that my bhagyo is very bad. Whatever wishes I had, I could never fulfill them. If our economic condition was good, then maybe I would have been able to study more.*

From the above narrative it can be seen that Lata received very little guidance in her studies from anyone around her that made it very difficult for her to understand certain concepts in her class. In addition to these problems, Lata also faced the problem of financial crunch and transportation issues to continue her education after passing her higher secondary exams. All these factors have made her feel that her *bhagyo* is very bad, as a result of which she has not been able to do anything worthwhile in her life.

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[152] Lakhimpur is an administrative district in Assam. It is located at a distance of 264km from Guwahati.

Among the women from the rural areas, it was only in the case of Gargi, whose mother had said that she was denied admission to a government school due to the severity of her impairment and the fact that she used a wheelchair for mobility. She said,

> *Initially the government school did not admit her. The school authorities said that she cannot walk and she is not able to go anywhere on her own. How can we give her admission at school? Then* [Suchismita] *Baideu and her husband conducted a meeting with them, after which she was given admission in the school. She was about 8-9 years old at that time. First she got admission in the LP school. Then after passing out from there she got admission in the High School… Actually she was able to talk when she was about 9 months old. But she was not able to walk or sit properly. That is why the school refused to give her admission.*

From the above narrative, it is clear that the presence of the disability organization facilitated Gargi's admission into the school. In addition to this, government programmes and legislation such as the *Sarva Shikshya Abhiyan* (Education for All Movement) and Right to Education Act, 2009 that have facilitated free and compulsory education for all children between the ages of 6 to 14 years, including children with disabilities, have ensured that children like her do not get discriminated during admission in government schools. As a result of these changes, young children with disabilities in today's era no longer have to forgo 'mainstream' education like their counterparts from a previous generation such as Nayana and Risha. Notwithstanding these developments, it is necessary to note that infrastructural barriers still cause tremendous difficulty for Gargi and her mother, and it is only because of their strong determination that she has been able to attend school (as mentioned in Chapter 5). At the time of the interview, Gargi was studying in the 9th grade. Her mother said,

> *If she is able to pass her matric nicely by studying well, then I would make her study further. So that in the future she can survive on her own. I will not be there forever. So that she can at least do some tuition at home and earn a livelihood and survive that way. She need not have to go out for this. That is what. If she studies well, she will be able to survive on her own.*

Gargi's mother, therefore, expects her daughter to study well so that she can study further and secure her own future. At the time of the interview she scolded Gargi for using her phone too much instead of concentrating more seriously on her lessons.

Apart from Gargi, other women also faced physical barriers while going to school. During the interview Bandana said that she needed her parents to drop her at school.

On those days when both her parents had morning shifts at work, Bandana had no other option but to miss her classes.

> *I liked going to school. The Baideu-s* (teachers) *in the school were very affectionate towards me. However, I did not attend many classes. Only if Ma took me for the classes, I was able to go. Now I have the confidence that I will be able to go out on my own. At that time I was not like this. It was only when Ma took me along or Deuta took me along, that I was able to go to school. If both of them had morning shifts at work, on such days I could not go to school. They could not even send me to school on a rickshaw. Either Ma or Deuta can help me while getting into the rickshaw, but I face difficulty while getting down from it. That is why, if both Ma and Deuta had morning shifts, on those days I could not go to school.*

From the above narrative it can be seen that Bandana was very dependent on her parents in her childhood to take her to school. Her outlook towards life, however, was changed by Kishore Kamal Bora, the founder of Moromi, who gave her the confidence to move about alone in Guwahati, something that her mother considered unimaginable for Bandana, particularly due to her impairment. In her narrative, Bandana also mentioned that while her brothers were educated in English medium schools, she and her younger sister were educated in two different Assamese medium schools. This points towards the gender discrimination that was prevalent in their household. This kind of discrimination, however, was not found to be universal. In my study among women with locomotor disabilities in Delhi-NCR, it was found that the parents gave more importance to their disabled daughter's education, rather than their non-disabled children's education (Sarma, 2014). Addlakha's study (2007) has shown, the presence of an impairment can have certain benefits for women with disabilities, as it may relax the traditional practice of getting married at an early age and thus, encourage them to study more in comparison to their siblings. Additionally, the benefits under the Persons with Disabilities Act, 1995, such as reservation of seats in government educational institutions and government jobs also play a crucial role in breaking away from the shackles of patriarchy and poverty that other members of the family still have to grapple with (Sarma, 2014).

As noted above, the study also found that some of the women were not able to study because of the nature of their impairments (cerebral palsy). Chitra had acquired her impairment in her childhood (she did not remember the exact age) after an episode of 'typhoid and pneumonia' fever, followed by *Aai Bhagoboti* (measles/ chicken pox). She said that the doctor was not able to recognize her ailment and gave her an injection after which she 'became like this'. After she acquired her impairment, Chitra was brought up under the care of her *Dangor Bou* [older brother's wife], as her mother had passed away by that time. During the interview, she said that she dropped out of school after her third grade. When asked why, she said,

> *I was not able to remember anything. Because of this, my Dangor Bou used to hit me. Because of this, I left my studies. She used to punch me on my face. She should have taught me properly. Then I would have been able to study.*

From the above narrative it can be seen that Chitra felt that her *Dangor Bou* could have been slightly more lenient towards her, and this would have encouraged her to study. She said that from her family it was only her *Xoru Kaka* (second brother), who had encouraged her to study, although he himself had not studied much. When she told her brother that she will not be able to continue her studies as she could not remember her lessons, according to her, he was very hurt.

Like Chitra, Sobiha and Ananya were also not able to study due to the nature of their impairments. It is, however, noteworthy that because Chitra is slightly older and from a rural area, she did not have access to a school like Senehi, which Sobiha and Ananya did as they live in Guwahati. During the interview they said they were both placed in the non-academic section, where they received different kinds of pre-vocational training to help them in their futures. The vision of the school was that such kinds of training would empower students like them to earn a livelihood in the future. But for this to be successful, the support of the parents was necessary as ultimately only they will have to take the responsibility of their children. According to Rekha, parents did not have a positive image of their impaired children due to which they had very low expectations from them. It is, however, necessary to remember that by the time the girls had passed out from their schools at the age of 18 years, their parents also age and find it difficult to engage with their children as they had in their childhood. In certain cases, like in the case of Sobiha's mother, she was so focused on earning a livelihood for her family that she had hardly any time to spend with her daughters, and much less to focus on the future of her disabled daughter.

The study also found that some of the women had to drop out from their schools and stop their education in midway because of the occurrence of their impairments. The following narratives bring this out clearly.

After Hema's condition aggravated due to lack of appropriate medical care, she had to drop out from her school. During the interview she said,

> *I was studying in class IX at that time. I was studying in an Assamese Medium school. I was not able to sit for my matriculation exam. When I was studying this happened. After that one of my brothers passed away. Due to this I was not able to study. I was very interested in studying. I was very interested in passing my matric. But I was not able to do it. I had the desire to study. I had the desire to go to college. But I could not do it.*

The above narrative shows that even though Hema wanted to study further and go to college eventually, she had to give up her dream because of her impairment. Similarly, other participants also had to give up their studies due to the occurrence of their impairments.

As cited above, Korobi and her mother in their narratives had talked about the way she was discriminated and not given admission in Assamese medium schools because of her impairment. Eventually her parents found a prestigious convent school where she got admitted along with her sisters. However, she was not able to continue her education after her 8th grade because of her burn injury.

> *Korobi: I had studied in this school from KG till class 8. I really liked to study. Everyone liked me in the school. I had taken up singing as my extracurricular activity. I was the monitress in the red house. I did not have any difficulties in going to school. Deuta took me to school and also brought me back in his official car.*
>
> *Korobi's mother: They loved her a lot in the school. She may not have got so much attention in another school. That is why we gave her admission in that school. It was good for her.*
>
> *Korobi: But after the burn accident, I was not able to attend my classes. Due to this reason, they removed my name from the register.*
>
> *Korobi's mother: If she had passed out from there, it would have been really good for her. But because of the burn accident, it was not possible for her to study. The nuns from the school even came to the hospital to check on her recovery. They always told me not to be worried about her.*

From the above narrative it can be seen that Korobi's mother was very happy about the kind of attention that Korobi had received at the school. She expressed her regret that Korobi was not able to complete her education from the school because of her burn injury. After her recovery, Korobi had joined the Open School several years later to complete her education. At the time of the interview, she was doing her BA in History from IGNOU. She also talked about her plans to study other courses, but was rebuked by her mother for being too ambitious.

Pronoti had studied in a government school in Guwahati till her 5th grade, where her father had worked. When she was 11 years old, she acquired her impairment which made her take a break from schooling for almost 5 years. During this period, her father also passed away in an accident because of which her family returned back to their village in the Joonaki Block. Pronoti started going to the village school for a few years, but when she was in her 9th grade, she decided to leave her studies due to circumstances in her family that she did not elaborate upon.

From the above narratives it can be seen that some of the women had to leave their studies incomplete due to the occurrence of their impairments. After dropping out from school, many of them found it very tough to continue with their education. It was only Korobi who seemed to be interested in studying further. But she never seemed to be serious about the subject that she was studying and instead wanted to study other subjects like astrology, something related to the field of medicine, etc. only because she found such subjects interesting. Although her mother pays for her education, it is only to keep her entertained so that she does not get bored by not doing anything at home. However, she did seem irritated when Korobi was not able to decide what all she wanted to study next in order to quench her interest for the subject.

Some of the research participants also had to leave their studies incomplete due to their familial commitments. The following narratives give a glimpse of this:

Jeuti had studied in a government school in Guwahati not very far from her home. She had to leave her studies after the death of her father. She said,

> *After Deuta passed away, I left my studies. He had passed away when I was about 12 years old, after I had attained my puberty. He was an alcoholic. Even when he was alive, Ma had sent my second sister to Hyderabad to work as a domestic worker... One day when he was returning home in a drunken state, he fell down from the hill and passed away immediately. After his death, Ma had to take up more work in order to provide for us. At that time we were staying on rent. Ma used to leave my younger sister alone at home to go for work. She was very young then, she was just able to crawl. She used to fall down often in our landlord's verandah. After her falls, she used to fall sick. One day we got to know that like me, she was also suffering from typhoid. It was not exactly typhoid, but it was the beginning stage. We informed our Mama about it. They took her to a doctor. The doctor scolded them. He said that she could have died. He said that she was taken to the hospital at a very crucial period. I heard all that, and I felt very bad. My hand is also like this, what if something also happens to her? That is why I did not study further, so that I can work and we both can look after my sister.*

From the above narrative, it can be seen that Jeuti left her studies in order to lessen the burden on her mother's shoulders so that they both can look after her younger sister. After leaving her studies she took up a job at a PCO where she earned Rs. 300 a month. She worked there for almost 5 years till she heard about a hotel management course at the Industrial Training Institute (ITI).

In another instance, Dolly had left her studies because she was never interested in studying. Her family members, especially her father, also understood her difficulty, and so never pushed her much to study. It is only much later, after she had acquired her impairment, that she realized the importance of education. She said,

> *I have studied only till 5th grade. After that I was at home. Actually, one of my fingers in my right hand was fractured. Due to this I had faced problems in writing in the exams. Seeing me, Deuta said she has no much difficulty in studying. I told Deuta I am not interested in studying. After that I did not study. I told him that I would like to go to the dance school. He promised me that I can learn it. But after Deuta passed away, I could not continue with my dream. I was not very old at that time. I must have been 13-14 years old… Initially my parents had insisted that I study, but I was not interested at all. Everyone else at home had studied. But Deuta supported me in my decision… After my amputation, however, I have started feeling that I should have studied. Today I am regretting my decision to not study. If I had studied, people would have thought of me in a different way. Now because of not having education I feel inferior to others sometimes. But I do not cower down. What if I am not educated? Whatever I have is enough for me.*

From the above narrative it can be seen that some of the women had to give up their schooling because they were expected to contribute to the household economy due to unavoidable familial circumstances like deaths in the family of the primary breadwinner. According to a UNESCO study (2012), the three major reasons that girls in India dropout from schools include expectations to do domestic work as part of their training for future roles as wives, mothers and daughters-in-law; concerns about their safety and the family's 'honor' and lack of infrastructural barriers such as common functioning toilets for boys and girls or separate toilets for girls. While women with disabilities also face similar problems, lack of education in the absence of any other feasible role for them, makes their lives very precarious as we will see in the following sections of this chapter.

The aim of this section was to show the many challenges that the women had to face in their journey to attain education. As can be seen from the above narratives, such experiences had a profound impact upon their mental well-being.

Entering Adulthood with a Disability: Reactions from the Society

As cited above, the women usually did not hold any grudges against the children who had made fun of them in their childhood. During this stage of their lives, it was found that the women did not experience any kind of stigmatizing or discriminatory behavior from other adults directly. It was usually their mothers who had to endure this on their behalf. This, however, changed when the women grew up and began to meet different kinds of people outside their families, schools and immediate neighborhoods. Unlike children, when adults made fun of them, the women were deeply hurt, and in certain instances they even had nasty fights with them. Such experiences have left a lasting impression in their minds. The following narratives bring this out clearly.

Minakkhi became aware that there is something different about her when she came into contact with the health system at the age of eight years, for a surgery of her hands. In spite of this awareness, she did not feel any different about herself until she met one of her distant relatives who made fun of her disability.

> *I have never experienced anything in school. No one had behaved badly with me until this one incident when a woman from my own zak* [extended family] *made fun of me. Since that time I started feeling that I am different from others. Otherwise there is no one else. No one behaves badly with me. They all behave nicely with me. They even praise me. But people from my own zak had made fun of me* [tears roll down her cheeks]*... They made fun of me for being disabled. Once I had a big fight because of this reason* [she laughs remembering the incident, although tears were still rolling down her cheeks]*... I do not feel good about the fight. But the ones who made fun of me, their own son is also like me now. He also became bikolango* [physically disabled]. *It was not since birth for him… I do not know what happened. It is due to some pain that he became disabled. Now I feel that it is not good to laugh at others, isn't it? Now I tell others, they had laughed at me, now the same thing has happened to them* [her voice breaks down]. *He is younger than me. He has bent down and walks about like an old man. He is from our zak… I have not talked to them since that time. Whenever I see them, I remember this incident.*

From the above narrative it can be seen that Minakkhi, an introverted person, was so deeply hurt by the comments of her distant relative that she had a massive fight with her, and has not been able to forget the incident till date. During that period her family members consoled her by saying that she should not fight and that they would suffer from their deeds in the future. According to Minakkhi, she had seen the fruit of their deeds now, as the son of that woman has developed a disability due to some kind of chronic pain.

The other women also talked about being ridiculed by their own family members. Hema said that after her amputation, her *Dada* (elder brother) and *Bou* (elder brother's wife) are the only two people who make fun of her because she is a *lengeri*. In the interview she said that even though the people in the neighborhood sympathize with her predicament, and help her out with her difficulties, it is her own family members who make fun of her.

> *Dada does not help me with anything. Bou also does not help me at all. They are all very different. They do not like us at all, and we also do not like them. It is like that. We do not have any relation with them. They hate us a lot… They stay here, but they stay as if we are not their own people, as if we are their enemies. It is like that. They stay with such thinking. That is why I do not like them. They laugh at me, because I am like this, they laugh at me… Others do not make fun of me. All our neighbors they feel sad about this. If someone makes fun of me, then it is just them… If someone laughs at me, fights with me, or comes out to beat me, then it is just them. They torture me all the time.*

From the above narrative it can be seen that in the case of Hema only her brother and his wife have made fun of her. She later elaborated that there has been a property dispute within the family. It seemed as if her brother was not interested in sharing the property with Hema, a disabled woman with almost no possibility of leaving her natal home after marriage. According to Hema what has compounded the problem even further is that her father has also started taking her brother's side instead of standing by her side.

In the case of Korobi it was found that she was never invited for weddings or other social gatherings by the members of her extended family, especially her father's relatives. The relatives were apparently afraid that other invitees would look at her and start asking questions about her.

> *Korobi's mother: Our own family members used to say, why have you brought her here?*
>
> *Korobi: Our own family members are not good, my father's family especially.*
>
> *Korobi's mother: They used to say do not bring her in front of people. People would start asking questions. That is why. Why do you have to bring her? [...] I said she also wants to come. Even if they did not allow me to bring her, still I always took her. Otherwise also I took her outside for a stroll in the evenings. In the middle she would start screaming, or she would start crying. That is why they did not allow me to bring her. But I felt that if I take her out, maybe she would be better.*

Korobi said that she started feeling that her relatives treat her differently from the time of her burn injury at the age of 17 years. From the above narrative it can be seen that both Korobi and her mother were immensely hurt about this behavior. It seemed that the relatives were more concerned about their reputation of having such a member in their family, than trying to overcome her inhibitions. It is due to this behavior that Korobi does not prefer to visit some of her relatives who ‘see her through a different eye’.

> *Korobi’s Mother*: *[...] She visits her relatives sometimes. But she does not like to go to everyone’s home. She only likes to go to those places where she is loved. When people see her through a different eye, she does not like it. That is why we do not take her to such people’s homes. She does not want to go there either.*

Like Korobi, it was found that several other research participants, especially those from Guwahati, do not like to go for family functions and other social gatherings because they feel conscious about their impairments. Ananya said,

> *When I grew up and began to understand things, from that time I do not like to go to weddings. I need to take the plate and serve myself in a buffet. I feel bad. I can take the food by myself. Still I find it hard to take the plates and move ahead. There are no tables to sit. I find it difficult. That is why I do not like to go for weddings.*

From the above narrative it can be seen that Ananya finds it difficult to take food and eat at social gatherings due to the way food is served. She said that her parents also understand her difficulties, and so do not insist her to go along with them for such functions. On the other hand, Dolly dislikes going for such gatherings because she feels that others would feel disgusted (*ghrin koribo*) seeing her eating with her left hand.

> *After my amputation, I started eating with my left hand. But I felt very ashamed of going in front of other people. When I go to weddings, and other functions, I feel very ashamed. If I eat with my left hand, what if other people get disgusted? I thought people would stare at me. I did not like it. I do not like to go to parties. Ma says come with us. But I go very less. Ma says nothing will happen. Eat with your left hand. Earlier I did not even eat in the streets. I did not eat. Now I do. Let people watch, I do not see that. I do not look at them and eat. I feel ashamed.*

From the above narrative it can be seen that Dolly felt very conscious about eating with her left hand in public spaces. In order to understand this, it is important to remember that in Hindu tradition the left hand is considered to be inauspicious, due to which even left handed people are expected, and sometimes even forced, to eat with their right hands. Dolly said that her mother understands her problem and has given her the courage to eat outside.

While several women from the urban areas talked about being (or perceived being) ridiculed and stigmatized because of their disability, very few study participants from the rural areas faced similar inhibitions and constraints. This is not to suggest that the social structure of rural Assam is less discriminatory, but it could be because most of the study participants from the rural areas had milder disabilities and worked as CBR workers and DPO members for Sanjeeboni. Because of this, they have been able to garner a certain amount of respect from the community members through their work. Anamika said that although she felt that she was different from others in the village earlier, after working for the organization, the people from her village ask her for information regarding various schemes introduced by the *panchayat*. As a result of this exposure, she does not feel that she is any different from other *bhaal* [nondisabled] people. Similarly, after joining the organization Minakkhi considers herself to be a *bhaal* woman as it is only now that she has met so many other disabled people like herself, and this has increased her self-confidence.

There are, however, a few women in the rural areas who because of the degree of their impairment or because of the social space that they inhabit have felt constrained and ridiculed. Gargi said that she does not go out anywhere other than her school because it causes a lot of difficulty for her mother.

> *I do not go for weddings or other social gatherings. If I go it is so problematic for Ma, she needs to carry me. That is why I do not go. If it is something nearby then I go. Ma and Bhonti* (younger sister) *they go. I have grown up now, it is troublesome for her. She will have to carry me, and then again bring me back.*

While Gargi has never been ridiculed or stopped by anyone to go to social gatherings, looking at the difficulties of her mother, she has stopped herself from attending such gatherings. On the other hand, before her marriage Uma felt that she was singled out by the people of her village because of her disability, and this made her very conscious about herself. However, after she moved to her husband’s village, she felt that the people were more accommodative and looked at her with the same lens as they looked at other *bhaal* people. One of the reasons for this could be that since the people of her husband’s village were already acquainted to his disability, and were aware that it was his disability that helped him in getting a government job, they did not make fun of Uma.

In other cases, it was found that complete strangers have shown the women 'their place' in the society and have left them with hurtful memories for the rest of their lives.

As cited in Chapter 4, Dolly had acquired her impairment after a traumatic accident at the age of 14 years. Due to this reason, she is acutely aware about the sudden change in the gaze of the society towards her. She said,

> *See one thing, I have come to know about it after coming here, earlier I had a name. It was* [Dolly]. *Now it has become an identification mark that the girl does not have a hand. I think that I do not have a hand today that is why I got this name. Otherwise the behavior of the people is very good. Whoever sees me, they feel sorry for me. But there are many people who say things without thinking. They say you do not have a hand, how will you get married? I say if I do not get married it is ok. I will work and survive as long as I can. That is it. People are good. Many of them are my source of support.*

Dolly narrated the following incident that made her feel very sad about her impairment.

> *There was one person, he is no more now. He had given a blouse to Ma to stitch. Ma was not able to give it on time. So he went and badmouthed about her in front of others that she cannot give the blouse. I told him Ma cannot give the blouse, you take it. If you want you can give it later. But why do you have to say it in front of others? I did not like that. Then one day my friend, she also stayed on rent nearby, she had gone to the market to buy some things. She did not go to his shop, but went to another shop, so he asked her if the haat-katuwa-jonie* [the one with the amputated hand] *stopped her from coming to his shop. I felt very bad hearing this. He knows that my name is* [Dolly]. *Today this has happened to me, and that is why they are calling me by such names. It's okay. God is there, I am not going to say anything. If God is there why should I say anything?*

From the above narrative it can be seen that after her amputation, people started referring to her through her impairment and not by her name, and this was very hurtful for her.

Ananya hardly goes out of her home. One time when she was coming out of a mall, her hand got locked with another woman's hand. She said that after this the woman spoke to her very rudely.

> *Once I was going in the streets. My hand got stuck with another woman's hand. She said can't you see? Why did you touch me with your hand, etc.? The way she spoke to me, I got very angry. I asked her, "Did I touch you intentionally? I did not do it*

> *intentionally. My hand got stuck in yours, now what can I do?" I said this, made a face and then walked away. Later I told Ma about this incident. She asked me why I didn't call her then. She was walking a little ahead of me. She said "If you had told me, I would have taught that woman a lesson".* [She laughs].

She further said that another time when one of neighbor's sons imitated her bent hand and made fun of her in this way. She complained to her father about this, who scolded him for his insensitivity.

> *Papa scolded that boy. He said, "Why are you making fun of her? Is she doing it out of her own volition?"*

Ananya feels that her parents neglect for having an impairment. But in such situations, where they stand up for her, she feels very good that there is someone to support her.

Apart from the taunts and jeers about their impairments, some of the women also had to tolerate comments about their unmarriageability. While such comments made some of the women very furious, others got very depressed about what would happen to them in the future. The following narratives show this clearly.

Korobi's mother said that people started commenting about the fact that she will not be able to get married right from the time she was at the hospital recovering from her burn injury at the age of 17 years.

> *Korobi's Mother: Everyone said how would she get married?* [She and Korobi both laugh about it]. *There was a lawyer at the hospital. Her older brother was sick. She told me you won't be able to get her married when she grows up. This has happened to her, she will not be able to sit on the floor for the rituals. How will you get her married? She went on saying such kinds of things. She said that the other two will get married, but what will you do about her? She said like that.*
>
> *Korobi: People also said that your parents will be dead one day. They made me scared about such things. That is why I cannot leave my husband and go anywhere alone. I get very scared when he goes to his home.*
>
> *Korobi's mother: Then another time one girl came up to me and asked me if Korobi's marriage has been fixed. I said no. Why have you asked such a thing? She told me that Korobi told her so. I told her no her marriage has not been fixed. Later I scolded Korobi for lying. Why did you have to lie? Your marriage has not been fixed. Why did you say that your marriage is fixed? Korobi replied that that girl told her that she will never get married. You will always have to stay like this, she said like that every day. That is why Korobi said that her marriage has been fixed, and after that the other girl did not say such things* [she laughs].

The above narrative shows how frustrating the questions about one's marriageability can be for women with disabilities that they decide to lie so that they can shut up such comments forever. Similarly, Minakkhi's relatives had also made fun of her by saying that no one will ever marry her because of her impairment. She said,

> *Three people had said, "Who would marry you? You will grow old without marriage* [tears again rolled down her cheeks]. *Now those women, their children have not been able to marry. Three people had said this to me and now all the three of them are going through this* [she laughs]. *Whoever said mean things to me, are also going through the same now.*

Taking these cases into consideration, Minakkhi invoked the karma theory and again reiterated that no one should make fun of the bad fortunes of others, as if they do so, the same thing can happen to them as well.

Similarly, Lata also talked about how people told her that she will never get married because of her impairment.

> *People used to say so many things. At that time I also had the wish to get married. Now I do not have any such desire. Now I do not care whether I get married or not. But at that time I wanted to get married. But everyone said who would marry such a girl? Then I used to feel what is the point of my existence in this world? They used to say I have just come to this world to devour my mother's love. And this is how I would live for the rest of my life. That I will not be able to do anything else in my life. That I won't be able to work at all. They said such negative things. All these things made me depressed.*

To summarize this section, it was found that as women with disabilities grow up, they have to endure different kinds of taunts and comments from the people around them. This may include comments about their impairments or the likelihood that they may remain unmarried for the rest of their lives. Regardless of who passed these comments, the women reported being deeply hurt by them.

Relationship with Non-Disabled Peers

Apart from those persons with disabilities who grow up in segregated settings such as residential schools or special schools, persons with disabilities generally spend all their time in the company of non-disabled people. This aspect differentiates persons with disabilities from other marginalized groups such as racial or ethnic minorities, who may share geographical communities, workplaces, religious or other voluntary organizations (Scotch, 2009). In the case of the study participants also it was found that apart from those four women who had studied at the special school, the other women had grown up among non-disabled peers and had varied experiences with them. Even though some of them had met other people with disabilities in their lives, the mental and psychological impairments involved were so different that it discouraged mutual recognition of a shared social status (Scotch, 2009). Due to this reason it is imperative that we understand how such relationships affect their psychological wellbeing. This section elaborates on their experiences to suggest that there is no prototypical relationship between the women and their non-disabled peers. While some of the women enjoyed the company of their peers, others had many grievances against them.

After her failure in the board exams, Anamika was requested by her Pehi (father's younger sister) to live with her in Lakhimpur. Her Peha (father's sister's husband) was in the defense services and so lived away from home. Her Pehi had three young children and found it very difficult to manage everything on her own. Due to this, Anamika, at the age of 15-16 years, moved in with her Pehi and lived there for almost 10-11 years until her Peha took voluntary retirement and came back home. In her narrative, Anamika talked about how her life changed after she met her peers at her Pehi's home at Lakhimpur. She said,

> *When I was at home, I did not have to do the agricultural work. It was only when I went to Lakhimpur, to my Pehi's home that I started engaging in such work. Everyone did it there. If you have friends who are engaged in such work, you also feel like doing it. Here everyone restricted me from doing such kind of work. They told me you won't be able to do it. So don't do it. Don't walk in the mud. I was not allowed to lift even a bucket of water at home. But after going there, when everyone else is doing such work, I also felt like doing it. After having breakfast in the morning, I went to the field to sow the grains. We used to have lunch in the field. Then I return back home around 12-1 pm. Then again the others would go to the field around 4 pm. They would ask me to come along, and I would go along with them. Ahar (mid-June to mid-July), Xawon (mid-July to mid-August) and Bhado (mid-August to mid-September), these three months we would regularly go to the field. When the dhaan (grain) is ripe, in the months of Aheen (mid-September to mid-October) and Kati (mid-October to mid-November), we go to the fields in the morning, and the entire day we would cut dhaan. In the evening I returned back home, and then prepare dinner. Here I have not done such work.*

From the above narrative, it can be seen that Anamika was not allowed to do physically strenuous work at home out of the fear that she will face difficulty. However, after she went to Lakhimpur and met other girls of her age, she felt like doing all those chores that the others were doing. While she engaged in such kind of work only to feel included initially, it eventually gave her the confidence that she is as good as others around her, something that she did not realize when she was living in her own village due to the overprotectiveness of her family members.

Similarly, Uma also accompanied her peers to the agricultural fields only to feel included amongst them. In her narrative she talked about how as a child she grew up isolated from other children of her age as she was not able to play with them due to the weakness in her legs. However, at home she learnt to do everything that is expected of a woman in rural Assam such as weaving, sewing, *dheki diya*[153], and so on by observing her *Borma's* [father's elder brother's wife] daughter. When she grew up a bit, she started going to the agricultural fields with her friends just to enjoy their company. She said,

> *I had a few friends. We went together to the agricultural fields. I know how to sow grains. I had some difficulties in this kind of work, but still I went there with my friends, just for the fun of it… But still, I felt bad at heart. Their legs are fine. I am like this. That is why I felt bad. Even when I was having fun, I still had this feeling at the back of my mind. They are bhaal, they have no problem, their hands and feet are okay. I am like this. That is what…*

From the above narrative it can be seen that Uma also went to work in the agricultural fields just to have fun with her friends. However, even while she was having fun, at the back of her mind she was never able to forget about her impairment. When I asked her if her friends made fun of her, she said,

> *No they have never made me feel different as such. They have never said anything to me. But sometimes other people have made fun of me. That I am like this, my leg is like this. They said such things. Since it is a village, people talk like that. I felt bad when people said such things. Sometimes I used to feel what kind of paap* [sins] *I may have committed that this has happened to me.*

After marriage, when she moved to a more developed village in the Block, she said that people no longer spoke to her like that, which in turn made her feel confident about herself. She also said that she was no longer required to do any kind of agricultural work as her husband was capable of hiring waged laborers for the work. Moreover, her husband also restricted her from doing other physically strenuous work such as weaving, *dhenki diya*, and so on as he was concerned that it might aggravate her condition. All such restrictions made her feel very upset initially. But he also

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[153] Dhenki is an old style rice mill or husk lever, which is made out of hard wood. It has a fulcrum that supports the weight. Due to the force of the weight upon the rice pods, the rice and the golden brown rusks separate. Dhenkis are found in the eastern Indian states of Assam, West Bengal and Odisha and the neighboring country, Bangladesh. They are usually operated by women to produce rice from paddy and grind rice to powder.

introduced her to the organization Sanjeeboni through which, for the first time in her life, she was introduced to other women with disabilities. This exposure enabled her to overcome the initial grief in her heart about being different from others because of her impairment.

Some of the study participants, however, said that their non-disabled peers do not understand their problems, and sometimes also make fun of their concerns. Lata said that when she was young, she wanted to write songs and sing professionally. But she never received any encouragement from her friends. She said,

> *When I was young, I liked to write songs and I had the wish to sing professionally. I used to sing a lot in my childhood. I only remained quiet during my time in school. I have not done any programmes. But I used to sing at home all the time. I have never performed at any platform till today. I had the wish, but I was also very scared at the same time. There was no one who encouraged me. I used to feel somebody would say something because of which I might feel ashamed… When I shared such things with my friends, they would make a joke about it. Not everyone can understand about others. When I was in Higher Secondary, I told my best friend that I have written a Bihu song. She just laughed at me and said, "You would now become a singer". Nobody took me seriously. I found no one who could give me strength. Otherwise I could have done so many things with my life. This is what I feel. No one ever gave me any strength.*

From the above narrative it can be seen that as a child Lata wanted to sing professionally, but she was never encouraged by anyone around. In fact, once when she shared her dreams with her best friend, instead of supporting Lata, she made fun of her. This had a deep impact on her self-confidence. She also said that when she was young, she often went for Bihu[154] dance rehearsals but she never had the confidence to for the actual performances.

> *I did not have any self-confidence. Because of my disability I used to feel, I am like this, can I even dance? I can do Bihu dance. Before the Bihu festival, I go for the Husori[155] rehearsals. After coming back from school, some 4-5 of us would wear mekhela sador and assemble at someone's yard or at someone's home to practice. I really liked it. But I never went for the actual dance thinking that someone might say something. I was able to do it, I was also thin at that time. My friends used to ask me to come along. But Ma never allowed me to go. It was so sunny, she used to say. And*

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[154] Bihu is a set of three non-religious festivals that are celebrated in the state of Assam. Rongali or Bohag Bihu is celebrated in the month of April; Kongali Bihu or Kati Bihu is observed in October; and Bhogali or Magh Bihu is celebrated in January. Here Lata is talking about the Rongali Bihu, which is celebrated at the onset of spring in mid-April. In this festival, young men and women dance Bihu, which is an indigenous folk dance and an important part of Assamese culture. Although the festival is primarily identified with the Assamese society, parallel forms of the festival are also celebrated among the different ethnic communities of Assam.

[155] Husori Bihu is performed in the courtyards of villagers of Assam.

> *what if someone said something about why such a girl has come to dance Bihu. I would be hurt. She thought it would be better if I do not go.*

From the above narrative it can be seen that her mother was also responsible for dampening her spirit as she felt that it would be better than getting humiliated by her audiences later. She said,

> *I used to feel slightly bad when I was not allowed to go for the performances. I wanted to go… When I am with everyone, I forget all my sorrows. I go with them and I am engrossed with the work, whatever it is. I really like it. But when I am alone, then I am surrounded by all the worries.*

From the above narratives it can be seen that Lata wanted to participate in Bihu and other song and dance functions but she was always very self-conscious about whether others would accept her or not because of her impairment. As the narrative shows, Lata's mother also restricted her from participating in the social events because she was unsure about how the society would react to seeing her daughter being a part of such functions. She felt that it would be better if she doesn't participate in such events at all, than to go there and get humiliated. Moreover, during her growing up years she also realized that her peers did not understand her desires and aspirations that made her even more reclusive. All these factors had a considerable toll on her mental wellbeing.

This section tried to show the relationships that women with milder disabilities shared with their non-disabled peers. While some of these women were accepted unconditionally by their peers, others were often made fun of and excluded. Later when some of these women discovered the disability organizations, they also started to realize the problems that persons and women with disabilities face as a collective. This enhanced their self-consciousness that what they had gone through in their growing up years was unfair. On the contrary, women with severe impairments either had restricted entry into the non-disabled world, like all the four women who were interviewed from Senehi, due to which they did not have non-disabled peers; or those who had interaction with non-disabled people experienced subtle exclusion and paternalism (as explained earlier in the chapter in the case of Gargi and Korobi).

Gender and Impairment: Experiences of Women with Disabilities in Public Spaces

Much of the literature in disability studies has focused on the accessibility of persons with disabilities in the public spaces (Barnes & Mercer, 2003). In spite of this, much less work has been done on how women with disabilities experience public spaces. In this study, the participants narrated different types of fears they have of public spaces, that sometimes bring to the fore their gender, while at other times their disability. As cited earlier, the participants of this study represent a range of disabilities ranging from mild to severe. Accordingly their access to public spaces is defined by their disabilities as well as the amount of support they have received from their families and through other factors such as level of education attained, contact with the disability organization, and whether or not they are employed. As can be imagined, the women with severe disabilities had a tough time in coming out of their homes because of the infrastructural constraints they faced due to their impairments, as well as their dependence on others for mobility. The following narratives give a glimpse of this.

Ananya's biggest problem is that she is not able to go out of her home alone, and has to depend on someone else for this. During the interview, she said that she loves coming to Senehi for her ICT classes as this is the only social contact she has with the world outside, and gives her a good opportunity to connect with her friends, who also come for the classes. These classes take place twice a week from 11 am to 12 noon. The timing of the special school is from 9 am to 1 pm. As a result it is not feasible for the students of the ICT class to avail the bus facility, at least in the morning, even though some like Risha take the bus in the morning and wait till 11 am for the classes to begin, and then wait for another hour for the bus to drop them home. In the case of Ananya, who does not live very far from the organization, this is considered to be a wastage of lot of time, and due to this reason, she comes to the school around 10.30 am with her father, who drops her on the way to his work. Sometimes she is also dropped early, depending on her father's work schedule. On the days he is too busy, she has to skip the classes, which makes her very sad, as it is only two days in a week that she gets this opportunity. Apart from these classes, Ananya's social life is very restricted. On one of the days of the interview, she narrated that she was very upset with her parents as she would not be able to go to her best friend's birthday party the same evening. Her friend's home was located in another end of the city, and she knew very well that her father would not take her to the party, so she did not even bother to ask him. She said,

> *They know that I get bored at home. But what can they do by knowing about it? Tell me that. They know about it. But what can they do? Today is my best friend's birthday. She invited me for the party. But she lives very far. Had it been near, Papa would have taken me there. But because it is far, he would not take me. There is no point in even asking him about this. That is why I haven't even told him. Even if I tell him, he would not take me there. I would feel bad if he says no. That is why I haven't told him… When I feel sad about all this, I usually take a walk in our front yard, or I play with my young cousin. My parents do not come to know that I am sad. How can they know? When I am laughing and playing with my cousin all the time, how can they know?*

The above narrative shows Ananya's helplessness and dependence upon her parents to take her out of her home. She also said that because of her dependence on them, she has not been able to go even to Fancy Bazaar or Paltan Bazaar [popular local markets in Guwahati] and she feels very sad about this.

> *I have never been to Fancy Bazaar or to Paltan Bazaar. I have been to the malls, but not to these markets. I want to go there, but my parents do not take me. So what is the point? I cannot go there because of the crowd. That is why they do not take me.*

She further said that her clothes are usually chosen by her mother, who, according to her, does not buy her as many clothes as her sister, because she does not go out so much. Ananya said,

> *It is Ma who usually buys our clothes. When Ma buys Kurtas for Ba, she does not get them for me. I feel bad in such situations. Even if I have many clothes, even though I do not go anywhere, I agree to that. But sometimes I do go out, isn't it? That is why sometimes I feel bad. She got two Kurtas for her, but she did not get anything for me. I feel bad.*

The above narrative shows the difficulties that women with severe disabilities face in going out of their homes because they need to depend on their family members for the same. In certain cases, like that of Ananya, parents and other family members are too busy with their own work schedule to take out time for their adult children's leisure activities. As a result, some of them develop resentment against their family members. Her narrative also shows that due to her lack of access to the outer world, she also feels that she is being discriminated at her home, as her parents give her sister more importance than her. In other cases, parents and siblings seem to go out of their way to ensure that the women have access to the world outside.

Risha also talked about the difficulties she faces in coming out of her home especially after her fall that resulted in severe back pain. Prior to this accident, she often went out with her mother in the evenings to the parks and market places in the city buses. However, after her fall her social circle is limited to going to the organization for her ICT classes. But she finds it very difficult to walk to the bus stop to board the school bus. She said that this difficulty is eased by her younger brother who drops her at the bus stop on the way to his workplace so that she is able to attend her classes. In the afternoons, her father picks her up from the bus stop and together they come back home in a rickshaw. Similarly, Sobiha and Gargi are helped by their family members in going out of their homes so that they can attend their respective schools. While Sobiha's mother's effort is to keep Sobiha engaged so that she is not bored alone at home, Gargi's mother wants to give her a proper education so that she can live independently one day by giving tuitions to young children in the neighborhood.

In the above narratives it can be seen that parents and other family members make sufficient effort to help these women in going out of their homes and engaging with the world outside. It is worth mentioning that the women with severe impairments have hardly ever gone out alone of their homes. Risha and Nayana mentioned that when they were students at Senehi, the school had organized camps for them in places like Darjeeling, Sikkim and Kolkata. They cherish those moments immensely as these camps gave them the opportunity to stay away from their overprotective family members. However, as adults they have gone out only once for a friend's wedding. Both of them said that they enjoyed the experience of freedom a lot, but were not sure if they would ever go out again together for such leisurely outings. One of the reasons for this is the lack of accessible transport facilities and public spaces where persons with disabilities can go and hang out with their friends, and also the lack of confidence that they would be able to manage on their own in places outside of their comfort zones.

While some parents' vision is limited to education, mostly because of the lack of knowledge of the lives of people with disabilities, other parents have supported their daughters in achieving what they are capable of, primarily through the help of the organization that they are associated with. Nayana's narrative gives a good illustration of the support that she has achieved through the disability organization Senehi. Considering the financial background of her family, the teachers of the organization decided to get her engaged in the work available in the organization itself. Initially she was involved in running the canteen of the organization, but when it became apparent that she is not much interested in this work, she was considered to be eligible as the coordinator for the new project on women with disabilities. Despite this, Nayana, who uses a wheelchair for mobility, narrated that her difficulties with accessibility continue to exist. She said that since there is no ramp in the school bus, either her mother or her *Khura* (father's younger brother) have to physically lift her up to her seat in the bus. Due to this reason, people often stare at her in the streets. She said that only a few days before the interview, one woman stopped on her way to see Nayana being carried to the school bus by her *Khura*.

> *Only a few days ago, a woman was staring at me. Khura was carrying me to the bus. That woman looked at me so much. She stopped and looked at me as if she is watching something else. She watched that way. I literally laughed looking at her. I thought, how nice! ... I don't know why people stare at me like that. Maybe they think, let me see how they are carrying her. They may feel like that. Or they may think why they are carrying such a big girl. Everyone thinks differently. We cannot predict what they think.*

From the above narrative it can be seen that women with disabilities experience accessibility issues in buses, which is overcome only due to the support from family members. It is ironic that even in the school bus of a disability organization, persons with disabilities have to face accessibility problems. Additionally, Nayana also talked about the staring that she needs to endure on a daily basis because of her accessibility problems.

Lata also said that she feels self-conscious when she is out in the streets and even people are not looking at her, she feels that they are looking at her.

> *I feel sad when I find people staring at me. They are looking at me to see how I walk. Some people are looking at me. Some people when they see me for the first time, then they would look at me. Even if someone sees me nicely, I think I still have the same feeling. I do not know. If some boys look at me, I feel they are looking at me because I am walking in this way. I feel I would not look at them* [she laughs]. *I feel in this way.*

Similarly, Dolly also said that people stare at her when they come to know that her hand is amputated. She further said that she does not mind the stares, but she hates when others tell her life is now worthless because she does not have her hand. She said,

> *I feel sad when people stare at my hand. I feel that they are staring at me today because I do not have a hand. That is why I usually hide my hand. Due to this reason,*

> *they do not usually get to know. But when they get to know and look at my hand, then I feel sad. Then I think, okay keep watching. What can I do now? How much can I hide? But I feel bad. I do not mind the staring, but when they suddenly that your life is a waste now, you will not be able to do anything, then I feel angry. Then I feel that whatever I am earning today, I am doing it by myself. I feel that way. Let them say whatever they want*

From the above narrative it is seen that Dolly gets very angry when other people comment about her hand. In such moments she feels that regardless of her difficulties at least she is able to work and earn a livelihood, while there are so many other people who are not working despite being non-disabled.

Other than the difficulties of coming to the school or workplace, several women citied their problems in accessing public transport for their other work activities. Some of these problems include the inaccessible design of these modes of transport to accommodate persons with disabilities and the attitude of fellow passengers who do not vacate the seats that are reserved for persons with disabilities to these women. The following narratives give a glimpse of the kinds of problems that the study participants have faced while accessing public transport that have curtailed their freedom in going out.

Bandana said that there was a time when due to her overprotective parents she found it extremely difficult to go to school by herself. However, all this changed after she came into contact with Kishore, the founder of Moromi, who took her around to different places in relation to work, and also to familiarize her to the world outside. This often angered her mother who asked Kishore not to take her out as she was scared for her daughter's safety. Bandana said that during such moments Kishore told her mother that he or her mother would not be there with her forever, and for this reason there is a need to teach her how to be independent. She said that it is because of his efforts that now she is able to go anywhere in Guwahati all by herself. With great pride, she said that she has even been to her Mama's home in Nalbari[156] all by herself without the help of anyone. In spite of her confidence, Bandana still has to confront unnecessary staring in the streets. During such occasions,

> *I do not pay much attention. I see them and then I move away. I do not think about it. Let them do what they want to. I sometimes show them that I have not seen anything and I have not heard anything. I do not react that I have seen or heard them.*

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[156] Nalbari is a town in the Nalbari District of Assam. It is located at a distance of 71 km from Guwahati.

Developing a thick skin, therefore, becomes imperative for these women. However, not all women have been able to do this, and the comments of other people have often hurt them. Despite the courage displayed by these women, there are times when fellow-passengers show them 'their place' by pointing out how different they are from others. Bandana narrated that there was one time when she was travelling with her mother in a bus when a person pointed her out to some others and said, *"What has come, just see!"* Her mother retorted back to those people by saying, *"What has come can you not see? Why do you have to say it like that?"* This incident made her feel very hurt and also very angry.

Unlike the experiences of persons with disabilities in many other studies, majority of the women who were interviewed for this study had positive experience of traveling by public transport. The following narratives give a glimpse of their experiences. According to Bandana, conductors and handymen of the buses have always helped her in boarding buses.

> *The conductors and handymen in the buses have always helped me. They stop the bus for me. They also ask me if I have problems in getting onto the bus. They ask Baideu do you want help. I say no need. When there is no need, I say no need. Some buses are very high. Then I say hold my hand for some time I will get down. Or even when boarding the bus, I say someone help me. When buses are not very high, I take such buses. Now it is good. There are lower buses* [low floor buses], *it is easier to get on to them.*

Similarly, Uma also talked about her good experience of taking a shared auto to the organization for her vocational training.

> *I tell them, Bhaiti stop a bit. I have a bit of difficulty* [oxubidha] *in my leg. I tell them wherever I go. That I have difficulty in my leg, Olop Lahe Lahe* [drive slightly slowly]. *I tell them like this… I tell them, Bhaiti stop the vehicle nicely, I tell them like this… Then they drop me nicely. I have not faced much of a difficulty.*

Pronoti also talked about the difficulties she faces especially while boarding a bus.

> *I have difficulties in boarding a bus. I do not have difficulties in other vehicles. If the vehicle is taller then I face difficulty. I have difficulty in alighting. Sometimes my foot would twist while getting down. So I usually alight very slowly. I ask the driver to stop the bus slowly, I have difficulty… They ask if I need any help. Sometimes they help in getting down or getting into a vehicle.*

She also mentioned that since the last couple of years she is able to move around on her own. But prior to that, she always needed someone from her family to travel with her so that she can hold their hands while alighting from the bus.

Gargi's mother also said that the handymen of these shared auto-rickshaws help Gargi in boarding and alighting from these vehicles when she has to go to Guwahati for her treatment. She said that it is very difficult for her to make her sit on her laps while traveling, and in this kind of situations they help her in managing these difficulties.

In spite of all the help that is provided to them from the conductors and handymen, some of the women have complained that they do not get the seats that are reserved for them. Bandana points this out vividly in her narrative:

> *One mistake that the handy man or the drivers do is that the seat that is reserved for us, general manuh [non-disabled people] occupy those seats. And they do not say to them that Dada or Baideu vacate the seat as it is reserved for such people. They do not say anything. We are the ones who need to ask for the seat. If we say Dada please ask them to vacate the seat, some help us, but others do not… But if gents sit on a lady's seat, then they say vacate the seat. But if someone is sitting on this seat, then they never say that vacate the seat. I do not know if they do not know how to read, or they do it intentionally. I think they do not understand it. Some people might be like that… When I travel by buses, I am very vocal if people do not vacate their seats. I tell them to erase the sticker, what is the point of uselessly sticking the poster when nobody abides by it. And those who sit there, those who vacate the seats it is fine, if they do not then I say Dada if you are literate then please see there. What is written there, just read it. I need to stand there. Even when I ask them to vacate their seats they don't. They say it is not ladies' seat. They say like that. It is not a seat for ladies. I say it is not ladies', but something else is written there. That is why I am saying so. Read it properly and then vacate it.*

The above narrative shows that fellow-passengers are aware about the seats that are reserved for women and often do not sit on those seats, or vacate it when they see a woman boarding the bus. But the same is not true in the case of seats that are reserved for persons with disabilities. Unfortunately, bus conductors and handymen, who are supposed to help these women in such matters, also remain silent through their predicament. In the city buses, eight seats on the left side are reserved for women, while two seats each are reserved for persons with disabilities and elderly persons on the right side. When Bandana, a woman with visible physical disability asks a person to vacate the seat for her, he retorted back saying that the seat is not reserved for women, even when it is clearly mentioned that the seat is reserved for persons with disabilities. Jeuti also mentioned that in a majority of the cases, people who occupy the seats of persons with disabilities do not vacate it in spite of showing them that the seat is not meant for them. Jeuti said that for someone like her who has a mild disability, are able to manage without getting a seat on the bus. However, others with severe disabilities need to be considered and given a seat. She feels that the world is too selfish to consider the needs of others. It is a matter of speculation whether this lack of awareness is due to the lack of visibility of such persons in the public arena, or just a matter of ignorance of their needs as a special category requiring special benefits. In either case it is a matter of serious concern that the rights of persons with disabilities are not met and they have to fight for a seat every time they board a bus.

While some of the women are very vocal about their rights, perhaps also because of their enhanced awareness about disability issues, other women do not want to ask for special privileges because of having a disability, something that is guaranteed to them through the Persons with Disabilities Act of 1995. Some of the women are seen to consider it to be a matter of great disgrace to ask for their rights while traveling by public transport. Dolly's narrative gives a good illustration of the thoughts that run though the minds of women who refuse to ask for special concessions that are, as a matter of fact, their rights.

> *I usually hide my hand. Because of this, they do not come to know that I do not have a hand. Only if they see me, they will give me the seat. And I do ask for help showing them my hand. I do not want such help … I realize that if I show this hand, I will get some help. I will show them my hand. I do not have any problem. But for myself, showing this and getting the ticket for half the price, I do not want that. I want to live like a normal person. Would you want to give something to me in pity? I do not want anyone's pity. You can give me saying that this girl can do it, but do not take pity on me.*

From the above narrative it can be seen that Dolly considers it to be something beneath her dignity to show her hand or her certificate to get a ticket for half the price or to get a seat that is reserved for her. This is in spite of the fact that she finds it extremely difficult to travel in a bus by standing because of the difficulty in holding onto something. When she travels with her friends or her family members, they ask her to sit down in case there is a vacant seat.

After her burn injury Korobi finds it very difficult to board a bus or take a rickshaw for going out. Usually she travels in her mother's car for going for her health checkups or for going to the homes of her relatives. She usually awaits the visit of her second sister, who lives with her family in Calgary, Canada, to take her out to restaurants and hotels for eating out. Her husband said that she loves to go out of her home, but due to the difficulty of arranging a driver for the car, she has to live at home most of the times.

It is probably due to such kind of difficulties that several women with severe disabilities have not travelled in a bus in spite of the fact that they receive travel concessions in the buses. Nayana, who uses a wheelchair for mobility has not travelled by a bus since the age of 10-11 years, that is, roughly the age when she grew up and it became difficult for her parents to carry her around. She also said that the buses do not stop for people like her because they see her disability first. As a result she travels by auto-rickshaws which charge exorbitant fares for very short distances. On top of that Nayana is also asked to pay Rs. 20-30 extra for taking the wheelchair. All this makes her very angry. She also said that due to the condition of the roads she is very scared to go out of her home in a wheelchair.

> *Sometimes I need to keep waiting for an auto-rickshaw. If I do not get one from our home, I need to come to the auto-stand. But the road to the auto-stand is very uneven. I feel scared that I might fall down. I cannot take the footpath also as their conditions are even worse. Due to this reason, we need to take the road and come in between cars. It is very scary for me and the one who is pushing my wheelchair.*

From Nayana’s narrative it can be seen that persons with disabilities are often exploited by unscrupulous auto-rickshaw drivers who charge her more only for using a wheelchair. Such an attitude further curtails the movement of persons with disabilities outside of their homes.

Other than these difficulties that are directly related to their impairments, women with milder disabilities have also experienced sexual harassment in public spaces (or anticipate sexual harassment in public spaces) that have curtailed their movement outside their homes or have made them fearful about going out of their homes late in the evening or even in the day hours in isolated places. While most women, regardless of disability, have such fears (Mahadevia et al, 2016), what makes their fears more palpable is their notion that they would be unable to fight back a potential perpetrator. Minakkhi gets down from the shared auto-rickshaw and has to walk for about 500 meters in the highway to the organization on the working days. During the interview she said that she finds this walk very frightening. She said,

> *I fear that someone might just take me away, from the way. I have such kind of a fear. I come to the office by walking. Although it is not very far, I am scared of walking this way on the road. When the vehicles are coming, I fear that someone might stop and take me away… Sometimes, some mad persons, if they see me, they might take me away and do something… that is the kind of fear I have. Although it is not very common, I have heard that such things happen sometimes. Otherwise, I have no fear. I have been to places as far off as Rangia[157] all by myself.*

Several other women recounted their fear of going out in public spaces out of the fear of sexual harassment and rape. Nayana said,

> *As a woman, what would I be scared of? I am scared of only one thing. What I have been hearing. Earlier I was not scared of this thing. Now I have heard so much about it that I am really scared at heart. I have heard of it, I have seen it. The cases of abuse, rape and molestation: these kinds of incidents. When I will have to stay alone, maybe something of this sort will happen to me. Now I stay fearlessly, may be due to this reason people are scared of even looking at me, even though they do want to look at me.*

Many of these women have experienced eve-teasing on the streets or were inappropriately touched in city buses and found such encounters extremely uncomfortable. Jeuti said,

> *Yes I have such experience in the streets. Nowadays the 'system' is such that the younger boys they do not tease us. Now it is the middle aged men who tease girls on the streets. He is an elderly man, he would be the age of our father. If a boy is teasing that is a different thing. We have gone out so they have teased us, that is a different thing. But an elderly man teasing us? When we get into a bus and an elderly man stares at us badly, that is very strange for us to see. That is the thing… According to me in such situations one should make a public spectacle out of it and must give them a public 'dhulai'* [beating]. *If an elderly man teases a girl who is as young to be his daughter, or we get to hear that it is the men who mostly get involved in such things, younger boys have reduced nowadays.*

Similarly, Dolly has also faced sexual harassment in the buses.

> *I cannot tolerate crowd. Someone would step on me, and I would not be able to ensure my safety. That is why I do not get into a crowded bus. That is why I get into buses which are not so crowded. One day this has happened to me. I got into a bus, and I do not have this hand, I was about to get the ticket. I hate it when people touch me. When he gave me the ticket he was about to touch me. I got very angry. I threw away the water bottle, the bus started moving. I did not come to know about it. I kicked him and I was about to catch him. I was not able to kick him. I thought today I will beat you up. You were going to touch me. You were about to touch a girl. Why*

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[157] Rangia is a town and a municipal board in the Kamrup Rural District of Assam. It is located at a disatance of 53 km from Guwahati.

> *are girls not safe? I cannot understand this. Why are girls not safe enough to get into a bus? I do not understand it. That is why I feel if I am a big person then I would help girls. I think in this way. I am very scared about travelling by buses. Ma says why don't you get into a crowded bus? I tell her that I am very scared. If required I will travel by a trekker, but not in a crowded bus. I look for light buses. Bhaiti says it would be good if your travel with a boy. Whether it is a boy or a girl, everyone is busy… My only fear is what kind of boys will get into a bus, what they will do. That is all. Otherwise I have always found it good. I have never had a bad experience. That was the only bad experience in my life. For my safety someone has to be there with me. No matter what is done for the safety of girls, girls will never be safe. That is why I feel that I will have to ensure my own safety. I told Bhaiti teach me Kung Fu, teach me Karate. I will have to ensure my safety in order to go out. Bhaiti says you have gone mad. How will you save yourself with one hand?* [She laughs]. *You have gone mad, now you keep quiet and sit down… I felt very bad when that person touched me. One day a woman was traveling with me. She was facing some difficulty, and she told me I am facing this difficulty. This man is pushing me. That man was drunk. Immediately I stood up. I told him to get down from the bus. He asked what happened. The conductor and the driver asked what happened. He is doing bad things, get him out. They got him out. Places should be safe for women.*

From the above narratives it can be seen that unlike the popular perception about women with disabilities as asexual (Ghai, 2003) that often make parents neglect their vulnerability (Ghosh, 2013), women with disabilities do in fact face sexual harassment in public spaces or while accessing public transport that sometimes make them wary about going out alone. Unfortunately there is not much talk about this, perhaps because they are seen less frequently in public spaces.

Relationships with the Significant Other: Finding Love and Marriage

As elaborated in Chapter 2, since arranged marriage is the norm across different parts of India, women with disabilities are least expected to get married. In cases where their marriages are fixed, it is adequately compensated by a handsome dowry. In rural areas, however, parents of women with disabilities are under tremendous pressure to get their daughters with disabilities married, and due to this they apply almost any means that is available to them. This in turn puts the women concerned under the risk of violence, abandonment and separation. Studies have also shown that 'love marriages' are also not very secure as defying the family and marrying someone of one's own choice can lead to absolute isolation later in life in case the marriage does not work out well. While this is true for all women regardless of their disabilities, having a disability puts them in a more vulnerable position as they usually do not have the skills to earn a livelihood to sustain themselves and their children.

This section elaborates on the theme of the relationships of the study participants with their significant others, or why they consider marriage to be an impossible ideal for them in the context of Assam. This section is divided into two sub-sections. The first sub-section deals with the experiences of the unmarried women, or of the married women when they were unmarried, while the second sub-section deals with the experiences of married women.

The Concerns of the Unmarried Women and their Parents: As has been stated earlier in the chapters, a vast majority of the study participants were unmarried. When asked if they have ever thought about marriage, the oft repeated reply was, "*But who would marry me*?" because of their impairments. During the interview, Ananya found it funny that I can even ask her such an outrageous question. She considered herself unattractive because of the nature of her impairment, due to which she felt that her marriage was a distant possibility. Ananya professed her love only for the Hindi film actor, Siddharth Malhotra. She said that sometimes, out of fun, she would ask her mother if someone would marry her. Her mother's response speaks volumes about what the society thinks about the marriageability of women with disabilities.

> *Sometimes I ask Ma, if someone comes to marry me, would you give me away? Then Ma replies, we would but in today's world there are no Mohaan* [great] *people like that. There are no such people.* [She laughs].

Similarly, Risha also laughed off the question of marriage by saying that it is not possible for someone like her. She also said that her parents have never given her marriage a thought. These narratives show that women with severe locomotor disabilities consider themselves to be unattractive and incapable of getting married.

Hema also felt that in her condition, no one would accept her for marriage. She feels that due to this reason, her father is supposed to give her a share in the property so that potential suitors get attracted towards her for this reason. Her father, however, has refused to take any stand on this matter.

> *No I haven't met anyone at all. Now in this condition no one would accept me, that I know. I am saying this to you as my own. People ask me, won't you get married? I say are you mad? Who would marry me? Such a thought comes out. People have asked me, but I do not want to get married. Marriage is not a big thing, to be able to*

> *work and survive, that is a big thing. That if I get married, I would find happiness. There are so many bhaal girls, they do not find happiness. And I am a lengera manuh, who would accept me? This is what I think. Then if someone presses a lot, then I say, ok bring someone I would get married. Then they remain quiet* [she laughs]. *It is like that. According to me, if I find some happiness, it would be good. There is a lot of chaos in our family from all sides. Actually if the main person is good then there is no chaos, then who is Dada and who is Bou. They are all others. If my own Deuta is fine, then others cannot do anything. Isn't it? If today Deuta says I would give her away in marriage, otherwise who would look after her. Now in this era, if you are trying to find a boy, then you would definitely have to give him property. Only then he would accept. I am talking about a girl like me. If I have property like this, then I would get many suitors. Would they come or not? But without property you cannot look for a boy. You would have to give something.*

Some of the women also expressed their fear of getting married due to the possibility of domestic violence. Surabhi said,

> *If I get married, we hear so many stories about bhaal women, we are bikolango. So they will see us with evil eyes. So I am scared. That is why I do not open my heart for getting married. I am okay this way. That is what I think.*

From the above narrative, it can be seen that Surabhi considers herself to be more vulnerable to domestic violence because of her impairment. Although she did not mention it explicitly, it seemed as if she only considered a non-disabled person as a prospective husband. It was found that her family also preferred a non-disabled husband for her. This point came out clearly during my interview with Surabhi's sister, who said,

> *There was one proposal from a boy, who had some problems like her. Ma did not want to get her married to him. How would he feed her? Later they would have had problems. She is not able to do anything. She is not even able to comb her own hair. When she comes out either Ma or I comb her hair. She is able to wear her clothes, but she is not able to comb her hair. How will she run a home like this? After marriage, whatever it is, all the responsibilities of her xonxaar* [conjugal life] *will be on her. How will she manage?*

From the above narrative it can be seen that Surabhi's family decided to decline the marriage proposal because of the prospective bridegroom's impairment. Comments such as *"How would he feed her?"* and *"After marriage ... all the responsibilities of her xonxaar will be on her"* clearly shows the gendered assumptions about husbands and wives in a marital relationship, that clearly men and women with disabilities fail to fulfill due to their perceived incapacities. Unfortunately such perceptions are not an exception, but the norm that perhaps all persons with disabilities have to struggle against when they decide to be in a relationship and get married.

In the case of Minakkhi it was found that when she was younger, she was interested in getting married. But with the passage of time she has begun to realize that she is in a much better condition in her parents' home. She said,

> *When I was younger I wanted to get married. But now my age has passed, isn't it* [she laughs]*... Now I am working here at* [Sanjeeboni]*, I am living well. If I want to eat something, I eat it. If I want to travel, then I travel. I have no tension. After marriage there is too much tension from husbands. I will have to care for the needs of the family members and so on. Who would keep on doing such work all the time?*

From the above narrative it can be seen that Minakkhi feels that she is living quite peacefully with her natal family who value her concerns instead of worrying for the needs of other family members as would have been the case if she was married. She had seen several examples of women in her village who need to suppress their own wishes and desires for the wellbeing of their husbands and children. She feels that at her age she will not be able to think this way anymore. For her parents, however, her marriage is not so much about companionship, but more about securing her future against any kind of uncertainties. Minakkhi's mother said,

> *If something happens to us before fixing her marriage, then she would be really sad. We would also feel very sad. If we are able to give her to some family, then we would have been free. This is what I feel at heart. For parents, if we see our children married off, we can die peacefully. Isn't it? But if her marriage is not there in our bhagyo, in our kopaal, then how can it happen? This thought still keeps on haunting me. If it was possible to get her married, she would have been able to survive somehow. She is able to do all the work. She can read, she can weave, cut, wash, she knows everything. If only we can get her married, this is what I feel. But who will take her? They look at her face, and then they look at her hands. That is why she is still here. Many proposals had come for her. I cannot say that proposals had not come. Many boys had come to see her, but none of them were successful. Sometimes we did not like them from our side. Some did not have land; some did not have a source of livelihood. That is why we cancelled them. They were all bhaal lora* [non-disabled men]*. No beya lora* [disabled men] *had come for her. All bhaal lora had come to her kopaal. I do not know if she cannot be a part of a couple or if she is not supposed to get married. This I do not know... I have only this one worry for the future. If she was bhaal, I could have given her away* [at marriage]*. Since the other two are bhaal, they are both gone now* [married]*. If she was also bhaal, I could have given her as well. Now Mai-Bapok* [parents] *will have such worries. We have not been able to get her married, what to do? She will remain like this. We cannot throw her away because she is not married. She will work at home and eat.*

From the above narrative it can be seen that for Minakkhi's mother the marriage of her children (especially of her daughters) is the most important sacrament. She feels that only after seeing Minakkhi (her only unmarried child) married, she and her husband can die peacefully. It was found that she was so desperate for Minakkhi's marriage that she had even consulted a *gonok* to find whether she would marry or not.

The *gonok* told them that she ‘might’ get married due to which her family seemed to be very hopeful. Her mother said that Minakkhi is capable of doing all the household chores and so she will never face any problems in her married life. However, according to her, her daughter is probably unmarried until now as it is something that is not written in her *kopaal.* Even though she seemed to be very concerned about Minakkhi’s marriage, she and the other family members have given her the agency to decide whether she wanted to get married to a particular person or not. This becomes clear in the following narrative.

> *Recently we received a proposal from a boy. Anyways her brothers and her father, the entire family, in fact, we have all decided that just like the brothers get their share in the property, we will also give Minakkhi her share. We have decided that we will have to build her a home. We have all decided about that. Because of this, one proposal had come for her. We liked the boy. He is from Nagaon side. He does not have anybody in his family. He does not have his parents. Since childhood he has lived with others, and now he is able to do some pukka work, he is able to make homes. That is why we liked the boy. When he came here, Minakkhi did not like him. He was a working man, he slept anywhere. There was this difficulty of arranging food. There was no guarantee of it. He eats at the homes of others. He comes back after work, someone else cooks for him and serves him, and he eats. And then he goes elsewhere. Can such people have good health? His health was not so good. If good care was taken, maybe his health would have improved. That is what we had thought. We tried to explain it to Minakkhi. He is a working man, and that is why his health is not good. Maybe when he starts his own xonxaar, it will be better. We really wanted to get her married to that boy. We wanted to see him, so we invited him here. So that we can also see him, and he can also see us. The boy and the girl would also see each other. That is why we asked him to come here. After seeing him, we all felt a little sad in our hearts. She also felt a little bad after seeing him. She did not like him. That is why she just left the matter behind her. Otherwise they would have been married off this year… We also did not have bhagyo, he also did not have bhagyo. That is why this had happened. Only when things are written in their kopaal, such things happen. Isn’t it? Things should be written in their kopaal.*

From the above narrative, it can be seen that even though Minakkhi’s mother was very hopeful that she would get married to this person, Minakkhi rejected him. The narrative clearly corroborates the findings from existing literature that have shown that parents are sometimes too desperate for the marriage of their disabled daughters that they feel that the greed of property would interest prospective bridegrooms to marry their daughters, regardless of the man’s social class or health condition. Fortunately, Minakkhi was given the agency to decide whether or not she wanted to get married to the person, an opportunity that many women with disabilities in this country are denied (see Klasing, 2007). One of the reasons why parents gave so much importance to marriage was because they were unsure whether their non-disabled children would eventually look after their disabled children or not after the parents have passed on. Ultimately, her mother considered Minakkhi's *kopaal* to be responsible for her unmarried status.

In certain cases the women were also found to blame their *kopaal* for their unmarried status. Dolly said,

> *I think marriage is not written in my kopaal* [she said this with a sarcastic snort]. *That is why I am not tensed about it. I feel that my kopaal is very bad. I know that marriage is impossible for me. My kopaal is not so good. It is not like other peoples' kopaal. Sometimes I see others and I feel good that they have been able to get married so nicely. They have a shonshar* [Bengalis pronounce *xonxaar* as *shonshar*]. *I feel that it is not for me, and I have made peace with this realization. That is all. When I am idle, sometimes I feel good. But at other times this thought comes to my mind. It comes to the mind of every girl. I also feel that someone should be there. Slowly I have realized that is it good to be married, but I also feel that the person whom I trust, what if one day he breaks my trust?*

From the above narrative it can be seen that Dolly blames her *kopaal* for not being able to find someone to marry. On the other hand, she is also skeptical about marriage, because she is scared that one day her husband might break her trust and go away from her, and she will not be able to handle the situation emotionally. She further said that her impairment has changed not only her condition but also the condition of her entire family.

> *Ma, Bhaiti and Bhonti, they all love me a lot. They can do anything for my happiness. But what can they do about this matter? They have told me that you get married to whoever you like; you can do whatever you wish. They have tried their best to hide their concerns about me, but I have understood… I feel very sad that this has happened to me in my life. But this incident has not only affected me, but has affected everyone around me. Ma is so tensed for me. She thinks how I will ever get married. Bhaiti says if you both* [Dolly and her younger sister] *are not married, how can I marry? When they say such things, I feel that I am a burden for them. They haven't said this thing to me. What they think is that if I do not get married, I will feel bad. But I have told them I will not be sad, but you people should get married. Whatever has to happen will happen. But I am tensed about my Xoru Bhonti. She is very young now. I want to do something for her. Now I do not want to do anything for myself, but I want to do something for my Xoru Bhonti. Today I am alive for my family… I want to see my Bhaiti getting married. I want to make my Bhonti stand on her feet. Now I feel what I should do to make these things come true.*

From the above narrative it can be seen that Dolly's impairment has affected her entire family as they often worry about her marriage. While Dolly herself has made peace with the fact that she may not marry, her mother and younger brother feel that if she remains unmarried, she would be unhappy. Due to this reason, her brother has told her that he will not marry until Dolly's marriage is fixed. Her family members have also given her the liberty to decide her own life partner, something which other women in her family may not have. Although it is very empowering for a woman to choose her own life partner, it also shows her family's helplessness and inability to find a suitable partner for her.

In certain cases it has been found that the women had refused to marry in order to look after their parents in their old age. Anamika said that she has never thought of her marriage, even when she was younger, because as the eldest daughter in her family, she will have to look after her father and step-mother in their old-age, and also ensure that her young step-sister gets educated and married at the 'right age'.

> *I have never thought of marriage. Even earlier I have never had this feeling that I will get married. I had never thought of this. There is no one else in the family. Dangor Bhonti* [her own sister] *is there, but she is now married. Maa-Deuta both are there, but they are now getting old. That is why I have forgotten about marriage. Xoru Bhonti* [her step-sister] *is there, she is now studying. After her studies, we will have to get her married. Now Maa and Deuta are at home, I will have to look after them in their old age. That is what I think.*

From the above narrative it can be seen that Anamika has taken the responsibility of her ageing parents upon her shoulders and due to this reason she has refused to get married. It is, however, interesting that none of the elders in the family have tried to persuade her to get married, as would have been the case had she been non-disabled, like her sister. According to her, since they do not have a son in the family, she will have to fulfill the responsibilities of a son. Again it is interesting to note that both her sisters have been exempted from this responsibility due to their non-disabled status. Although Anamika did not say it herself, it is very likely that her father never gave much attention to her marriage because of her disability. Now that she is the only earning member in the family probably they do not want her to get married because this would mean that they would also lose out on her income. Moreover, her step-mother is only a few years older than her in age (they had gone to school around the same time). So the comment about her ageing parents is only true in the case of her father and not her step-mother. All of these explanations ultimately seem like a defense mechanism to protect her family from being criticized for showing no concern regarding her marriage.

Even though arranged marriage is the norm in the country, 'love marriage' or companionate marriage is considered to be the ideal, thanks to the junk that young minds are fed through the popular Hindi films. Love stories of usually younger, fairskinned, good looking and able-bodied couples are very prominent in this industry, where love thrives despite all the odds in their lives. Young minds are usually influenced by such love stories, and often want such a relationship for themselves and consider arranged marriages to be a remnant of older conservative customs. While women with disabilities are widely considered to be unfit for romantic love, in a few cases they have found that the opposite sex is attracted towards them, which forces them to dream of a future together. Jeuti's narrative gives a good illustration of this. She said,

> *Before my husband there was another boy who had loved me. It was about 6-7 years ago, He had given me a lot of hopes about getting married. He had come to my home, he had even talked to Ma. He had even come to my home to eat. He is from Nagaon. The last time when he came to meet me here, we had met after one whole year. He stayed with us for the night. When Ma broached the topic of marriage, he would not talk about it. He said that he has not spoken to his father yet. He promised that this time when he would go home, he would talk to his father. Next morning he had tea and left. That same night he called me and said,* [Jeuti], *I want to eat*[158] *at your wedding. I told him how can you eat at my wedding*[159]*? You will have to come and marry me. He then told me if you find a good boy marry him, because his marriage has been fixed. He should not have given me hope. I was waiting with the hope that someday I would get married to him. From that time I started feeling that there is no point in liking a person like me. Men just want to hang out with us, but they do not want to understand us. He has cheated me, would he ever be happy in his life? But I pray to God that he is happy and safe. I have never cursed him. I will never even do that ... I have suffered so much in this life. That night Ma had set the meal for me, but I pushed*[160] *it away. I was so upset. Why should he cheat me like this? Why do such boys cheat us? If he did not like me, if he did not want to get married to me, I had never forced him… This thing has happened not only in my life. Such things have also happened in the lives of bhaal girls. But this should not happen. There are some boys who cheat the girls who love them so much. There are also some girls who cheat the boys. But it should not be like this. This is a bad thing. No one should play with someone's feelings.*

From the above narrative it can be seen that Jeuti's heart was once broken by someone who claimed to love her. However, when her mother broached the topic of marriage, he conveniently broke up with her. This had a huge impact on her mind such that she began to feel that men only like to flirt around with women like her, but never see a future together. During the period when they were together, he gave her many hopes about marriage, all of which according to her were actually hoax, before he got married to someone else who is chosen by his family. This incident shook her

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[158] In Assamese language, people say they are going to eat at someone's wedding [biya khabole jaam], and not attend their wedding.

[159] In Assamese weddings, the bride and the groom fast the entire day till about midnight when they eat their first meal as a married couple together.

[160] Pushing the meal away is considered to be inauspicious and an insult to the Hindu Goddess Lakshmi, the goddess of wealth.

completely and it took her a very long time to get out of this shock. This incident, coupled with the taunts that she had heard all her life about not getting married had a very deep impact in her mind. She started to feel that no one would ever marry her because of her impairment. It was during this period that she came across Moromi and met several married persons with disabilities. These interactions changed her outlook towards life. She said,

> *I do not know* [Bandana] *Baideu directly. But I have heard a lot about her from my colleagues at* [Moromi]. *They keep taking about her. From them I got to know her. I had heard so much about her that I really wanted to know who she is. Who is this* [Bandana] *Baideu? One day I had gone to her home with one of my colleagues. She is not able to walk properly, yet she is married to such a dhuniya lora* [good looking able-bodied man]. *Seeing her I thought when she is not able to walk, she is so short, when such a dhuniya lora has married her, what about us? I am much better than her. My disability is not so severe. At that time I felt like that.*

Apart from Bandana she had also talked to the other persons with disabilities at Moromi.

> *I asked this question to a few more people. There is one woman who cannot walk. I asked her Baideu, are you married? She said yes I am. I asked her if she had children. She said that she has two children. I asked her if her husband is also 'handicapped'. I asked her this question because I felt that I am the only one who felt that no one would marry me because of my handicap. I asked her that question. She told me that her husband is bhaal. He does not have a handicap. I asked her even after not having a handicap he has married you? You cannot even walk. She said yes he married me and he loves me a lot. Whatever work I cannot do, it is my husband who does them for me. After asking her these questions, I asked another woman about her marriage. I asked her if she is married. She said that she is. I asked if her husband is handicapped. She said no he is not. Then I thought if such women can get married, they cannot even walk. I do not need any kind of help as such. I can do my work by myself. So why wouldn't anyone marry me? I am also like a bhaal manuh. I felt this at that time. At that time I thought that for a long time I have been carrying a big burden that no one would get married to me. I would have to stay at home like this. I thought of it in that way. After that I started feeling that I would also get married at some point. I will also start my xonxaar. Thinking this I started having many dreams about my future.*

From the above narrative it can be seen that after her breakup Jeuti felt that she would never get married. However, after she came into contact with Moromi, and met several other women with disabilities, whose conditions were much severe than her, she began to feel that if they have been able to find someone, one day she would also find someone. She further said that her mother was also very worried about her marriage.

> *Ma was also worried about my marriage. I was also worried when my friends were getting married. I began to think when I would get married. I had that thought in my*

> *mind. When I met these women and talked to them, I also started thinking that I would also get married and I would also start my own xonxaar. But I never spoke to Ma about these things. I only thought about them myself. Sometimes if Ma said something then I would say Ma if it is written in my kopaal that I would get a good man in my life, then I would find him. Why wouldn't I find him? God has written the lives of everyone. Maybe the boy that is designated for me has not come in front of me as yet. He would come at some point.*

The narrative shows that for Jeuti, marriage was an important sacrament that she wanted to be a part of, and the thought of not being able to marry often haunted her badly. Even though she had these worries in her heart, she never showed them to her mother. In front of her, Jeuti often showed a brave face and kept the hope alive that she would also get married someday.

The above section shows the many apprehensions that women with disabilities have about getting married. While some of them wanted to get married to fulfill their gender roles, others did not want to get married out of the fear of domestic violence.

The Concerns of the Married Women: This section elaborates on the experiences of the married women among the study participants. Out of the 18 women who were interviewed for this study, only five of them were married at the time of the interview, and one was widowed (Suchismita). The duration of the marriages varied from one year to seventeen years. It was found that almost all the ever-married women, regardless of their class status or their place of residence, had faced some difficulties while getting married. The husband's families especially were reluctant to accept a disabled *buari* (daughter-in-law). In some cases, the husband's family members have even misbehaved and discriminated against their *buari-s.* The following narratives give detailed description of their experiences.

Due to her previous experience with her ex-boyfriend, when Jeuti's future husband approached her for marriage, she was quite wary about committing to a relationship without the permission of her elders. Due to this reason, she advised him to speak to her mother directly. Jeuti said,

> *I got introduced to him at a friend's wedding. Actually the bride was my friend, and the bridegroom was his friend. It was just after the surgery of my hand. I had just removed my plaster. But she was a very good friend, so I had to go for the wedding. I was introduced to him there. After that, he called me on my phone one day and told me that he loved me and wanted to marry me. After he said all that he came to my home directly. He talked to Ma. Ma told him that even though I am her guardian as a mother, I am not really her guardian. Her Mama is there, you should speak to him. He said OK and went to my Mama's home the next day. He talked to Mama very*

> *nicely. Mama said that he is not a bad person, he is good. Since he is willing to take such a girl that means that the boy is not bad. So after that we went for a court marriage initially. After the court marriage, we got married at a Mandir one year later. Now I have been married for a few months, it has not been a year yet.*

From the above narrative it can be seen that due to her prior experience with her ex-boyfriend, Jeuti did not want to go through another episode of heartbreak. Due to this reason, she asked him to speak to her mother directly. However, her mother was also not courageous enough to take this decision and so asked him to speak to her Mama. Her Mama gave his final verdict depending upon his willingness to marry a disabled woman like Jeuti. From the interview, it seemed as if Jeuti idolized her husband for choosing to marry her, in spite of her impairment. She, for instance, did not talk about the other details about their relationship, which her mother did in a separate interview. Her mother said,

> *I always thought who will accept her. But there was a boy who kept coming to our home. Jeuti told me, Ma this boy likes me. I told her it is okay if he likes you, but one of your hands is like this, what if cheats you later. We would be hurt. And the neighbors would also laugh at me. But he kept on coming to our home for about 2 years. One day there was a naam at someone's home. I worked there the entire day. I came back in the evening. At that time the boy used to come to our house. He came home every Sunday. The neighbors, they are Nepali, they chased him. They said that they would beat him up. They asked are you doing dhandabaazi* [prostitution] *here. They chased him like that. I came in the middle and did not allow them to beat him up. By that time I had informed everyone who lived downhill that this boy would marry her. The people were happy about it. The people on our side* [who live uphill], *only they are bad. The ones who live downhill, they are not bad. I had informed them that they are chasing the boy. They accused us that we are surviving by doing dhandabaazi. I said no he likes her. He wants to marry her. Everyone knows about it. Everyone from the downhill knew about it at that time. Like this we had a heated argument. Then I fainted there. I am not able to fight. The more agitated I get, I am not able to breathe. I fell down. He drives the police vehicle. That made them scared. I also thought, what if they bring the police? I was scared. If they bring the police, even then it would be difficult. What will I do? The people from the downhill they also came up. They said that this boy said that he would marry her. Why are you chasing him like that? They said no he is doing dhandabaazi here. I said no he is not. I told them that he wants to marry her, I have met the boy, he is good. The boy did not have the approval from his family. They did not have any other problems, but his mother had a problem because of her hand. I asked the boy, what do you want to do? If you come here every day, people would say bad things. They would say your character is bad. What do you want to do? I had also informed in my home. He said that he would do court marriage. I said okay go ahead with a court marriage. But after the court marriage, you will have to take her with you. He said I will not take her, she will stay here. But I will do court marriage. After two three months of court marriage, he kept on saying the same thing. Then I told him to take her out. I told him to rent a place nearby and to take her from here. I asked him to take her to his home. He said I won't be able to do this. I asked him what he wanted to do. He said I will think about it. After that I spoke to my Dada. Dada said you ask him, we would get them married at a Mandir. Then we took them to a Mandir and got them married. His mother did not*

> *know about it. She actually knew everything, but said that she did not know anything. After six months or so, he went home. But he did not take her along with him. I told him that it won't do if you just go on your own. You will have to take her with you. You will not take her today, you will not take her tomorrow. But one day you will have to take her. Then he took her. His mother did not scold her. Now I have seen that his mother also comes here. Her Xahu* [mother-in-law], *she comes to her home nowadays. Now it is going good for them.*

From the above narrative it can be seen that Jeuti had to get married under the pressure from her neighbors who accused her and her husband of engaging in prostitution. However, even though her husband initially agreed for the court marriage, he did not set up home with her immediately. He also did not take her to his home to meet his family. It was only after one year that he agreed for a social marriage ceremony and took up a rented home near her mother's home. But even after that he did not take her to his home. It was only after her mother insisted many times that he agreed to take her home. Even though her husband's mother had initially refused to accept the relationship because of her impairment, after meeting her she no longer seemed to have any problems with her. Jeuti's mother was happy that her mother-in-law has now also started visiting Jeuti and her husband in their home in Guwahati.

Unlike Jeuti who has been accepted by her in-laws eventually, in the case of Bandana it was found that her mother-in-law still feels ashamed to introduce her as her daughter-in-law to other people, even after five years of marriage. In her narrative, Bandana gives a detailed description of the circumstances under which she and her husband got married. She said,

> *I met him at Lakhi Mandir. I was working at Moromi at that time and he was working at a company in Beltola. I used to frequently come to the* [Social Welfare] *Office at Lakhi Mandir for my work. We got to know each other at that time. I had known him for about eight months before marriage. Our marriage is astonishing. On first of January 2012, he asked me out on a date to Bashistha Mandir. There he put vermillion on my forehead. At that time I had not thought that I would go with him* [get married to him]. *I just went for a day out with him. On 1st we went to Bashishtha Mandir and on 2nd I had to go for a picnic. At that time I was learning computers from a private school at Sarab Bhatti. I asked him if he would like to come for the picnic with me. He said no I won't go. I do not have money for it. I was working at that time. I told him I have money, you come with me. Computer Madam has come to know about you, she wants to meet you. But instead he had other plans. I did not know that he would take me to his home the very next day. That evening he told me come out with me tomorrow, I have some important work with you. I asked him what it is. He suddenly told me that I will go home and I will take you along with me. I did not know at that time that he would take me forever. From a long time I had taken some of my clothes and kept it in his room* [she laughs]. *I got angry with her for*

> *beating me and kept some of my clothes with him. Ma always beat me up for being with him. She hated him at that time. But now she likes him more than me* [she laughs]*... He took me to his home in Biswanath Chariali*[161]*. I stayed there for 10 days. He left me there and came back. I cannot even describe the way his family behaved with me. His mother and sister did different things to me. I got very scared. It is so far from Guwahati. If something happens to me, no one would come to know anything. Ma did not talk to me during those days. She was very hurt that I left like that. What would people say? What will the other staff members*[162] *say? What kind of education have I given you? Then Bhonti talked to me, and through her I spoke to Ma. I told her Ma I want to come back to Guwahati. I will not stay with you, I will stay with him. But please take me back from here. After hearing me plead like that, Ma came to take me back from Biswanath Chariali. I was sick at that time. Ma brought me back from there. Then I stayed at home for about a month. Bhaiti and Bhonti also started hating me at that time. It was a matter of the family's honor. They asked him* [her husband] *to meet them. They told me to ask him to come home at that time. They said, "If he is seriously interested in getting married to you then he must say so and we would make the arrangements for the marriage". He had not married me till that time and that was why Ma was ashamed. Then Bhonti said, "You left home like that, and now he has left you here. He should take you from here. He should take the responsibility". Ma called his mother, she said, "Baideu, they have done a mistake, now let us do something for them. Otherwise the society would blame you and me". Ma also said, "I live at the staff quarters of a hospital, where ten other people live. It is a question of my honor". His mother responded very rudely to my mother. She said, "You do whatever you want, I do not have the time for this". Then Ma took us to court, him and me. Ma and Mama got us married at the court. After that he was hiding me from others. He was not allowing me to say that we live together. Then one of his friends told me, "Why would you hide it from others? It is not your fault. Her son has made the mistake. It is not your mistake. You do not hide anything. If someone comes, you should go out. Otherwise you would be in trouble. Anyways you are a 'handicapped' girl. After all this, if you have to take the stains of all this, then you would have a lot of problems". So I followed what he said.*

From the above narrative it can be seen that Bandana's husband took her to his home, left her there and came back to Guwahati. During this period, there was a lot of tension in both the families. Bandana's mother was concerned about her family's honor, and so wanted to get her married to her husband soon. Her husband's mother, however, was not in favor of this relationship due to her impaired status. As a result, she did not attend her son's wedding. After their marriage, however, her husband still hid her from other people. It was only at the insistence of one of her husband's friends that Bandana decided to come out in front of other people as his wife. She further said that her husband's family has still not accepted her. She said,

> *His family is ashamed of me. Their son is so good-looking, but he has married a girl like me. They find it difficult to introduce me to others in their family. His mother does not like me. His sister also does not like me. He loves me, but not his mother and*

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[161] Biswanath Chariali is a city in the Biswanath District of Assam. It is located at a distance of 230 km from Guwahati.

[162] Her mother worked at a government hospital in Guwahati. They lived in the staff quarters of that hospital.

> *sister. Now look at me. Even if I am handicapped, I am not dependent on my mother or my brothers. I have not given any kind of hardships to anyone. But his family… OK fine, neglect me because I am a handicapped girl. I know I am a handicapped girl, but I am working on my own. I am not a burden on anyone. You all are ashamed of introducing me to others as your Buari* [daughter-in-law] *or as your Bou* [sister-in-law]. *I also understand that. I will not go anywhere near you. I would work on my own, and I would live on my own. Sometimes they neglect me. So I am working and living on my own, what is your business to neglect me? But every time they face any difficulty, they run to me. They would take me along. This is because if they take me, in many places they get concessions. I get certain things for free. They get the work done through me, and then they kick me from behind. That is how I feel. Last winter I had accompanied his mother to the GMCH to visit a patient, who is his neighbor at Biswanath Chariali. When we went there, that person asked who I am. His mother replied that she has a shop near my son's shop. How would I feel in such a situation? I have taken you to GMCH at 7.30 in the evening. It is so difficult to find patients in that hospital. She does not know anything about the hospital. I was the one who found the patient's room. After all that I get that kind of treatment from them. How would I feel?*

Bandana's mother-in-law neglects her completely and speaks to her only when she needs some help from her. Bandana finds this very upsetting because she herself does not feel as if she is disabled, but gets annoyed that her mother-in-law behaves with her in that manner. After elaborating on how her mother-in-law behaves with her in front of others, she lashed out on her husband for never supporting her in her work and for putting her down in front of others.

> *That day I came back home and told my husband what his mother had said. He just asked his mother why you said this thing. This is all. He said nothing more. Sometimes I feel that he is with me because of some selfish motives… If there was no motive… Now the amount of hard work that I do, he never appreciates me for this and puts me down in front of others. He helps me, it is not like he does not help me. He helps me with certain things, but there are other things for which he puts me down in front of others. That is why I feel very bad. Now I feel why I came with him* [got married to him]. *I could have stayed at home without working. Now I have to do all the work. Now I am going through a lot of troubles* [she cries]. *I have never been treated nicely by his family members. They have only avoided me. What is the need to avoid me? You will get all the work done by me, and then you would avoid me? … I have started this shop. He is just running it. All the finances are from my side. My documents have been used. The loan is in my name… I am a handicapped girl. But I do not stay like a handicapped girl. People neglect me because I have a handicap* [she cries]. *I have told him. Sometimes he says I am handicapped, this and that. I have told him that you had seen me before getting married to me. After seeing me why did you come close to me? I did not force myself upon you. You took me to your home. Now you listen to your mother and behave like this. But he said that he loved me so much at that time. His mother scolded him saying you have brought such a girl home. Where is my honor? At that time he had said, I have brought her so I will look after her. You do not have to look after her. At that time he was good. But with the passage of time, he has changed. He had promised me so many things when he took me with him. I will not give you any hardships. I will keep you this way and that way. It has all become the opposite. I keep smiling, I keep having fun. But I cannot share my sorrows with anyone. And one day he said that I had married you because I*

> *thought you would get a sakori* [government job]. *There are no women in my family who has a sakori. I knew that you would get a job. Now I got to know that you won't. He put me down like that… He* [husband] *gets angry with me for no reason.*

From the above it can be seen that Bandana's husband had married her because he thought that she would find a government job, and he would be able to survive with the money that she would earn. However, because she has not been able to find a government job, he gets angry with her for no reason. It seemed as if he also called her names for being impaired during such situations. Bandana is unable to understand the logic behind his behavior as he had known about her condition before marriage. Bandana further said that she gets upset about the fact that her mother-in-law refuses to come and stay with her, but prefers to stay with her own daughter and son-in-law.

> *I feel bad about one thing. His sister is married now and lives in her home. She does not do any work. I am working. So my Xahu* [mother-in-law] *is supposed to help me, isn't it? My Xahu should help me in running my home, in running my shop. But she does not have time for me. She has time only for her daughter and son-in-law. I feel very hurt about this. I told my Xahu that she can stay with me. She need not do any work here. You stay with us. You do not have to take any tension for the cost of food and so on. Two of us are eating, so we can accommodate a third person also. She simply ignored me and said that she finds it hard to stay with me. That is why she does not stay with me. How can I say that these people are my own? How can I call such a person Ma or Xahu? She has not understood me in the past 5 years. Now whenever I think about such things, I feel very hurt* [she cries]. *My Ma does not know about such things. I have told her that they are good. I say that everything is good. Ma scolds me sometimes for acting stupidly. I have never shared these things with anyone. I feel very hurt in my heart. It is very difficult to live like this* [she cries].

Bandana gets upset with her mother-in-law for showing her preference to stay with her daughter and son-in-law instead of her son and daughter-in-law. In a patriarchal society, since mothers of sons are expected to live with their married sons in their old age, instead of their married daughters, Bandana finds it very humiliating that her mother-in-law has refused to stay with her. What is more problematic for her is that because she has chosen her own life partner, she is unable to share her emotional problems with anyone in her family. She feels that they would either not understand her problems, or they would taunt her and ask her to manage her own problems as after all she had chosen this life for herself.

Discrimination from in-laws was experienced not only when the couple chose each other for marriage, but sometimes also when the prospective husband's family approached the woman and her family to marry their son. Uma met her future husband at a meeting organized for persons with disabilities at the Block level. Her husband had acquired his impairment when he was about 19 years old after a bout of ‘typhoid fever’. During the interview, Uma talked about how she had met her husband:

> *I got introduced to him at a meeting. We talked there. He then asked me to visit his home someday. When I visited his home, his mother asked me if I would like to marry her son. My family also did not raise any objection. They said okay. He had a government job at the veterinary hospital. They felt that my future would be secured. My parents were happy that his family was able to understand my problem. That is how I got married to him and moved to this village.*

From the above narrative it can be seen that Uma’s parents did not have any objection in marrying their daughter with a disabled man because he had a government job. As is evident from her narrative, they would not have accepted this alliance if he did not have this job. At the time of the interview Uma had been married for 9 years. She said that she did not face any difficulty in adjusting with her husband owing to his own disability that enabled him to understand her difficulties well. She said,

> *He understands my difficulties well. Because he is also like me. If I have some difficulty while sweeping the floor, or while moping it, he does the work for me immediately. Or when we are about to have our food, he fills in the water bottles. He helps me with the domestic chores. He is able to understand everything. If I were married to a bhaal manuh, he would not have understood my problems so well. He might have said this and that. But with my husband it is not like that. He does not think that I am disabled, and I do not think that he is disabled. We consider ourselves as equal, like everybody else. Even before we got married, we were able to understand each other’s problems.*

The above narrative shows that Uma’s husband is able to understand her difficulties well because he himself also faces similar difficulties. Uma feels that if she was married to a non-disabled man it is quite possible that he may not have understood her problems. Uma further said that sometimes she feels really sad about her impairment. But when she realizes that the amount of support that she receives from her husband is immense, she does not feel sad anymore. She said,

> *Sometimes I feel very sad about what happened to my leg. If I were better, I wouldn’t have had to live like this today. Sometimes I get this feeling. But when I get all kinds of help from him, then I do not feel anything. Then I feel that I have everything I want in this life. After marriage, my husband is the main person in my life. If he would have behaved badly with me, then I would have felt worse. Now since he is able to understand everything about my problems that is why I do not feel anything. I am also happy after coming to this village. The people are really good. They have never expressed anything about my disability here. They see everyone with equal eyes.*

Uma’s narrative also shows that she idolizes her husband for the kind of support that she has received from him which has enabled her to forget her insecurities somewhat.

She also feels better after moving to her husband’s village because here people look at her as an equal and not as a freak as was the case in her own village. In spite of all this, Uma feels that she is discriminated in her husband’s family as her three *Jaa-s* [wives of husband’s brothers] often exclude her when they have to go somewhere, which hurts her immensely.

> *My husband has three brothers, two are older than him and one is younger than him. My two elder Jaa-s they are very proud about themselves. Because I am like this, they never take me along anywhere. They do not even inform me that they are going somewhere. All three of my Jaa-s go out together but they do not inform me. I feel very bad when this happens. If the three of them are going somewhere together, they should at least inform me. What will happen if they just inform me? Whether I go out with them or not is a different matter. I may not even go with them. But at least they can ask me. The three of them form a group and go together. I feel very bad about this. But I am not able to say it to anyone… I have never asked them why they do this. They do not say such things to me. Why would they say so? But I know. I am like this, that is why they behave this way with me. The four of us have the same position in the family. If there is some occasion in the main house, we all gather together to work. I also get involved equally. They behave nicely on the face. But they never inform me if they are going somewhere. That really hurts me.*

From the above quote it can be seen that Uma feels excluded by the women of her husband’s family, and this hurts her immensely. Uma also said that she did not receive any kind of support from anyone from her husband’s family at the time of her son’s birth, even though they all lived next to one another.

> *At the time of Babu’s birth, I had some difficulties. His father has problems in his hand. I also have problems with my leg. In between all these problems we have still been able to bring him up. At that time my Xahu was alive. My Jaa-s* were *also there, my Nonod* [husband’s younger sister] *was also there. They do not live very far from our home. But still none of them came to help me with my child* [she said this with tears in her eyes]. *They never felt that my leg is like this, my husband’s hand is like this, so they should help me with caring for my child. No. They did not give me any support. This is what I feel sad about. With great difficulty we have brought him up. Now by the grace of God he has grown up. There is no worry. God must keep him well, that’s all. He is seven now. It was my older brother, who is slightly ojola type* [mild mental disability], *he is the one who came to my house and helped me with everything. He stayed at my home for about a month during that period. I had my son through Cesarean. He helped me with everything. From making bhaat, tea, to giving me hot water. He helped me with everything.*

It can be seen that Uma feels very hurt that none of the women from her husband’s family came to support her after the birth of her son even though they lived very close to her home. Uma’s narrative clearly shows that even in cases where women with disabilities get married with the approval of the husband’s family, they are still treated as secondary members of the family and not given as much importance as the able-bodied *buari-s*.

Unlike the husband's family who provide negligible support to the women, it was found that the women's natal family provides them with sufficient support, at least till the time the woman's parents, (particularly mothers) are alive. Korobi's narrative illustrates this clearly. As elaborated in the earlier chapters, Korobi had always wanted to get married and not be a burden on her second sister who had wanted to take her responsibility. When her parents got the first marriage proposal for her, they seized the opportunity.

> *Korobi's mother: They have not married on their own. His Khuriyek* [father's brother's wife] *worked at an office nearby. I have known her for some time. She saw that I live in this house. So one day she came over to have tea. Then she met everyone here. She asked me if I have thought about Korobi's marriage, and about my other daughters' marriage. I told her that it is only after Korobi that we would think about the other two. She then told me about him* [Korobi's husband]. *I paid attention to her, and that is how we discussed about their marriage. We made both of them meet each other, and we met his parents. After that we got them married in 1999. He lived with his uncle at that time. His uncle was at a very critical stage. He passed away a day after their marriage. Their reception party had to be organized later because of his death. His uncle had lived in the veterinary campus in Khanapara. After marriage she stayed with his uncle's family for a few months. At that time she did not have any fears* [monophobia]. *I was very scared about sending her after marriage. At that time she did not have this fear, it has only gradually increased with time. Her Xahuwek* [mother-in-law] *was also alive at that time, she passed away only recently. They used to visit Rampur*[163] [husband's village] *very often at that time and stayed there for a few days.*
>
> *Korobi: The thing is, in Rampur, the bathroom is very far away from the house. Due to this reason I had difficulties in staying there. I was not able to go to the bathroom after dark. I found it very difficult to stay there. Otherwise I really like the environment in the villages.*
>
> *Korobi's Mother: Then her son was born one year later in 2000. I live alone, so I brought him up. He lives with me upstairs. He has grown up with me. He is now 16 years old.*
>
> *Korobi: We also decided to live here with Ma for my son's future.*

From the above narrative it can be seen that after Korobi's marriage and especially after her childbirth, she started living with her mother. Her mother pays for all the expenses of Korobi and her family through her family pension and house rent. When I asked Korobi's husband about his work, he said,

> *Husband: I used to do business earlier. Actually I used to act in theatres. Only when I faced some financial crisis, I did some business. I got involved with some business for about two months or so, get the money, and then I leave the business and get back to acting. After I got married, I had so many responsibilities. Actually when one is into business, they need to work day and night. After our son was born I was not able to*

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[163] Rampur is a town in the Rampur Tehsil of Kamrup (Rural) District.

> *switch between jobs. After his birth, only sometimes I have been able to do acting. I used to work with a poet. We had formed a group. Now I am not able to give any time for this. Korobi needs me all the time. It is only her phobia that has made my life very difficult. If she did not have this phobia, her others problems are minor in comparison. I write songs also. I write whenever I am in some need. Now I am not in any need. It has been a long time since I have written something. It is all about time. I have not written anything for a long time because I do not get time. Now because I do not get time, I have also lost interest in writing. One day I had written something and it became very popular. It is a very old song. It has been about 30 years since then. Actually I need complete silence when I am trying to write something. I cannot do it in the daytime. So I tried writing at night. But whenever I tried to write something, she will call me from the other room, because she is scared. Due to this I have not been able to write anything in the last few years. Now I have lost interest in writing also.*

Korobi’s husband who was a theatre actor and writer has not been able to write anything substantial because of her monophobia. In order to overcome her fears, she needs someone around her all the time. Even when she is asleep she often gets up from her sleep and gets very hyper if no one is around her. Due to all these factors her husband said that he has not been able to do any work after marriage. Korobi’s mother, in a separate interaction, however, said that she considers her son-in-law to be very lazy due to which he has not been able to sustain in any kind of work and has to depend on her for sustenance. Even though she seemed upset with him for not engaging in paid work, she seemed pretty satisfied with him for caring for every need of her daughter. Korobi also said that her husband loves her very much and is very supportive. She said,

> *Korobi: I have received everything from my husband. Love, care, sympathy. Everything. [Listening to her everyone starts laughing].*
>
> *Korobi’s mother: He loves her. He does not beat her.*
>
> *Korobi: Sometimes when I make mistakes, he scolds me. That is a different thing. Then I ask him about my mistakes. Then I say sorry.*

Korobi, therefore, considers herself to be fortunate that her husband loves her very much and does not beat her. She also considers it to be normal if he scolds her for committing a mistake. She further said that other people often make fun of her for being married to a *bhaal manuh,* and they scare her that he would leave her and go away someday. She said,

> *Korobi: People laugh at me. They say you have married a bhaal manuh. They say that one day he would leave me and go. They scare me in this way. They say such things and laugh at me. These are very bad things. One should not say such things… Some of these people are our own relatives. Others are our neighbors. They say that we should scare her and make her faint. They say such bad things. They say that then*

> *she would die and my husband and son would be able to live peacefully. They say such kinds of bad things. There are many such people. They should not say such things.*
>
> *Husband: These things have started more after her father passed away. When he was alive, things were different. But after he passed away, things became different.*

Some of Korobi's relatives and neighbors make fun of her because she got married to a non-disabled man. According to her husband, these people have started troubling her after the death of her father. When I asked her what she does in such situations, she replied,

> *Korobi: I come back home and complain to my mother. I do not say anything bad in front of others. I am scared. I do not know in what way they would take revenge. And sometimes I stay alone with Ma. They can come and do something to me.*
>
> *Husband: I asked her not to pay so much attention to this. There is no point in thinking about others. She should think about herself. Those people actually are jobless. That is why they think in such a way. My thing is that if I do not like somebody, I do not talk to them. They should not face any inconvenience because of me. Likewise, I also should not have any inconvenience because of them. She is scared to live alone. Actually this fear is due to the people around us. There are some people who ask her what you will do in case there is an earthquake.*
>
> *Korobi: Yes, I am very scared when there is an earthquake.*
>
> *Husband: They ask what you will do. There are people who have made her scared. They say she would not be able to run also. What will you do? Actually it is all because of the people. They make her scared.*

It can be seen that people around Korobi try to scare her by saying useless things. Such kinds of comments have actually aggravated her mental condition and she is not able to live without her husband for a single day as she feels that he may not return back to her. As noted above, this fear has had a direct impact on her husband's ability to work as Korobi needs him constantly to be around her. In turn this has raised the resentment of Korobi's mother against her husband who considers him to be lazy and not committed enough to earn a livelihood for his family.

In one case it was found that as a goodwill gesture the organization members of Sanjeeboni got two disabled individuals married. At the time of the interview, Chitra was married for two years and had an 11 months old son. Chitra had acquired her impairment (cerebral palsy) after a bout of 'typhoid' fever, pneumonia and measles/ chicken pox when she was in her second standard. Her husband had also acquired his impairment (cerebral palsy) in his childhood (he does not know the exact cause). The following narrative illustrates the complexity of the situation under which Chitra lives with her husband and son.

> *I got introduced to my husband here at* [Sanjeeboni]. *I used to come here for the meetings with my Bhotija suwali* [brother's daughter]. *He used to stay here at the organization itself. He has been living her for over 15 years. But even then, I did not know him. I did not know that I will get married to him. We had never talked to each other. One day* one *Baideu introduced me to him. She asked us directly if we like each other and would want to get married. She got us married like that. It is not a love marriage.*

From the above narrative it can be seen that Chitra and her husband were introduced to each other through one of the organization members who asked them if they would like to get married to each other. She said that one of her brothers did not approve of this proposal because of her impairment and the fact that her husband did not have a stable source of livelihood. Chitra said,

> *My Xoru Kaka was a little worried. He thought I am like this, how I will manage. I have only one functional hand, how I will manage with this one hand. How will I cook? He was also worried that he did not have a sakori* [government job]. *But I told him that I want to get married. My Dangor Bou troubled me a lot. She had created a lot of difficulties for me. She used to beat me up sometimes. Even when I did some household chores, she used to say that I don't do any work. "You cannot work, but you can eat? You can have tini kaanhi bhaat* [have rice/ meals three times a day], *but you cannot work?" She used to say such bad things. Her behavior was very bad. She used to call me Johoni, Naak-kaati* [abusive words]. *All this used to make me angry. One day when she behaved badly with me, I had bitten her hand. Blood had come out from her hand. She had to take 5 injections after that. The mark is still there in her fingers. Her behavior was very bad towards me. That is why I told my family that I want to get married.*

The above narrative shows the circumstances under which Chitra was living with her brother's family. Due to these reasons, she left that getting married was a better option than continuing to stay with her *Dangor Bou* under the same roof. When asked if her family was looking for someone for her to marry, she replied,

> *There was a man. He was blind, he could not see with both his eyes. He had come to see me for marriage. My Xoru Kaka did not want me to marry him. He said that the man is not able to see, and my hand and leg are like this. He thought, "How will they survive?" So he cancelled the wedding. But later they gave me away, for my own peace of mind. So that I do not face any difficulties. But I am his only sister. Even though I am Khora* [physically disabled], *I am his own. Kaka still regrets my marriage.*

From the above quote it can be seen that Chitra's *Xoru Kaka* still feels that she shouldn't have married her husband. When I asked her if she had faced any difficulties after her marriage, she replied,

> *No. Now we do not have any difficulties as such. I have mental peace now. It feels better now. I had faced a lot of hardships at home. Now Baideu* [someone at Sanjeeboni] *is helping us survive. That is why we are not facing any difficulties. I do not know what will happen in the future. Till the time Babu does not grow up, we would face certain difficulties. That is the thing. We do not have any other difficulties. We are not able to hold him in our arms. Somehow we are trying to bring him up.*

It is clear from the above that Chitra's family, especially her second brother, didn't want her to marry a disabled man because he was unsure how they would manage their *xonxaar*. Chitra, on the other hand, wanted to get married as she wanted to come out of her elder brother's home where she was tortured by her *Bou*. Eventually when she received the proposal from her current husband, she did not want to decline it because she was finding it unbearable to live with her *Bou*. As noted above, Chitra feels that she has got peace of mind with her husband after her marriage. However, now she has other kinds of worries. After a few days of interaction, Chitra spoke to me more openly. She told me about the fears she has about her future with her husband and young son. She said,

> *We have only one worry. What are we going to do in the future? Now Baideu is looking after us. What if one day she tells us that she cannot take care of us anymore? How would we feel? This is what we are thinking. If in the future Baideu says that she won't be able to take care of us? My family would not look after me, now that I am married. That is one thing. They will look after me for one or two days, but they will not look after me forever. That is what we are thinking. How will we live our lives? Baideu will look after us till the time she is alive. I would not say that she will not look after us. She has been looking after us all these years. It will be a wrong thing if I say that she has not looked after us. She brings milk for Babu. She has done a lot for us. But I am talking about the future. Baideu will not be able to help me in the future. She will not be able to walk in the future. My husband also would not be able to help. When Babu grows up it will be a big relief. But there is so much time for him to grow up.*

It can be seen that Chitra is very worried about what would happen to her family in the future as there is no sustainable source of support for them. She is unsure whether the organization would support her family in the future. She is, however, clear about one thing that her natal family would not support her because she is married now. She said that before her marriage, her father had given her 2 bighas of land (out of a total of 8 bighas). Now that she is married, she is unsure if her brothers would transfer the land in her name or not. She further said that she and her husband are living in a very meager sum of money which is insufficient for them to consume nutritious food. Now that her son is also there, she feels that they should be given more money than the Rs. 500 they each receive from the organization every month.

> *We get Rs. 500 each per month. Sometimes we do even get this amount. She looks after Babu, I would not say that she does not look after him. Sometimes we do not ask for money. But sometimes when it is necessary, we have to ask for money. Sometimes we want to eat fish and chicken. We do not feel like eating only bhaat and dali every day. We also want new clothes. We got clothes last time during Durga Puja. We do not get to eat anything. There is no strength, only if we eat meat we would get the strength. Would we be able to hold the child? His Deuta's body also does not have much strength. When we asked for money from Baideu, she gave us only Rs. 30. What can we get for such little money? Sometimes she gives Rs. 50, then it is good. Sometimes she says she does not have any money. I sometimes find it difficult to eat. But there is no option not to eat. He keeps on saying to Baideu that if we get Rs. 100 in a week it would be good for us. Isn't it? We would be able to eat fish and meat. He keeps on asking her for money. If we would have got it, our health would have been better. We get Rs. 500 each. Now we have the boy. Is this money sufficient for us? In a few days he would say, Ma I want to have this, I want to have that. This money won't be sufficient then. I feel that we should get a little more money. Now we have our own xonxaar. If we get some more money, it would have been better. How can we survive by just eating bhaat* [rice] *and dali* [lentils]*? How would it affect our bodies? Sometimes I get very angry about all this.*

The above narrative shows the kind of financial problems that Chitra and her husband are facing after their marriage. What is more worrisome for them is that they do not have a reliable source of support to help them in the future, as she expects neither her family nor the disability organization to support her. They cannot rely on her husband's family either as his father had abandoned him after the death of his mother, when he brought in a second wife. The above narrative also shows that she laments a lot about not getting to eat good food like fish and meat whenever she wants. When I asked her if she got good food to eat in her family, she said,

> *Yes. I got to eat good food at home. Even though I was treated badly, I was given good food to eat. I used to have fish and meat every now and then. We were poor, but still I got to eat sufficient food.*

From the above quote it is clear that Chitra misses the good food that she used to get at her home before her marriage, in spite of the ill-treatment she received at the hands of her *Dangor Bou.* She further said that the economic condition of her family was not as bad as the condition that she is living in now. In her frustration she gets very angry sometimes, but she is not able to lash it out on anyone due to her vulnerability. She also mentioned that she is unsure for how long they would be able to stay as caretakers of the organization as there is a plan of moving them away and building a separate house for them. She said,

> *Our worry is that Baideu has told us that she will make a home for us on the other side of the office. Now she cannot make a bad house for us, isn't it? It will not do if she makes us a house with Torjar Bera* [a house made of bamboo sticks]. *We would*

> *be scared to live in such a house. Nowadays you know how the thieves are. She will have to give us three rooms at least. One for cooking, one for sleeping and one extra for Babu. When our guests come, one for that also. Now our guests do not come here because we live in the office premises. We have many relatives. They do not like to come here because we live here in the office. My mother's brother, he is a professor. He is very rich. He has his own vehicle. If he comes to this house, we would be ashamed. That is why Baideu will have to make us a nice house. If she makes us a broken home, we would not be able to make it our own. Would we be able to do it? No it is not possible. She will have to understand this.*

Chitra was very scared that they would be removed from their present home. She also seemed to have a lot demands in case they were actually removed from their present home. Later, however, it was found that it was just Suchismita's personal driver who was pulling the legs of the couple just to have a good laugh. Even though it was not a real threat at the moment, Chitra and her husband felt that this threat of being removed from the organization would always lurk in their hearts as they cannot really claim that they must be given a space to live in the organization. According to Suchismita and the other organization members, Chitra and her husband were very lazy and were unwilling to earn a decent livelihood for themselves, but instead preferred to remain as parasites sucking out money from others.

In spite of all the problems with their married lives that have been cited above, all the women said that they share a very good understanding with their husbands. Bandana who had an emotional breakdown and complained about her husband during the interview, even she said that her husband is the only person with whom she is able to share her problems. In many ways it seemed as if the women considered themselves lucky to be married, as they are very well aware about several other women with disabilities like themselves who have not been able to find a life partner due to societal perceptions.

Experiences of Childbirth and Childrearing

Childbirth is a critical time in the life of a woman. There is a lot of ambiguity concerning whether childbirth is a health issue or not. This ambiguity arises from the conflicting messages that women receive from the health personnel, their social networks and from their own bodies. While on the one hand young girls are socialized to see that being pregnant is a natural part of womanhood and femininity, when they get pregnant they are told by doctors that pregnancy is a medical condition that requires checkups and monitoring by ‘experts’. Even when women have unpleasant experiences during pregnancy, they regard their overall state to be healthy. Doctors, on the other hand, regard the entire state of pregnancy to be a medical concern. It would, however, be wrong to assume that all women regard their pregnancies to be healthy and all doctors regard pregnancies to be a medical concern. This is because studies have shown that women’s notions regarding pregnancies have been conditioned by several generations of expert advice. On the other hand, in the case of doctors, obstetricians are likely to regard pregnancy as a pathological state, while general practitioners view it as a natural process and may refuse to prescribe medicines to pregnant women (Miles, 1999).

Existing studies have shown that women with disabilities experience numerous barriers while accessing healthcare for childbirth (Thomas, 1997; 2001; Sarma, 2014). In the current study, only four of the women have children, out of which only three of them had discussed their birthing experiences and the difficulties they had faced in raising their children. As explained earlier, Suchismita, who has two children, never discussed her life experiences with me. Unlike other studies on women with disabilities’ experiences of childbirth and pregnancy, the women in the current study did not elaborate on their experience in the labor room, but also how difficult it was to bring up their child.

As elaborated earlier, Korobi got married in the year 1999 and gave birth to her son in the year 2000. During the interview she said she was a little scared about her delivery. When I asked Korobi what kind of fears, her mother replied,

> *Actually the doctor was more scared than her. The doctor had said, my heart is beating, what am I going to do now? She was so nervous. How would she give birth to her baby? What would happen? She was very nervous. One time, the doctor was not able to understand the movement of the fetus. She asked Korobi if she can feel anything. Korobi replied that she is not experiencing anything. This made the doctor very scared because of which the doctor made a lot of fuss. She asked me to think about what can be done. I told her, you are the doctor. What can I think now? I told her to do a sonography if she has any doubt. She is the doctor, and she asked me for opinion! Then she did the sonography and said that the child is normal. The doctor called me and said look how active the child is. She said you do not have to worry about anything. I told her I am not worried, you are the one who is worried. So this is how it happened.*

Her mother further said that her delivery was through Cesarean Section at the private clinic of her doctor. Like Korobi, Uma also had her mother by her side at the time of her delivery. When she was in labor, she was very worried about what might happen to her. Her husband's older brother had booked a cabin for her at GMCH through some contacts. Uma said that it is because of this reason that she did not face any difficulty during the birth of her son. Uma further said that when she met the doctor, she herself requested her to do a Cesarean Section as she was unsure whether she would be able to go for a normal delivery. After the C-Section, she faced certain difficulties at home for a few weeks.

Chitra said that she had gone into labor around 11 in the night, due to which she faced a lot of difficulties. Initially her husband had called the 108 ambulance and took her to the nearby PHC. Since it was late in the night, there were no doctors at the PHC. So the ambulance took her to GMCH instead which is 33 km from there. She said,

> *I was in so much pain. The person in the 108 vehicle told me that it would be difficult if I give birth in the vehicle. He asked me to be quiet. I did not know what to do. I just wanted to have the baby as soon as possible. Babu was troubling me in my womb. He was born the next day around 11 am. I had difficulty for one night. It was a normal delivery.*

When I asked her if she faced any difficulties during childbirth, she asked her husband to go away, so that she can talk more openly. When he left, Chitra said,

> *The doctor asked me to give a little pressure. Then I gave a little pressure. Then he took a machine and made the area big* [episiotomy]. *Then the doctor hit my abdomen. After hitting the abdomen, they took out Babu. I was able to understand that.*

While delivery was one experience that they mostly feared, what they did not realize is that raising their sons would be even more difficult, a task that they were not prepared for. It was found that all the three women faced a lot of difficulties in bringing up their sons, especially in the initial few months. They were also very concerned about what their sons would do in the future. It is probably due to these reasons that they decided not to have any more children. Korobi and Uma did not make any comments about the sex of their child. Chitra, however, was very happy that they have a son and not a daughter. According to her, God has given her a son knowing well that they will not be able to have another child. She said that had it been a daughter she would have been very sad, because after bringing her up with all the love, they would have to give her away at marriage. Their son, she said, would look after them in their old age.

Korobi said that all her family members were present to help her bring up her son.

> *Korobi: Ma looked after him. My husband and my Bhonti also looked after him.*
>
> *Korobi's mother: I was the one who gave him baths. His father looked after the rest of the things.*
>
> *Korobi: I looked after him at night. I was not able to sleep thinking that he might fall off from the bed* [she laughs]. *He kept on turning on the bed. Sometimes I would pull him towards me.*
>
> *Korobi's mother: This is how we all brought him up. When he started going to school, I was the one who used to drop him. In childhood he used to say that I will grow up and become a doctor. I will make Ma's leg better. But now that he has grown up, he does not listen to anyone. He does not study much. He is more interested in sports. He spends much of his time in playing cricket. He is busy all day.*

From the above narrative it can be seen that Korobi received help from all her family members to bring up her son. Such kind of support is very necessary for young mothers for their mental wellbeing. For someone like Korobi, apart from mental wellbeing, her physical condition also necessitated support from someone to bring up her son. We can appreciate the support that she received from her family members when we contrast her experience with the experiences of Uma and Chitra who have not received any help from anyone else besides their disabled husbands in bringing up their sons.

Uma, as mentioned above, had faced a lot of difficulties in bringing up her son in the initial months after her delivery. Her husband's family who live very close to their home did not provide them with any support during that period, for which she is still hurt. She is very grateful to her mildly mentally disabled older brother for understanding her difficulties during that period and for coming over during her hour of need. At the time of the interview her son was 7 years old. They have admitted him to an English medium school not very far from their home. She said that since neither she nor her husband are very proficient in English, they have appointed a tuition teacher to help their son with his lessons. She said that her son is the centre of her universe, and she has refused to go anywhere for leisure fearing that it might hamper her son's education. Even though her natal home is not very far from her home, she has not been there for several months because she worries too much about her son's education. She further said that she really enjoys coming to Sanjeeboni for her the training programmes as this is where she gets to meet several other women with disabilities. She said that spending time with them makes her forget about her own problems. However, after the birth of her son she had even stopped coming to the organization because she had to take care of her him. On the day of the interview, Uma said that it is only now, when her son has turned seven years old and has started going to school that she fits in her time according to his school schedule and comes for the trainings. She further said that now her son is able to understand to all the difficulties of his parents, but is unsure if he would also show similar interest when he grows up.

Like Uma, Chitra also did not receive any help from her family members at the time of her delivery. It was in fact found that when Chitra and her husband decided to start a family, they faced stiff resistance from the organization. Their disability, economic condition and lack of support from any family members were the prime reasons for this resistance. The organization members tried to talk them out of this by telling them that since they are not able to look after themselves, bringing a child to the world would be very difficult for them. However, both Chitra and her husband were adamant that they wanted a child. During her pregnancy, Chitra said that Suchismita took care of her diet and gave her the necessary tips regarding what to do to maintain her health. After her delivery, she lived with her *Dangor Bou* for less than a month, after which she was asked to leave from there. After the birth of their son, Chitra and her husband also had to give up their work of making doormats as they could no longer find the time for this kind of meticulous work. It was found that both of them complimented each other in their work and needed each other’s support for making the doormats. When after her delivery Chitra was not able to devote time for making doormats, her husband also couldn’t continue with this work. It was found that after she returned back from her *Dangor Bou*’s home, both the parents found it difficult to take care of him. At the time of the interview, their son was 11 months old. She said that with a single hand she found it very difficult to wash her son’s behind or to make him wear his clothes. Her husband especially had very little strength in his hands because of which he often dropped him while trying to make their son sleep. In one such incident, when I was present in the organization, it was found that when Chitra’s husband dropped their son, she got very angry with him, and since she could not show this anger on her husband, she started beating up her young son. When her son started crying, the other members of the organization came out to check what was wrong. When they found out what happened, they scolded Chitra and her husband, labeling them as bad parents. Later Chitra told me that she is very anxious about her son’s future and whether they would be capable in taking care of the child. Instead of supporting the new parents in their distress, the other organization members, especially the able-bodied ones, started saying things like, *"You were restless to have a child. Now when you have one, why are you beating him?"* and *"Let him grow up, I will teach him how to beat you both up. Why can you beat up a helpless child?"* The observation shows that while the organization members were very frightened about the child's future in the hands of his parents, yet none of them forwarded a supportive hand to ease the difficulties of the suffering parents, but instead reminded them about their bad parenting. Due to this reason, every time Chitra and her husband made a mistake with the child, it seemed to reaffirm the fears that they already have about their child. It was also found that when any new person came to the organization, Chitra and her husband were showcased as a 'success story' for getting married with full support from the organization. While all the people appreciated them for finding love with each other and defined it as 'cute', they all expressed their surprise when they learn that their son is non-disabled and was born from a normal delivery. This shows that even people working in a disability organization, many of whom are disabled themselves, have stereotypical notions about persons with disabilities. Chitra further said that many people came to her and asked her to give away their son to them in exchange for money. Chitra said that it is not possible because they have brought him to this world with much love. She expects that later when he grows up a little her *Xoru Kaka* would take his responsibility as her son is his only nephew.

Ability to do Household Chores

Household chores are an important aspect of women's life, and from a very early age women are taught to do such work so that they are prepared for their adult roles as wives and mothers. Studies on women with disabilities have also shown that they are not exempted from doing such chores. It has also been seen that women with disabilities get concessions in their natal families, while in their marital homes they are given no exemptions on the basis of their disabilities. In the current study also it is seen that the women have been taught to do domestic chores from a very early age depending on the severity of their disabilities. This was found to be especially true in the case of the women in the rural areas.

Minakkhi said that she had learnt to do household chores from a very early age by observing her mother and her female cousins. She can sweep the courtyard, wash the dishes, make tea and rice. She, however, faces certain difficulties in some kinds of work due to the nature of her impairment, like drawing water from the well or in cutting vegetables while making food. In spite of the difficulties, she said that she tries to manage with this work. Similarly, Surabhi also said that she can do all the household chores since the time she had gained consciousness. She said that she does not face any difficulty in doing this work. As cited earlier, Anamika had also learned to do household chores from a very early age due to the absence of any adult female members in the family. The burden of domestic labor was so much for her that it left her with very little time to concentrate on her studies. This eventually led to her failure in her 10th board exams. After her failure she went to her Pehi's home in Lakhimpur, where she continued to get involved in household and agricultural chores for the 10-11 years that she lived there. After she returned back from Lakhimpur, however, she no longer engages in such work. She said,

> *After returning back from my Pehi's home, I joined* [Sanjeeboni]. *So I do not do much work at home. I come out of home in the morning, and then I return back in the evening. I am busy the entire day, that is why… Since childhood I have been doing the household chores. I learnt by observing my Borma. I learnt to make rice, fish, sabzi, everything in my childhood. Washing clothes. In my childhood, I liked doing such work. But now I feel it would be better if I do not have to do these chores [she laughs]. How much work I will do? I do not feel like doing this kind of work. How much domestic work will we do? The house will be dirty every time. Who will work all the time? I do not feel like working.*

From the above narrative it can be seen that most of the women in the rural areas learned to do their household chores from a very early age by observing their mothers and other female family members. In certain cases, like in the case of Anamika, young girls have no other option but to engage in such kind of work due to the absence of any other adult female members in the family. However, after she started working at Sanjeeboni permanently as a CBR worker, it can be seen that she no longer engages in domestic work due to the paucity of time. It is also true that now her step-mother does much of the household work, so that Anamika need not come back and do anything after she returns back home from work. Her narrative also shows that she considers household work to be monotonous because she has other work to do outside her home.

Similarly, Pronoti also said that she likes doing her household chores which she had learnt to do from a very early age. When she was at home, she helped her mother and elder sisters in the household work. However, after joining the organization for work, she feels very lazy to do such kinds of work.

Unlike the women with milder forms of disabilities, it was found that mothers of women with severe disabilities did not expect their daughters to help them with the domestic chores. In most cases the women had the choice to decide whether or not they wanted to help their mothers with the chores. Gargi's mother said that she never asked her daughter to help her with any kind of work. Similarly, Sobiha's mother had also said that she never asked her daughter to help with any kind of work. Ananya said that if she is in the mood she fills up the water bottles before mealtime, but if she is not in the mood then she does not do any work. It was found that since these women were younger, and their mothers were relatively physically fit, they never had to think about helping with the household chores. Unlike them, the women who were slightly older than them emphasized on their abilities to do certain kinds of work regardless of their physical limitations. Risha said that before her back injury, she was able to help her mother with certain kinds of domestic work like mopping the floor, stirring the food while her mother was cooking or washing her own dish after eating and so on. Even though her mother objected to her working, she had started helping her mother from the age 12-13 years of age. After her back injury, however, she is no longer able to bend down to do these tasks due to the unbearable pain. She said that now she helps her mother with simpler work like cleaning the dressing table and folding washed clothes.

Like Risha, Nayana also helps her mother in her household chores in whatever way possible. She said that sometimes she sweeps the floor by sitting on her wheelchair, while at other times she washes her own clothes. She said that sometimes when she is in the mood, she also helps her mother in cooking. But usually she avoids cooking because she needs a lot of space and sometimes ends up burning herself. Nayana further said her father had taught her and her younger sister to sit and observe how he is cooking so that later they do not have to depend on another person to cook for them.

> *I try and do whatever I can. Sometimes I help Ma in sweeping the floor, by sitting. Sometimes I wash my own clothes. At one point I could cook also. When I get a*

> *holiday, I used to cook. Even now when I get a holiday, I cook, by taking out time. I cannot work in a hurry. If I work in a hurry, then I will burn myself. I hurt myself everywhere. That is why, I take out time and cook. I learnt to do the household chores by observing my parents. Ma and Deuta did all the work. When Deuta used to cook fish or meat, he would make both me and my sister sit and observe what all ingredients to add, how to make it and so on. In childhood he showed us these things. Sometimes Ma also showed us… They didn't expect us to cook as such. Deuta just said one thing, that we should be able to cook and eat by ourselves. He taught us to never be dependent on anyone. That someone would make food for me, and I will get to eat, he taught us never to be like that. He taught us to cook and eat by ourselves, whatever it is. We both listened to his advice.*

In the above case it can be seen that parents took it upon themselves to teach both their disabled and non-disabled daughters household chores like cooking as it is very important to not be dependent on others.

Dolly, who had acquired her impairment at a later stage, said that she does not suffer from any problem in doing her household chores, although her work is comparatively slower than a *bhaal manuh* [nondisabled person]. She said,

> *I have now adjusted to my disability. Earlier I had many difficulties like in washing dishes. One day I was washing dishes and the plate just fell off. I tried two three times and the plate fell off. I brought it back again and threw it myself. I again tried throwing it. I felt like no I cannot accept defeat […]*

In this way she tried to overcome her limitations. She also said that after her amputation when she stopped going for work, she started helping her mother in the kitchen. She also said that in certain kinds of household work, she is better than her *Baideu*, who encourages her to do such kind of work. She also said that she has never been interested in her studies, but she has always preferred to do household chores.

In the case of the married women, it was found that they did not have any other option but to do their household chores as their husbands did not help them at all with this kind of work. Bandana said before her marriage she did not have to do any work at her mother's home. However, after her marriage, she has to finish all the household chores before coming to her shop, and later after they have closed the shop at 10.30-11 pm, she has to go back home and make dinner

> *In the morning I get up and finish my household chores, clean the home, cook and only after that I come to the shop. I come to the shop around 9.30 in the morning. I go back later at night. I do not go in between for lunch. I make the food and keep it in a lunch box and my husband brings the food here. I find it difficult to climb the stairs to go back home, especially in the summers. I go back at night around 10.30-11 after closing the shop. Either of us has to be at the shop at all times. Since he only sells*

> *groceries, I can do his work, but if I am not there, then my work does not get done [tailoring]. That is the problem. After going back home, I make dinner.*

From the above narrative it is clear that Bandana works throughout the day, first at her home, and later at her shop, and then again at night when she returns back home. She said that her husband is very lazy and has never made her food. Even when she is sick, she does not ask her husband to make food for her. In the above narrative, it can be seen that Bandana now regrets marrying her husband as he does not appreciate the work that she is doing but instead puts her down in front of others. She is also troubled by the fact that she does not get any amount of respect from her husband's family in spite of helping them with their work. It seemed as if during the interview Bandana was troubled by her husband, and she took out her anger and sorrow during the time of the interview, when her husband was sitting just opposite us, but did not say a word. Towards the end of the interview she seemed to be happy after releasing all the anger and anguish within her. She said that people in the neighborhood praise her for the hard work she does in looking after her household, being a good wife and also her shop, and this seemed to make her proud of herself. She said,

> *I am a handicapped girl, but I am not dependent on anyone. My husband has never made food for me. No matter how sick I am, I am the one who cooks the food. I have never asked him to cook for me. I do not feel like a handicapped girl. But when others behave with me in a bad way, I get very angry.*

From the above narrative it can be seen that Bandana reiterates the fact that she does not feel like a 'handicapped' girl as she does not depend on her husband for any kind of work. The narrative shows that she repeats this over and over again because she has been made to feel this way by her husband and his family. She further said that because of her husband's laziness to cook, she has not been able to go and stay with her mother since her marriage.

> *My husband is very lazy. When I go to Ma's home, on that day there will be no cooking in the house. He will just have milk and bread and sleep. Till the time I return back from home, he would just have milk and bread. He won't have rice. Due to this I do not get any peace at all. When I go home, I can only stay for a night. I cannot stay for long. They call me so much that I should stay at home, but I cannot go. When I go home, he does not eat rice. That is why I cannot go. They say he would have his meal. But I know that he won't. Even if I make the food and go, still he would not take it out and eat. I am saying the truth. He is very strange, he is like a small child* [she laughs]. *After getting up from bed, he would come to the shop after a bath. He would ask me where his clothes are. Even though everything is right in front of his eyes, he cannot see it. He wants me to keep everything on the bed and only then he would wear it and come to the shop. He would do such things. I feel a little lazy to wake up in the morning. After leaving from here I need to cook and clean the utensils.*

> *I want to sleep for some more time. But he would make so much noise in the morning as if there are not two but 6-7 people in the house. He shouts a lot.*

Bandana, who had broken down several times during the course of the interview while talking about her relationship with her husband and his family, recovered quickly from her emotional state, and started talking about her husband with a shy smile on her face. She shared that her husband is almost like a child, who cannot live a single day without her. For instance, if she visits her natal family for a day, her husband would not eat anything other than bread and milk, till the time she returns back and cooks for him, and serves him herself. It seemed like she found this cute, and not restrictive of her mobility. This also made her feel more confident about herself as in spite of her disability, it is she who looks after her household and not her husband as is commonly assumed by others. Such kind of pride about doing household work was also seen in Sarma's study (2014) in Delhi NCR. In fact, in the Indian context, where girls are trained to do household chores from a very early age regardless of their disabilities, such pride about the ability to do household chores is only natural (Dube, 1988; Mehrotra, 2004; Ghosh, 2013).

Unlike Bandana, Uma had learnt to do household chores since her childhood by observing her cousins. She said that since she could not play with her age mates in childhood because of her impairment, she preferred to stay at home and learn different kinds of household chores from her cousin. Other than this, she also learned some useful skills such as sewing, weaving, *dhenki diya* and so on. After her marriage, however, her husband no longer allows her to do such kind of work thinking that such activities may aggravate her difficulties.

> *We have a dhenki in our house, we also have a mixer grinder. I like to work in the dhenki but my husband does not allow me. He says that I will face difficulty. Since one leg is already impaired, I will have to use my bhaal bhori. I will be putting more pressure on the bhaal bhori and that usually leads to pain. That is why he asks me to use the mixer. But I do not like it. I like the village atmosphere of using the dhenki.*

Like Bandana, Chitra had also never worked at her natal home. She only helped with a few things like plucking the grasses from the yard, sweeping their home and watching over the house when no one was around. Earlier she did not have to cook as her *Dangor Bou* did the cooking, while her *Bhotija suwali* (niece) washed her clothes. But after her marriage she has to do all the household chores in spite of all her hardships. She said,

> *Earlier I did not cook. But now even though I face hardship, I am doing it, now that I am married. He [husband] makes food, but I do not eat it. Even if I am dirty, with regard to food I am very clean. The way I do it, he does not wash the things properly. This is why I do not like to eat what he cooks. That is not the way I cook. After all, he is a man. He does it in a hurry. My work is slow, but it has to be clean. I cannot eat dirty food. There is iron in the water here. For us we can just wash the rice in it and have it. But we cannot just wash the rice in iron water and give it to Babu. We have to wash it again with filtered water. Also the milk bottle and rice, we have to wash it in filtered water again. We are facing a bit of difficulties. If there was no iron in the water, it would not have been necessary to wash the rice twice. Once would have been sufficient.*

From the above narrative it can be seen that Chitra does not like the food being cooked by her husband, because ‘*he is a man who works in a hurry*’, and does not clean the food properly before cooking it. She said that even though she faces slight difficulty in doing her work, she has to do the household chores, as no one else would do the work for her. She said that before the birth of her son, she also swept the floor of the office and she and her husband made doormats. But after his birth she cannot do it anymore as she needs to be with him all the time.

In the case of Korobi, her mother said that they do not allow her to cook because she is a spendthrift and needs a lot of things while cooking. Korobi, however, said that she finds it hard to cook as she feels that she will burn herself again. She said that she does the other work like washing the dishes, cutting the vegetables, cleaning the house, cutting fish, folding clothes and so on. Her husband said that she is able to do all the work, but she cannot bend down to work. Her mother said that when Korobi visits her upstairs during the course of the day, she asks her to cut the vegetables. Her husband also said that she is very lazy. She always puts off the work for later. Korobi said that she does not like to do the household chores as she needs to do the same work every day. Instead she would like to go out and work as it will bring about a change in her life, she would meet other people and also be able to earn something. She said that she gets very depressed by staying at home all the time. Her husband did not take her concern very seriously, and told her that it is not necessary for her to go out and work, and it is sufficient if she is able to take care of herself inside the house.

In the case of all the women it was found that they did not expect any kind of help from their husbands, and if they received any kind of help from them, they considered it a blessing. This shows that socialization since childhood about the feminine responsibilities of women makes it impossible for these women to even imagine that they can expect their husbands to do some household chores.

Concerns for the Future

In the previous sections of this chapter we have discussed the how the life trajectories of the women have been shaped due to a number of factors. In this last section, we would look at the concerns that the women have for their futures. It was found that all the women were concerned about what would happen to them in the future. There was, however, a clear distinction between those who were unmarried and those who were married and had children. In the case of the unmarried women, it was found that they were very concerned whether their siblings would look after them in the future after their parents have passed on. The following narratives illustrate this clearly.

Minakkhi was concerned about whether her brothers and their families would look after her in the future, after the death of her parents. She said that even though her brothers, sisters-in-law and her nieces and nephews treat her very affectionately now, but she is not sure if this would continue in the future. Surabhi also said that she is worried because she is not well-educated and does not have a well-paying job. She said that she is worried if she would have to life like a burden on other members of her family. Similarly, Ananya also expressed her concern for the future after the death of her parents, as she is not sure if her elder sister, with whom she does not share a very good relationship, would look after her in the future.

> *I have so many worries. What to say? I have a lot of worries. When I think about that, my head becomes very hot. I have many worries.*

When I probed further, Ananya said,

> *Ma-Deuta are alive today. So they are looking after me. Tomorrow when they are dead, who would look after me? I have such worries. How will I survive?*

When I asked her if her elder sister won't support her, she replied,

> *She will look after me… But I do not have any trust. Who knows, Ba's husband may not look after me. What is the guarantee that he would be interested in looking after me? What is the guarantee? There is no guarantee. That is why I feel bad.*

From the above narratives, it is clear that the women were quite sure that they would be well looked after till the time their parents are alive. However, they were concerned about what would happen to them in the future when their parents are no more. It seemed that the women did not trust whether their non-disabled married siblings would look after them in the future or not. Unlike them, their mothers believed that their non-disabled children would look after them in the future. In the case of Gargi and Sobiha it was found that they encouraged and expected their younger children to look after their disabled daughters. Although the mothers felt bad that their younger children have to carry this burden, since there was no other option, they did not give it much thought. In the case of families which had money, it was found that parents ensured that their disabled daughters do not have to depend on anyone after their parents have passed on, by building a home in her name. Rekha, the special educator at Senehi, said that Risha's father had built a home in her name so that she does not have to depend on anyone else in the future and she is able to live off that property. Rekha, however, criticized this vision of the parents that they did not encourage their children to be independent but instead encouraged them to be further dependent on them. Risha, on the other hand, was more worried about her physical condition and if it would aggravate in the future. During the interview, she said,

> *I am worried about the future, in the sense, sometimes I feel that maybe I will have to use the wheelchair someday. I feel that way. Earlier I used to feel bad about this. Now I feel that if I need it, I will have to use it. There is no point in feeling bad about this. I have been able to accept this now. I have watchted many programmes in the Discovery channel. I have also seen other people around me who use a wheelchair, such as, Zohaan Da* [the Executive Director of Senehi]. *Seeing them, my view about using a wheelchair has changed.*

From the above narrative it can be seen that unlike other study participants who were more preoccupied about whether their siblings would look after them in the future or not, Risha seemed to be more concerned about her physical condition. The reasons for this could be her fast deteriorating physical condition as also the assurance that no matter what at least her father has given her some property with which she will be able to survive in the future.

Like Risha, Bandana was also scared about living with a physically deteriorating health condition. She said,

> *I feel that God should keep me alive only till the time I have strength in my body to work. If tomorrow I am bed-ridden; I should not be alive like that. Who would look after me? There is no one who would look after me. Even now there is no one to look after me. Who would look after me in the future?*

From the above narrative it is clear that Bandana does not trust her husband that he would look after her in the future. Due to this reason, she does not want to live till a period when she is not able to work. Similarly, Anamika was also found to be more concerned about her physical condition in later life.

> *Fears for the future? Yes I do have fears. Now I am here, I am able to do the work, that is why I am able to these things. Later, when I would be old, at that time I would not be able to come for work. What would I do then? That is how I feel. I will have to take money from home. There is money at home, but still. The work that I am doing here, if at that time I am not able to do this kind of work, I would be such a bekaar* [unemployed]*, isn't it. Whatever I can, whatever I am able to do now, wherever I am going now, when I cannot come here, what will happen then? Isn't it? I will be like a senseless person. Now I can go home, I can go to the agricultural land, now I can roam about barrier-freely, then we would not be able to roam about like this. Because money is also an issue. Every day family members may not be able to give. Now since I am earning on my own, I can decide what I want to do, what I want to eat, what I want to wear, I am doing all that my myself. In the future, I may not be able to do this. Maa-Deuta would grow old. They would not have so much income. We do not have Bhai-Kokai* [brothers]. *We have to do everything by ourselves. What to do, what not to do. Till the time Maa-Deuta are there, my life is there, who knows what will happen after them? That is the fear. I will have to think about the future. So for that I will have to do something. That is what I think. Your own Bhai-Kokai leave you, other Bhai-Kokai* [cousins] *will not look after you. I feel like that.*

From the above narrative, it can be seen that Anamika is concerned about whether she would be able to retain her autonomy in the future. As an employed person, she is able to decide whatever she wants to do in life. She is worried, if she can continue with this work in the future given her physical condition. She is also worried that she might have to depend on her family for money later in her life, but at that time, her parents would also age. Her other concern is that since she does not have a brother, there is no body that she can depend on.

Similarly, Dolly was concerned about her future with her family. She said that although now her younger brother takes care of all her needs, she is not sure if this would continue in the future, when he is married.

> *I am scared about living alone. Till the time Ma is there, she will look after me. But for lifetime, who would look after me? Bhonti will have her own xonxaar, Bhaiti would have his own xonxaar. I want to do something to secure my future now. I want to something so that I will be able to stand on my own feet. I am scared about living alone. I feel that even today if everyone leaves me, and I am left all alone, how would I feel?... I feel that I cannot work here* [Moromi] *for long. This is an NGO. I want to*

> *start something of my own. But there is no guarantee for this. If something happens to me on the streets? I do not have trust on myself. I feel that if I am able to start my own shop, my future would be secure. Bhaiti will be able to work in it, Bhonti also would be able to work in it. I want to do something of my own. For this I need help. No one can say that do not need help. I need help. In the future to stand on my own feet, I need help. I want somebody to help me to start my own shop.*

From the above narrative it can be seen that Dolly also feels that till the time her mother is alive, she will look after her, but she is not sure what would happen to her after she is no more. She also feels insecure about working at the organization because it pays very less and her future also is very uncertain in the organization. In order to overcome this, she has the desire to start her own fast-food joint, where her siblings would help her. However to turn this dream into reality, she needs capital, and she did not have any at the time of the interview. She was looking for some help to start her own business.

Nayana also said that she is concerned about what would happen to her if something happens to one of her family members. It was found that since the death of her father, she has this profound fear of losing someone close to her again. She said,

> *I have fears. If anything happens to me, then it is a different thing. Till the time I am alive, I want Ma and Bhonti to be close to me. I have nobody else. That is why I feel scared thinking about this. What if something happens to one of them? I feel much tensed about this. Otherwise, I do not have any fears. I want to live my life among disabled people. This is because bhaal manuh cannot understand us. Whatever I get, I want to share it with 10 more disabled people. And whatever they get, they should be able to share it amongst themselves. That is what I want.*

From the above narrative it can be seen that after the death of her father, Nayana is very scared about losing another member of her family. It is this thought that makes her tensed and gives her sleepless nights. She also said that apart from this fear, she does not have any other fears in life.

In contrast to these women, the women with disabilities with children were concerned about the futures of their sons and whether or not they would look after them in the future. The following narratives give a glimpse of this.

Chitra said that she was worried about how she would bring up her son. She said that because at the time of the interview he was very young, she was more worried about how she and her disabled husband would bring him up. She feels that once he grows up a little bit, she will not have to worry about these factors. However, there will be other concerns like how to make him study and how to make him a good boy. As cited earlier in the chapter, she was also worried about whether the disability organization Sanjeeboni would look after her family in the future; as she is sure that her own family will not.

Korobi also was worried about her son's future. She said,

> *I have worries about my son's future. What will he do if he does not study properly? Today his Aitak* [grandmother] *is there. If tomorrow she is not there, who would look after him? Others will not look after him. I am worried about his future. What kind of work he will do to survive. What will happen if he does not get admission into a good college? I have many such worries.*

From the above narrative it can be seen that Korobi was worried about what would happen to her son after her mother passes away, as now she is the one who is paying for all his expenses. As can be seen from the above narrative, she does not expect her younger sisters to pay for her son's education expenses. As the interview progressed, Korobi also spoke about her other worries about her son's future. She said,

> *After he passes his 10th and his 12th, I would give him admission in Guwahati Architecture College. After he passes from there, he would get a job in New York, and I would live with him there. Before his marriage, I would cure all my diseases. I will do all of this slowly. Step by step. He would have to study well and get a job. After he gets his job, we would go to America. We would stay in New York.*
>
> *Korobi's mother: Your Bhonti has said that if you are like this and if your buari comes and sees you like this, she won't stay with you. She will leave and go* [she laughs]. *Then you would have fun!*
>
> *Korobi: No! I would not get a bad girl for him. I would see the girl first and then ask him to marry her. Before getting married, I would make an agreement. I would tell her all my problems. I would make her sign the agreement.*
>
> *[Everyone laughs]*

From the above it can be seen that Korobi was very concerned about the kind of girl her son would get married to. During the interview, she kept on repeating that she would make sure that he gets married to a *bhaal suwali* [good girl] who would be able to adjust with her. When I reminded her that he is only 16 years old, she said that she will have to ensure the future gradually. When I asked her mother who gave her such ideas, she said,

> *Korobi's Mother: She has thought about them herself. I think she thinks about these things the entire day. But seeing her tantrums, her buari would not stay here. She would leave from here.*

> *Korobi: I do not want to bring an Assamese girl. If I bring an Assamese girl, she would understand our language, and she would know everything about our home, and everything about me. It would be good if she is a Punjabi.*
>
> *[Everyone laughs]*
>
> *Koorbi: It would be good if she speaks a different language. She would not understand anything that we speak. I would ask my Mama's daughter to look for a girl.*
>
> *[Husband laughs]*
>
> *Korobi: Ma has another flat in Bhangagarh. I would ask my son to live there. Ma, would you also stay there? After his marriage, I would keep them away from me. Then she won't know me much. When they stay away, their love for me would increase. Someday she would ask me to come to her home, someday she would drop me here at my home. Ma would also stay there with them.*
>
> *Korobi's mother: Only if they live separately her buarek would love her. That is what she is trying to say.*
>
> *Korobi: By that time I would cure myself.*
>
> *Korobi's Mother: Now what kind of girl he would bring, that is a big deal.*
>
> *Korobi: No. He would have to bring whoever I choose.*
>
> *Korobi's Mother: Nowadays such things do not work.*
>
> *Korobi: No he would have to listen to me. I have spoken to him about this the other day.*
>
> *Korobi's mother: Oh! You have already spoken to him? Now he may have said yes, but later he might say no.*
>
> *Korobi: No he cannot say no. I would get him married in the court.*
>
> *Korobi's Mother: What if he understands later that you are getting him married to this girl for your own selfish needs, and decides not to marry her? What would you do then?*
>
> *Korobi: I would get him married in the court. He cannot say no to me.*

From the above conversation between Korobi and her mother it is clear that she has different concerns about her own and her son's future. As can be seen, Korobi wanted to cure all her physical and psychological problems before her 17 years old son gets married. In her free time, and probably due to the influence of her 'well-wishers', Korobi thinks about what would happen to her in case her *buari* decides not to look after her. As can be seen from the above conversation, she has devised different plans in order to ensure that she would look after her later. Korobi said that she would choose the bride for him, and would not allow him to choose his own bride, as otherwise it can be a 'bad' girl who may not look after her. And then she would make her sign a contract that she will have to look after Korobi. She also said that she would ask them to live in a different flat as this would ensure that they do not have fights with each other.

To summarize this section, the narratives have shown that in the absence of adequate social security benefits and the dwindling ties with siblings after their marriage, women with disabilities are often left wondering about their futures, where the possibility of deteriorating health is a high possibility. In a context of limited financial resources and growing individualism, these women do not trust their siblings and their families to care for them in the future.

Conclusion

This chapter focused on the significant events in the lives of the women and these events have affected their lives from they became aware about their impairments. It was found that at different phases of their lives the women were made to feel aware that they are different from others due to their impairments. Such experiences had a profound impact on their mental well-being for which Thomas's (2004a; 2004b) concept of psycho-emotional dimensions of disability seems apt. Such experiences make us conscious about the fact that discussing personal experiences of impairment is not a weakness as has been suggested by some disability scholars, but is perhaps the first step towards acknowledging that there is a problem which requires collective support to counter it. In the case of the study participants it was found that such a collective was formed at the disability organizations, where they met other persons with disabilities for the first time in their lives. This helped the women in myriad ways in dealing with the problems. The following chapter would elaborate on these aspects.

Chapter 8

Support from Disability Organization

This chapter elaborates on the support that the study participants have received from the four disability organizations from which they were recruited for this study. It is important to understand this because in the absence of adequate State interventions, it is the disability organizations that most women and their family members have looked up to for the required support. The main objective of the chapter is to highlight the multiple forms of support that the women have received from these organizations and to question if such endeavors are at all sustainable for the long-term needs of the disabled community at large. The chapter is divided into three sections. Section I gives the case studies of the three disability organizations, Sanjeeboni, Senehi and Helen Keller Charitable Trust. As mentioned in Chapter 2, unfortunately I could not interview anyone from the organization, Moromi, due to which I have to leave it out from this section. Section II describes the specific kinds of support that the women have received from these disability organizations, such as help in making the disability certificates, in acquiring aids and appliances, getting the opportunity to earn a livelihood as well as certain kinds of support that the women have received due to their personal contact with the founders of the organizations. Section III elaborates on how this support has helped the women in gaining confidence and awareness about disability issues and in acquiring a reputation in their respective families and communities. The chapter uses the concept of *social capital* to underline the support that the women have received from the organizations, but also points out the drawbacks of such kinds of support in the conclusion section.

Section I

Case Studies of the Disability Organizations

This section elaborates on the case studies of the three disability organizations, Sanjeeboni, Senehi and Helen Keller Charitable Trust (HKCT), in order to highlight how these organizations came into being, who are the founders of these organizations, what are their viewpoints on disability issues and persons with disabilities and what are the constraints under which they function. The case studies are based on interviews conducted with the prominent members of the organizations. From Sanjeeboni, its founder, Suchismita along with an ex-Community Based Rehabilitation (CBR) Worker, who was later working as a programme officer, Lalit, were interviewed. From Senehi, Rekha, a special educator who has worked at the organization from 1996, was interviewed, and from HKCT, its President, Palash, was interviewed. Let us now look at these case studies in detail.

Sanjeeboni: Suchismita, as has been elaborated in the previous chapters, is a polio survivor, who walks with the help of a walker. Her own experience of living with disability has provided her with the motivation to work in the field of disability rehabilitation. She had worked in Senehi for a few years as a special educator, and received in-service training from there. She also has the license as a Rehabilitation Personnel from the Rehabilitation Council of India (RCI), New Delhi. In the year 1997, when she was still working with Senehi, she fell down and fractured her polio-affected leg. After this mishap, she was bed-ridden for several months, which made her decide to quit her job. But soon she started getting bored at home and was looking for some other job. Around the same time, she was approached by an international organization working in the area of village development in the Joonaki Block, to come and check on a few people who have ‘strange incurable illnesses’, whom they had discovered during their fieldwork. After her recovery, Suchismita along with two of her colleagues visited this organization where the latter had arranged a camp for the people. With one quick glance, Suchismita and her colleagues were able to identify that the people did not have ‘strange illnesses’, but had different types of disabilities like locomotor disability, mental ‘retardation’ and cerebral palsy. It is this experience that made her realize that the services for persons with disabilities are negligible in the rural areas and inspired her to work for them.

During the initial period, Suchismita’s organization, Sanjeeboni, conducted a household survey to ascertain the total number of persons with disabilities in the Block with the help of fieldworkers of the international organization. They also provided Suchismita and her team with the space in their office to operate, until they got their own land. In the initial meetings with the community, Suchismita had tried to build rapport with the parents of children with disabilities, and to explain to them that their children's conditions can be rectified. But the parents never believed her and were reluctant to go to Guwahati Medical College and Hospital (GMCH) for the treatment of their conditions. Due to this, she decided to arrange a medical camp in the Block itself, and for this purpose she invited doctors from the relevant departments of the medical college. These doctors distributed free medicines to the children with disabilities, and explained to their family members that their children will get better with corrective surgeries and therapies. The villagers listened to the doctors, but were still scared to go for the surgeries as they feared that their children will never return from the operating table. At that time, Suchismita told them, *"I have had nine surgeries on my leg, and still I am working for you people. What are you people afraid of?"*

It took the organization some time to gain the trust of the community and to convince them, but when they started seeing the results of those who had gone for surgery, their attitudes started changing, and the organization was able to carry on their work smoothly. Suchismita said that the organization functioned on a 'medical mode' for the first few years, and had focused primarily on surgeries and therapies. This, however, changed in the early 2000s, when they were approached by the CBRF[164], Bangalore, who wanted to fund the organization for providing community based rehabilitation[165] (CBR). The CBR project was for ten years, from 2005-2014. With the help of Sanjeeboni, the project also helped in forming Disabled People's Organizations (DPOs), which were trained in leadership skills and other soft skills. The DPO leaders were given appropriate information about the various government schemes and Acts so that persons with disabilities in the community can access them.

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[164] CBRF or Collective Action for Basic Human Rights Foundation is a disability and development organization that reaches out to the remote rural areas of the country. It began as a programme of Caritas India in 1996 but was registered as a separate society in 2011 under Societies Registration Act, 1860. CBRF promotes awareness, rehabilitation, inclusion and empowerment of all persons with disabilities, with a major focus on women, children and those with severe disabilities. It works with persons with disabilities, NGO partners, local communities and the government to bring about desired changes in the lives of persons with disabilities. Before it ends its association with persons with disabilities, it makes sure that persons with disabilities are fully prepared to look after their own futures. It works on five core areas: health, education, livelihood, social inclusion and empowerment of persons with disabilities (https://cbrf.in/something-about-us/ last accessed on 4.7.2019).

[165] The prime objective of Community Based Rehabilitation is to improve the quality of life of persons with disabilities, especially in the majority world. CBR establishes partnerships with local communities, persons with disabilities and their families, governments and rehabilitation personnel. It uses local resources to provide basic rehabilitation to a large number of people (Lang, 1999).

Sanjeeboni also collaborated with the local government bodies to ensure that the inclusion of persons with disabilities becomes a reality. After the end of the partnership with CBRF, it is the DPOs that ensure that the rights of persons with disabilities are taken care of.

Lalit had joined the organization as a CBR worker in 2010 and had worked in the project till its completion in 2014. From 2014, he has been working as a programme coordinator for a microfinance project. This new project is not related to the field of disability, and due to this reason, he is not in direct contact with persons with disabilities anymore.

The CBRF project worked on five broad areas, which include education, livelihood, health, social inclusion and empowerment. In the area of education, the CBR workers mainly worked for the inclusion of children with disabilities in government schools by conducting orientation programmes for government school teachers. According to Suchismita, the school teachers initially showed a lot of reluctance towards attending such programmes as they were already overburdened with school responsibilities. However, after attending these programmes, their attitudes towards children with disabilities changed and the organization has received positive feedback from them. At that time, sometimes the CBR workers also helped the teachers with their work. Now the members of Disabled People’s Organizations (DPOs) are continuing with this work.

In the livelihood sector, the project had organized skill training programmes in local trades for persons with disabilities in areas such as bamboo work, tailoring, weaving and crochets work. These trainings were conducted in the organization premises as it is difficult to arrange these in the villages. The main aim of these programmes was to enable persons with disabilities to start a trade of their own with financial support, in order to support themselves and their families. After receiving such training, several persons with disabilities from the organization had participated in the Abilympics[166] and were successful in winning gold and silver medals.

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[166] National Abilympics Association of India (NAAI) organizes vocational skill competitions to discover and nature the talents of persons with disabilities and to create awareness in the society about their productive skills. The participants in the age group of 18-35 from all zones of India are encouraged to participate in these events, either individually, or through NGOs or government institutions (www.abilympicsindia.org).

Within the health segment, the project organized screening programmes to assess the degree of disability and planned the type of intervention necessary for persons with disabilities. Additionally, the CBR workers provided training to the Anganwadi Workers to identify children with disabilities. They also assisted in the immunization of children with disabilities and provided referrals for corrective surgeries. The CBR workers also taught activities of daily living to young children with cerebral palsy or mental retardation in their home based training, in the presence of a family member, who in most cases is the mother. When the child grows up, the CBR workers conduct this training by keeping into consideration the gender of the child in question. According to Lalit,

> *We had made this rule that once the child grows up, only male CBR workers will conduct the home based training for male children, and female CBR workers will conduct it for the female children. This is because we realized that as these children grow up, they develop a sense of shame.*

According to Lalit, it takes some time to change the attitudes of the parents towards their children and to convince them that their condition can be improved with regular exercises. During his tenure as CBR worker, Lalit has seen significant improvement in many of the children that he had been working with. After the end of the project, however, Lalit has no idea how those children are faring, as he is no more in contact with them. He said that now the DPO members are continuing with this work. The organization also distributes aids and appliances such as hearing aids, crutches, wheelchairs, tricycles and walkers to persons with disabilities under the health scheme. Suchismita said that initially the organization had approached ALIMCO[167] for this purpose, but over time they realized that the quality of these aids and appliances are not very good. Subsequently, they started approaching the corporate houses like the Guwahati Refinery and Oil India Limited (OIL) for the same. Suchismita mentioned that the maintenance cost of these aids are very high, and due to this reason, if the quality is poor, they stop functioning very soon, and once that happens people just keep it aside. Due to this reason, the organization thought it best to provide better quality aids and appliances to the people. According to her, almost

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[167] Artificial Limbs Manufacturing Corporation of India (ALIMCO) is a public sector enterprise that manufactures aids and appliances for persons with disabilities. It main is to provide aids and appliances to good quality to a large number of persons with disabilities at reasonable prices (www.alimco.in).

99 per cent of the persons with disabilities in the Block have access to aids and appliances.

The project also worked on changing the attitudes of the individual, the family and the community at large in order to make sure that persons with disabilities are included in the society. The aim of the CBR project was to make it sustainable, and for this purpose it sought to empower the local disabled youth through DPOs to work on matters of their concern in the community. These DPOs were formed in 2011-12, and with the help of the organization DPOs were set up at the village, *Gaon Panchayat* and Block level, so that people are given the awareness about different government and non-governmental schemes that are related to persons with disabilities.

At the time of the study, the organization was working with 140 different villages from 12 *Gaon Panchayats* in Joonaki Block. About 700 people with different disabilities were associated with the organization. From her experience, Suchismita said that when they started working in this field they realized that some of the obstacles that persons with disabilities faced include negligence and discrimination at the family, neighborhood and community level. According to her, the CBR project has changed the perception and attitudes of the wider society of the Block towards persons with disabilities, and they are now seen beyond their disabilities. She said that since this project took off, non-disabled people approach persons with disabilities because of their involvement in the DPOs, which facilitated different kinds of activities, not only for persons with disabilities but for the entire community. Following the success of this project, the CBRF has funded them for another similar project in the Kushal Block of Kamrup (Rural) District in 2015.

According to Suchismita, community based rehabilitation is the best way to provide rehabilitation to persons with disabilities as it has a wide reach and is also more helpful in ensuring the inclusion of persons with disabilities to the mainstream society. In comparison to this, she feels that the reach of institution based rehabilitation, like what is provided in Senehi, is very limited as it cannot reach out to so many people. She also feels that the CBR project has brought about a significant change in the lives of persons with disabilities, especially the women. According to her, earlier women with disabilities in the Block faced a lot of difficulties in getting married. With the help of the CBR project, the community has been able to see the potential of such women, as a result of which there is a visible change in people's perceptions towards them. According to Lalit, persons with locomotor disabilities have benefitted more from this project in comparison to persons with cerebral palsy, mental retardation, hearing and visual impairments as *"their problem is only with their mobility, while their thinking ability, talking ability or ability to work is the same like that of a 'normal' person".* He also said that in terms of gender, men with locomotor disabilities face lesser restrictions in working outside of their homes, than women with locomotor disabilities, and this is the only gender difference that he has seen in his work.

In 2013, the organization became the nodal agency for making disability certificates in the district of Kamrup (Metropolitan). Many at the organization feel that after this move, the process of making the certificates has eased out a lot than earlier, as people no longer have to wait for a long time to make these certificates. Earlier doctors used to conduct the assessments at the organization, but this turned out to be non-feasible as they were not able to give sufficient time for the assessment as much of their time was lost in travelling from Guwahati. Over time, the organization solved this problem by making transportation arrangement for the villagers to go to Mahendra Mohan Chaudhury Hospital (MMCH) for the assessment on every Thursdays. After the completion of the project, now the DPOs have taken up this matter.

From the above discussion it can be seen that in the initial years, Sanjeeboni only provided medical rehabilitation to persons with disabilities in the Joonaki Block. Over time as the work of the organization started to get recognized, they received a ten years long project from the CBRF that helped in providing community based rehabilitation to the persons with disabilities at the level of the Block. After the success of this project, the organization received another similar project for another Block in the Kamrup (Rural) District. Meanwhile, at the time of the interview, it was found that the Sanjeeboni office at the Joonaki Block was hunting for other projects under the Corporate Social Responsibility[168] (CSR) scheme to work for the people of

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[168] India is the first country in the world to make corporate social responsibility mandatory following an amendment of The Company Act, 2013, in 2014. According to this amendment, a company with a net worth of Rs. 4.96 billion or more, or a net profit of Rs. 50 million or more during a financial year shall earmark 2 percent of average net profits of three years towards CSR. Businesses can invest their profits in areas such as education, poverty, gender

the Joonaki Block. This suggests that once a particular project is over, most often the schemes on which the earlier project was working is also abandoned for the newer schemes, and in the process it is the genuine concerns of poor persons with disabilities that are completely negated. For instance, during my interview with Suchismita, she told me that persons with disabilities from the Block often come to her and ask for money for their sustenance. In such times, she tells these people that her organization does not provide money to persons with disabilities but only equip them with the necessary skills so that they are able to earn their own livelihood in the future. She said that in this way, the organization is able to provide long-term support to the people. During my interview with Lalit, however, it was revealed that the skill development workshops are no longer conducted as one of the major organizations that used to fund these workshops had stopped working. This suggests that a person with disabilities cannot rely on the services provided by the organization as they can be stopped at any moment, without any prior notice. Lalit's interview also shows that at present he is not working for persons with disabilities directly. He further said that although he is very happy working for the organization, he gets upset about the low pay in this sector. This suggests that the people from the community cannot completely rely on the CBR workers for alleviating their problems, as they may either shift to another project, or due to the low pay in the sector, they might just move to another better paying job. Even though the organizations maintained that the DPOs are now carrying forward the work that was initiated under the CBRF project, a few interviews with DPO leaders showed that they were not happy with this line of work as they were not paid enough for their services. As a result, they were always on the lookout for other better paying opportunities. All these points suggest that although the organization considers the CBR project to be a success, its sustainability in the long-run is questionable.

Senehi: As cited above, from this organization, Rekha Chaudhury, a special educator, was interviewed. She had joined the organization in 1996, when she got bored of sitting idle at home after her children grew up and started going to school. At the time of the interview, Rekha had worked for the organization for almost two decades. Senehi was founded in the year 1987 by a group of educated upper class women, most

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equality and hunger (https://www.india-briefing.com/news/corporate-social-responsibility-india-5511.html/).

of whom were wives of tea planters. One of these women had the experience of working at the Indian Institute of Cerebral Palsy (IICP) in Kolkata. When her husband got transferred to Guwahati, she collaborated with a few other women to establish this organization. The school had begun with only two children with cerebral palsy and is affiliated to IICP. Rekha said that in the initial years mostly women with no qualification had joined the organization. At that time they were not provided appointment immediately. They had to work with the children for at least a period of three months in order to assess whether they would be able to do the work that is demanded of them at the organization. This time period also gave the women a chance to understand if they are suitable for the particular post. Due to this reason, Rekha said that at that time several women joined and left the organization in quick succession. The special educators at Senehi were given workshops at regular intervals from trainers of IICP, who came to Guwahati for inspection. In addition to this, the special educators learnt from each other and from their own experiences of working with children with disabilities.

Rekha said that in the initial years, there were only two units at the school: the Outdoor Services Department (OSD) and the Centre for Special Education (CSE). At the OSD, parents or guardians who were usually from outside of Guwahati, brought their children when they realized that something was amiss with them. There was a physiotherapist and a special educator at the OSD who assessed the child. After the assessment, they gave the management plan to the parents or the guardians who came along with the child. The OSD checked the progress of the child during checkups at regular intervals, which usually took the convenience of the parents into consideration. The CSE, on the other hand, was mostly for children with cerebral palsy. She acknowledged that the level of awareness about disability was not so much during that period, and the issues typically revolved around the physical management of the disabled child. She said,

> *[t]he work we did was more individual centric. There was a process by which assessment was done, after which his / her needs were taken out, and on the basis of these needs, goals were fixed. The goals were very small. There were not big goals for the disabled children. Considering their disability and capability, smaller goals were set up. We had to achieve those goals. At that time there was not much focus on vocational training. [...] There were two things: one was the OSD which only focused on physiotherapy; and the other was special education. The reports were given in two terms. We moved forward in that manner. We were also not so aware at that time. We all wanted to work with such children. We all genuinely wanted to work to see if we*

> *can do something for them. But what will happen etc. such kind of thinking we did not have. At that time the students who came here were very young. We looked after them as per their needs.*

The organization moved to its permanent location in 1998, after which several changes were brought about in its structure. Earlier all the employees worked under the instructions of the school principal. But after 1998, following the advice of one of the founders, the organization was divided into four distinct units: 1) training for special educators, 2) center for special education, 3) community based rehabilitation, and 4) outdoor services department (which was later renamed as early intervention unit). In each of these departments, there was an in-charge who had the responsibility of their own units. These changes were made as per the RCI guidelines which standardized special education in the country. It is at this point that Rekha realized the importance of a professional degree for her career, and so she along with several of her colleagues pursued their B. Ed in Special Education, that was being offered at Senehi. It is now compulsory for all the special educators of Senehi to be graduates with a B. Ed in Special Education, as mandated by the RCI.

Although the CSE was initially meant for children with cerebral palsy, over time they realized that some children with cerebral palsy also have mental retardation. Due to this reason, the organization also started including children with mental retardation as well as other learning difficulties such as Down’s syndrome. During this period the awareness about disability also started increasing in the community which made the school more popular among the masses. As a result, more number of parents brought their children to the school for admission. This is in contrast to the earlier period when parents were mostly referred to the organization from the medical college by doctors, due to which the number of children were comparatively very less. As the number of students at the organization gradually started increasing, another problem that it started to face was lack of space. By this time the organization also realized that most of the students who had joined the CSE in the initial years were already grown up and were approaching the age of 18 years. Taking all the factors into consideration, the organization after much deliberation decided that they would introduce an age criteria for the students such that children beyond the age of 18 will not be allowed to come to the school, so as to make space for the younger children.

The first batch of students who were about to attain the age of 18 came as a big problem for the organization as their parents had never considered that one day their children will not be able to come to the school. Rekha elaborated that this is because unlike 'normal' children, children with cerebral palsy and other mental disabilities did not have any social interactions outside of the school. In order to secure their futures and to make them self-dependent, the organization decided to conduct training programmes for the students, with the involvement of parents. The parents were also asked to give their feedback regarding what they wanted their children to do in the future. She said that the organization asked the opinion of the parents because ultimately it was their responsibility to look after their children. In spite of different trainings imparted to the students, none of the projects were successful. According to Rekha, this is because the parents and the guardians of the students had never thought of making their children independent, and since they did not have this vision in their minds, it was very difficult to make it possible in real.

A third wave that she considers as significant is the Right to Education Act, 2009, which made it possible for all children to receive education in 'normal' schools regardless of their disabilities. Due to this reason, nowadays the organization does not emphasize on special education for children who are identified as capable of studying in 'normal' schools, despite their physical problems. The organization has also realized that they may have to close down CSE in the future, as either the school would be transformed into an inclusive school or children would only come to the school for the management of their physical problems. In the recent years the organization has started new units like the disability law unit, the employment unit, and there is a project for the deaf-blind.

The school does not have regular classes like in the 'normal' schools, but has different units which are based on the mental abilities and ages of the children and not on their physical abilities. In the beginning, the child is put into the play group. After six months or a year an assessment is conducted on five basic areas of cognitive development of the child. Only after this assessment, their mental ability is assessed, and based on this it is decided to which unit the child will be put. Rekha said that the aim of the school is to normalize the student as much as possible, and if the students are able to go to normal schools, then it is considered as a plus point.

Rekha said that maximum of the students in the school have cerebral palsy, which they had acquired after birth due to jaundice, fevers, accidents or sometimes even due to wrong treatment by doctors. In the recent years the doctors have started referring even new born babies to the early intervention unit when they realize that the child is a high risk delivery. In this unit it is decided whether the child would require special education or not. In certain cases if the child receives special education at the developmental stage, it might be possible for him/ her to leave for ‘normal’ schools.

Over time Senehi has realized that after leaving school, the students do not follow what they had learnt in the school, and ultimately it all becomes a waste. In 2015, they conducted a survey on 21 ex-students and found that all of them were sitting idle at their homes. The organization then realized that until the parents of students are not aware about these issues, their lives cannot be changed. Rekha said that for this things need to change at the level of the family, but in most cases this is nearly impossible as the fathers of the children are not cooperative, while the mothers are overburdened with both household and caring responsibilities, for which they do not receive any kind of support from anyone. At the same time, sometimes the mothers are also blamed for the child’s disability. Rekha feels that it is useless to expect that after so much of work the mothers would be able to support their children in their future endeavors. As a result of this, once the children leave the school, expecting them to follow up on things that they had learned in the school is meaningless. She also acknowledged that the organization cannot do much in this matter because they lack human resources to follow up on the children.

In her experience, there is a lot of difference between boys and girls with disabilities. She has observed that in the case of boys with disabilities, if they have the mental capability to study, parents usually support them in their education even up to their post-graduation level. On the other hand, girls with disabilities usually do not receive the same kind of support (she gave the example of Risha). She further said that parents from poorer socio-economic backgrounds usually do not have any hopes for their children’s futures. After the age of 18 when they are not allowed to come to school, such parents usually engage them in activities such as working in the family’s grocery store etc. in which the children may not have any interest. On the hand, parents from financially sound background want to marry off their daughters in any way possible, usually without thinking about the repercussions of such action.

Rekha said that there is no sustainable funding for the organization. Since the government policies keep changing from time to time, they cannot rely on the government for support. With the Right to Education Act, 2009, the government has made it mandatory for all government schools to provide free and compulsory education to all children below the age of 14 years. As a result of this, the government has stopped providing funds for the CSE. Instead the government now provides funds to newer organizations, as it is felt that the older organizations would be able to sustain on their own. This, according to Rekha, is creating a lot of hurdles in their work. Due to these reasons now they have approached corporate houses under the Corporate Social Responsibilities (CSR) scheme to provide funding for the organization. She said that unfortunately such kind of funding is also not sustainable as it continues only for a few years at a stretch after which they have to look for new funders.

From the above discussion it can be seen that much like Sanjeeboni, Senehi also began working at a much smaller scale, but with time it expanded its activities to include different areas. Due to the nature of the organization, it had to make several changes in its structure to fit in with the RCI guidelines. Due to this reason all the students had to leave the school after attaining the age of 18, which at least the first batch of students had never expected could be a possibility. During my interviews with the women who had studied in CSE, it was found that most of them had fond memories of the time they had spent in the school. Almost all of them were sad that they can no longer come to the school as students like earlier, but had to depend on the ICT classes, which would eventually get over one day. Their sorrow is understandable given their lack of social contact outside of the organization. They, however, did not have any grievances against the organization for they understood the genuine constraints regarding lack of space. Most of them reported getting bored at home as they did not have anything to do. Thus regardless of the enormous support that the organization has provided the women during their younger years, such kind of support cannot sustain for all of their lives due to the rules that mandated an age criteria for the students. Such kind of helplessness and boredom was also reported in Chakravarty’s (2002) study on the parents of children with cerebral palsy that was conducted in Delhi and Chennai. In her study it was found that although the parents realize the constraints of space that the disability organizations were facing due to which their older children were asked to leave, they wanted the organizations to realize that as parents they have limited resources and have run out of the energy to take care of their grown up children on a regular basis. Many parents argued that since the organizations had provided them with the necessary help in the past when their children were young, they had high expectations from the organizations even when their children have grown up (Ibid).

In spite of this, I must report on the kind of disciplining that I had observed during my interviews. I had noticed that there was a strange kind of apprehension among the women towards anyone in authority, especially Zohaan, the Executive Director of Senehi. Every time he passed us at the corridor in his wheelchair, the women were supposed to greet him with "Good Morning, *Dada* (elder brother)" with as much reverence and sincerity as they could muster. This meant that the women who could walk had to stand up for their greetings, regardless of the inconvenience (like loss of balance) they faced in such sudden movements. Women in the wheelchairs (like Nayana) were also supposed to greet him with a bowed head to show her respect towards him. During the course of my interview with Nayana, she did not notice him passing by due to which she could not greet him. When she noticed him, he had already moved ahead. Nayana told me that she might get scolded for not greeting him later on. While these could be just their apprehensions, it is important to acknowledge that there was an explicit hierarchy at the organization where all the women, who were ex-students at the CSE, feared him immensely. Apart from this, it was also found that women policed one another and generated fear to be in their limits. During one of my visits to the organization, I had noticed that a few senior ex-students were talking to Ananya in a very grave manner. Later I came to know that the senior students were scolding Ananya for reaching the organization at 9.30 am while the ICT classes began at 11 am. They were telling her that their computer teacher might get offended due to this and she must ask the teacher's permission if she wants to come early. Ananya later told me that she had to come early because her father, who usually drops her at Senehi for her ICT classes, had some urgent work due to which he gave her the option of going to the organization early or not go at all. Since Ananya does not like to miss her classes, she decided to come to the organization early. Instead of understanding her problem, the senior students gave her a lecture about how not to break rules. Such kind of instances prove that even though the ex-students have now grown up and were now in their 20s and 30s, the organization still treats them as young children who need thorough unnecessary disciplining.

Helen Keller Charitable Trust: From this organization, the president, Palash, was interviewed at his residence. He is an IPS officer who retired from the post of Director General of Assam Police in the year 1992. At the time of the interview, he was 83 years old. When asked about how this organization came into being, he elaborated,

> *In our society, there are many physically and mentally disabled people, starting from children. Many of them do not have any means to earn a living. And for many of them their parents are not so well off that they would be able to feed their children their entire lives. Suppose a person is blind, we have been able to see that the person is on the street and is feeding himself by begging. It is very unfortunate. As a blind person, he / she is already sad. On top of that sitting in the streets, whether that person would be able to earn on that day or not, if on that day it rains heavily, there would be no people, he would not be able to sit. And if it declared a bandh[169] on that day, then there is no guarantee that the person would earn a living. Would that person be able to eat that day? Would he be able to eat at night?*

Apart from persons with disabilities, the organization also provides for critically ill persons who are living in poverty and are not able to seek treatment for their illnesses. The organization provides for these two categories of people all over Assam. Palash further said that the support provided to persons with disabilities by the government is insufficient, due to which an organization such as HKCT is very necessary.

> *The government provides only Rs. 500 or so to people with disabilities. With this amount he won't be able to even* buy his rice. *And in situations where such persons need care, because in many cases where the mother has passed away, sisters are married off, in such a situation they need someone to look after them. Like washing their clothes, taking them to the toilet, etc. Every day a person would not do it without money. They will need to be given a certain amount of money. For their food and care only Rs. 500 is given from the government. That also only about 20 people or so get it from each district. But in every district the number of people with disabilities is much more. According to the Social Welfare Department, at present, there are about 5 lakhs physically and mentally disabled people.*

Taking these factors into consideration, in 2011, Tuhin, who was the editor of a prominent Assamese newspaper and a well-known Assamese writer, called some

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[169] *Bandhs* are a form of civil disobedience in India where the political party that has declared the *bandh* expects the general public to stay at home and not report for work. It has a huge impact on the local community, due to which *bandhs* are much feared. Due to the political situation in Assam, *bandhs* are declared very frequently by different political parties, ethnic communities and insurgent groups.

likeminded people, including Palash, to discuss on this matter and to see if they would be able to do something about it. They started this organization in order to provide financial help to the people in the above two categories. Tuhin forcefully gave the post of the president to Palash, who was 77 years old at that time. Palash, however, feels that it would have been better if he himself had kept this position. At the time of the interview, nearly 900 people from both the categories of people had received financial help from the organization. HKCT primarily runs on donations from the public. He said,

> *There are about 3 crore people in Assam, if about 50 lakh who are well settled, if they also help us by giving donations, we would be able to help the people for whom we have started this organization.*

Palash said that the organization also seeks support from the government, but their expectations are very less "*as the government itself provides for only 20 or so people*". Due to this he considers relying on the government to be futile. HKCT had approached oil and tea companies, which are the major industries in Assam. Palash said that the money they had received from these companies was also very less. Additionally, they had also reached out to the State Bank of India (SBI) and the Life Insurance Corporation of India (LIC) under their CSR projects, but they have also not been able to help much because the CSR guidelines do not support such kind of initiatives. Palash said that when they had approached the Chief General Manager of SBI, he told them that although it is a very good initiative, SBI will not be able to support them with money. However, they would be able to help HKCT with tangible assets such as if they want a building to be constructed, or if they need aids and appliances to be distributed to the people. According to Palash, their organization provides money to feed people and the CSR guidelines are too narrow to accept such initiatives. He further said that OIL had sanctioned about 3-4 lakhs of rupees every year for HKCT since 2011, and then they had to send them a report after how they had used the money. But in 2016, when the interview was conducted, OIL wanted some proof before the sanction. Palash said that it makes no sense to call persons with disabilities from a remote village from a remote district only for the purpose of taking a picture as proof while disbursing Rs. 9000 as in the process the person will have to suffer from a lot of hardships while travelling. The accommodation and transportation costs will also have to be taken into consideration for this purpose. He further said that persons with disabilities face a lot of accessibility issues, but these practical problems are not given due consideration by the CSR rules.

> *We have provided food to some kona khora luk* [blind and physically disabled people] *from Dhubri to Sadiya* [from one end of Assam to another], *but we cannot show that this is the rice that we have provided.* [He laughs]. *We cannot show them that we have helped in feeding this person. They want to give some money for a cause that can be shown immediately.*

Palash compares their organization with another organization that functions as an institution and has provided for 100 children for the last few years. He said that for this organization it is easier to get a grant because they are able to show where the money is going. In contrast, for HKCT, even though they have provided for more than 900 people over the last few years all over Assam, who are living in their own social environment, it is difficult for them to show how they have helped the people if someone comes for inspection. He further reiterated that it makes no sense to bring a person from his/ her own social environment and make them live in an alien atmosphere like an institution. In his words,

> *Suppose a blind boy from Dhubri who is not able to do anything. If he is brought here and we keep him in an institution, it is like keeping him in an artificial environment. He will have to stay away from his mother, father, neighbors, away from his birth place. He will not be very satisfied with this. But if he stays at his own home and eats just aloo pitika bhaat* [mashed potatoes with rice, here meaning a simple meal], *and lives in his own yard, if two of his neighbors call out to him. That is his usual circumstance. If we bring him from there, that will be cruel.*

He further said that even if they bring such people and make them live in an institution they would be able to support only 150-200 people at a time, unlike the 900 people they have helped so far. Although they are more likely to get a grant for this, as an organization, the members of HKCT feel that persons with disabilities should be able to live in their own homes, and if possible, earn a livelihood by staying in their own homes. As an organization they are trying to support this cause where persons with disabilities will be able to live independently.

Due to the difficulty in getting financial grants from any other sources, HKCT depends on the general public for donations. At the time of the interview, they had successfully distributed about 2 crores and 50 lakhs to the beneficiaries. Most of the donors are people from the middle and lower middle classes who, according to Palash, have very soft hearts because they have also suffered from the injustices of the society which have made them empathetic to the predicament of others. In contrast, he said that the people from the business class, who do not face any scarcity of money for travelling abroad once a year, or for spending money on their children's weddings, find it very difficult to spare any money for the greater cause of the society. He said that they might have received only Rs. 10000 or so from this class of people in total in all the years since the organization started functioning. They require about 5 lakhs of rupees every month and he feels that if the people from the business class start donating generously, then they would be able to help a lot more people.

For collecting donations from the people, Palash himself had set up the *Sahayak* Committees in every Block of every district. In the bigger areas, these committees have also been setup at the level of the police station. The organization gives the receipt books to the *Sahayak* Committees and the trustees of the organization, and through these books they collect the money. Palash said that they generally like to receive cheques. The organization has three bank accounts and the cheques can be deposited in any of these accounts. The list of the beneficiaries and the donors are published every month in the newspaper where Tuhin had worked as an editor. The *Sahayak* Committees are supposed to return back the receipt books after every six months, after which an auditing is done. An internal auditor checks if the accounts are clear or not. Thereafter a new receipt book is given to the *Sahayak* Committees. The entire year's account is checked by a Chartered Accountant. The payment to the beneficiaries is also done with cheques and not in cash. Palash said that as the President of the organization he had made the rule that the cheque will have to be signed by three out of four people in authority which includes the President, the Working President, the General Secretary and the Accounts Officer. He made this rule so that any one member would not give away the cheques to someone he deems eligible. The matter has to be discussed with the other members and only after that the cheque will be signed. He said that sometimes people in dire need for money come to him directly. In such cases with a broken heart he has to send them back as proper procedure needs to be followed in every case, regardless of how much he wants to help someone. He emphasized that it is people's hard-earned money that they have donated for a great cause, and if he does not follow the procedures, it will be akin to cheating those people who had trusted them with the money.

People who wish to avail the money from their organization will have to take the application forms from either the *Sahayak* Committees or the trustees of the organization. After filling up the forms, they will again have to submit the forms to the Sahayak Committees in their respective districts. It is then the responsibility of these committees to scrutinize these forms and send it to the trustees for consideration for the financial grant. The applicants can directly also post their forms to the newspaper's address. Palash said that the organization receives several applications from different parts of Assam. The eligibility criteria includes: the person should be poor, so they will have to show either their income certificate or their BPL certificate, and they will need to have the disability certificate (in certain cases even the disability identity cards are also sufficient). Along with these documents, the person must also send a full size photograph of the person where the disability is clearly visible. For those who are sick, they will need to submit a certificate from a doctor. The applications are first scrutinized by three doctors who are trustees of the organization. Palash said that it was a conscious decision to include doctors in the trust and to assign them with the responsibility to decide about who is eligible for the financial assistance. The doctors sit together once a month and deliberate on who should be given the money, and how much money should be given to them. After this decision is made, a meeting is held of all the trustees once in a month, in which out of 21 trustees, about 16-17 are present. In this meeting, the other trustees look into the applications and depending on the opinion of the majority and the recommendation of the doctors, the President gives an order. Then the cheque will have to be signed by three persons. Palash said that this exercise is repeated every month, and for their services the trustees do not charge any money. In each meeting one of the trustees has to pay for the tea and snacks. Earlier the meetings were held at the newspaper complex where Tuhin had worked as the editor. But now they have a new arrangement with the Tennis Club which has a big room to accommodate 30-40 people. The organization is allowed to use that room for their meetings once in a month, and for this purpose they are not charged any money. Most of the administrative work is either done by Palash or by the General Secretary. They have hired only one assistant in the accounts branch who is paid Rs. 7000 in a month, and another person at the newspaper who publishes the names of the beneficiaries and donors. This person works part-time for the organization and is paid Rs. 4000 in a month. Palash jubilantly said that outsiders are often astonished at the way their organization is functioning with such less cost. Some people have also asked him about the location of the organization, and they are often surprised to hear that they do not have an office. He said that for this reason, they may also be doubted by others.

Palash further reiterated that the need for an organization like HKCT is immense as the government has not done much for this community. He emphasized that the public should come forward and support such an organization with large sums of money, so that they would be able to help more number of people. He also feels that there is a paucity of people who genuinely want to work for such a cause. A lot of people, he said, are hesitant to ask for money as they consider it as begging. Palash reasoned that this money is not for them, but for a bigger cause due to which they should not be hesitant to ask for money. At the age of 83 he feels that he should not be working for this issue, as he is old now and needs to rest more often. But unfortunately he has not found anyone to take on this responsibility.

From the above case study, one can see a lot of problems in the approach of this organization. For instance, the image they have about persons with disabilities is very degrading as they are identified as either beggars or as people who are sitting idle at home, waiting for mercy in the form of donations from benevolent people and organizations such as the HKCT. It complete obliterates the many ways persons with disabilities have struggled throughout their lives to achieve an education or a source of livelihood so that they can live a life with dignity. Secondly, the organization literally shames people for not giving donations while perhaps the very idea to donate should be based on one's wish devoid of any form of coercion. The organization has no right to tell people, regardless of which class they belong to, how they should spend their own money. Besides, the support from this organization is also unsustainable because there is no guarantee whether they would receive money from the donors for a particular month or not. For instance, I had conducted the interview in November 2016, just a few days after the announcement of demonetization. Palash said that as a result of this, people were not able to donate any money in this month and so even though they had made the list of beneficiaries for that month, they were not able to disburse the money. Although this is an extreme example, but there could be instances when the organization would not receive any money and they will have nothing to provide to their beneficiaries.

To summarize this section, in the absence of adequate state support, disability organizations have helped the women and their families immensely by providing them access to services. But as the analysis of the case studies have shown, these organizations have their own limitations due to which they are not always able to cater to the felt needs of persons with disabilities. Additionally, these organizations so not allow universal claims based upon social welfare rights as their activities depend entirely on the funds that they receive from the donor agencies (Chakravarti, 2002). As Chakravarti (2002) has argued, the state is the only institution that is capable of creating and implementing the rights of persons with disabilities. Unfortunately the state support for persons with disabilities is almost negligible. Additionally, the disability movement is almost non-existent in Assam because of which persons with disabilities generally consider impairments as persona; tragedy. Among the study participants it was found that they were not aware that they can organize collectively as a movement to demand for better healthcare, educational and employment opportunities from the state. Instead they had these expectations from the disability organizations.

Section II

Support from the Disability Organizations

The previous section had discussed the case studies of the disability organization. Regardless of the limitations of the support provided by these organizations, it is important to note that the women have received a lot of help from them. In fact, after the family, it was these organizations that have played a significant role in the lives of the study participants. This section elaborates on the kinds of support the women had received from these organizations. But before we go on, let us first see how they came into contact with their respective disability organizations.

Contact with the disability organizations: During the course of the study it was found that for many of the participants, coming into contact with the disability organizations was a life changing event that shaped their lives in a positive way. It was, however, found that for many of them this contact was not an entitlement, like State support, but a sheer stroke of luck. The following narratives illustrate this point clearly.

Anamika came to know about Sanjeeboni from her neighbors after she returned back from her Pehi's (father's sister) home in Lakhimpur in 2010. She said,

> *I came to know about* [Sanjeeboni] *from my neighbors after I came back from Lakhimpur. The CBR workers from the organization used to visit my locality. I did not know about it because I was not living at my home during that period. After I came back in 2010, my neighbors told me that there is an organization that works for 'people like me', for the bikolango* [physically disabled]. *They told me that it also gives the opportunity to 'people like me' to work … Actually one of my Pehi's* [a neighbor who lives close to her home] *daughter has MR* [Mental Retardation]. *They used to come here for the meetings. She is the one who told me about Sanjeeboni. She told me that I can register my name here. I came with her for one or two days. After that I started coming here on my own.*

The above narrative shows that Anamika came to know about Sanjeeboni through one of her neighbors, whose daughter is mentally disabled and has been associated with the organization for a few years. After coming into contact with Sanjeeboni in 2010, Anamika was asked to attend the meetings and training programmes arranged by the organization. From 2013, she has started working as a CBR worker for the organization.

Surabhi said that she had come into contact with Sanjeeboni about 10-15 years ago when she tried to make her disability identity card for a job at the Air Force office located at the Block level. She said,

> *I had come into contact with* [Sanjeeboni] *about 10-15 years ago. I wanted to make the* [disability] *identity card at that time. It was a year or two after I had passed my matriculation exam… Actually my family wanted me to get a job at the Air Force. My entire family had worked there. So they also wanted me to join there. For that job, the disability identity card was required. That is why I tried to make the certificate. Without the certificate, it is not possible to get that job at the Air Force. But I could not make the certificate on time. Age also does not stop for anyone. That is why I joined here. I was able to make the certificate only after I started working here.* [Suchismita] *Baideu had helped me in making the certificate.*

From the above narrative it can be seen that Surabhi came into contact with Sanjeeboni by chance as she needed to make her disability certificate, and she was told that the organization would be able to help her. When she couldn't make the certificate on time, her family requested Suchismita to give her a job at the organization. At that time she was employed to clean the rooms, to make tea and so on. She said,

> *In the beginning there was no work as such. There were no projects. Then slowly the projects started coming. After about five months, I joined a project for deaf children for about 3-4 years. After this project got over, I joined another project as a DPO*

> *leader. As part of this job, I had to go to* [mainstream government] *schools and teach children with disabilities and check if they received proper guidance from their teachers or not.*

From the above narrative it can be seen that Surabhi had joined Sanjeeboni simply as a cleaner during the initial years. As the organization began to get projects, she got involved in those. At the time of the interview, Surabhi had many years of experience of working at the organization. However, she did not seem to be happy with her job as she felt that other members of the organization often reprimanded her due to her inability to do her job properly (this will be elaborated later in the chapter).

Lata said that she came to know about Sanjeeboni through one of her social contacts.

> *There was an advertisement in the newspaper. I did not know about it. A neighbor, who works at the Block office, told me there is such and such advertisement. Do you want to apply? I told him why wouldn't I apply? I will apply. I came to know about it the day before the deadline for the application. I had never given an interview before, so I was very nervous. I got the form. The neighbor filled it up for me. Then I submitted it. I never thought that I would be selected in the interview* [she laughs]. *But I got selected.*

As mentioned in the previous chapters, Lata is from the Kamrup (Rural) district, where Sanjeeboni had started a new project from the year 2015. In order to recruit employees for the project, they had given an advertisement in the local newspaper. As can be seen from the above, one of Lata's neighbors came across this advertisement and informed her, as he knew that she was looking for a job.

The above narratives clearly show that the women came into contact with Sanjeeboni, a disability organization that works in the rural areas, through their social contacts. It was found that similar social networks also operated in the case of the women who are from Guwahati. As shown in Chapter 7, Risha and Nayana were introduced to the special school, Senehi, by their respective father's social contacts. Korobi came to know about HKCT through her family doctor, who introduced her to one of the trustees of the organization. She spoke to this trustee on the phone, who later helped her in filling the form with the required documents. At the time of the interview, Korobi had received financial assistance from the organization for just one time and was trying to get more financial support from the organization.

Jeuti said that she came to know about the disability organization Moromi from one of her teachers at the Industrial Training Institute (ITI) where she was pursuing her diploma in hotel management. She said,

> *I have worked at the ITI for one year. I have also got a certificate from there. But I have a problem with my hands. Although I am able to do all the work, but when I had to work at a hotel, I faced certain difficulties. Sometimes we need to use our right hands, sometimes we have to use our left hands. I can use my right hand, but my left hand is beya* [impaired]. *Then my Sir from the institute spoke to Kishore Sir from* [Moromi]. *Kishore Sir spoke to me, and from then onwards I have been working here. It has been 5 years now. Sir was very good. He was a very nice person.*

Similarly, Dolly also came to know about Moromi after she joined a computer institute in order to overcome the boredom of sitting idle at home without any work. She felt that through the computer education she would be able to find some job. At the institute she met someone who informed her that 'people like her' can find work at Moromi. During the interview Dolly said that at that time she was desperately in need of a job in order to supplement her family income. She came to meet Kishore, the founder of Moromi, who asked her to join the organization straightaway. At the time of the interview she had worked for the organization for almost 6 years.

It was found that some of the women were directly approached by the founders of the organizations or by others working at the organization. Bandana said that Kishore, the founder of Moromi, had approached her mother and requested her to send Bandana to work at the organization. She said,

> *My mother works at a hospital which is directly opposite to the office of Moromi. We lived in the quarters of the hospital. Kishore Sir knew Ma very well. One day he told Ma if your daughter wants, she can work here with us. He said that his organization teaches 'such children' to work. Ma told him, I would ask her, if she is interested she will work, if she is not interested then nothing can be done about it. That day in the evening Ma told me about this workplace. I told her I will go and see for myself, how it feels. If it feels good then I would work. Ma also agreed to this. On the first day Sir called me to his office. There were only two more people besides me at that time. There was one who was kola-buba* [hearing and speech impaired], *the other had a beya bhori* [impairment in one leg]. *At the organization we did tea leaves packaging in the beginning. I saw how it is done and I liked it. I was in school at that time. During school time, we are not much interested in studies. We are usually interested in other activities. I went to the office for 2-3 days and then I told Ma that I would work there. I would study from the Open School. I was in class 8 at that time. Ma was furious! She said you would leave your studies and work? Are we facing any financial constraints? I tried to calm her down and said no Ma, I like the work there. Sir also gave us time to study in the afternoon. The work pressure wasn't much at that time. We could work for some time, then we could study. When we were bored with studies, we could work again. It was like that. Later Sir got a lot of work. We had to do different kinds of packaging work. By that time, the number of boys and girls working at the organization also increased. Now there are more than 30 people who work there, all of them are 'people like us'. There are many of them.*

From the above narrative it can be seen that Bandana was approached by the founder of Moromi to work for his organization. Although her mother was initially reluctant to allow her to leave her studies, Bandana was adamant that she wanted to work. During the interview, she also mentioned that by that time her father had passed away and it was getting increasingly difficult for her mother to provide for the needs of four children. This was also one of the factors that motivated her to work for Moromi. She had worked there for six years until her marriage.

Minakkhi come to know about Sanjeeboni when CBR workers from the organization had gone to her village for a survey on persons with disabilities several years ago. She said,

> *Some people from the organization had come to my village for a survey several years ago* [she does not remember the exact year]. *When they asked around if there are 'people like me' in the village, the villagers showed them my home. They wrote my name in a register. Then* [Suchismita] *Baideu* [literally means elder sister, but is used to refer to any woman in authority] *asked me to come to the office for some meetings and trainings every other Wednesday and Saturday. I had come to attend those for several years. Then last year* [2015] *I joined here as a weaver. I was working in our handloom at home before this. I come to the office every Wednesday and Saturday for my work. Since this month I have also joined as a chowkidar* [watchwoman] *and cleaner.*

From the above narrative, it can be seen that Minakkhi had come to know about Sanjeeboni when people from the organization had gone to her home for a household survey to collect data on the number of persons with disabilities at the Block level. Even though she has been associated with the organization for several years, it was only in 2015 that she started working permanently for the organization. She weaves *gamusas*[170] and *mekhela sadors* and gives them to Suchismita, who later sells them at exhibitions organized in different parts of the country.

As mentioned earlier in the chapter, HKCT is an organization that provides financial assistance to persons with disabilities and critically ill persons. While it was found that social contacts helped the women in applying for the assistance (as in the case of Korobi mentioned above), in other cases it was found that anybody could fill up the forms on behalf of the women. While in certain cases, the women were able to get the money, in other cases it was found that the family members of the women did not even inform them about such an organization. The following two narratives illustrate this point clearly.

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[170] Gamusa is (usually) a rectangular piece of white cloth with a red border on three sides and red woven motifs on the fourth side. Gamusa-s hold great significance among the Assamese people. It is used for various purposes.

Jeuti said that she did not even know that someone had filled up her form on her behalf. She said,

> *I did not know that someone had filled up my form for* [HKCT]. *Later I got to know that Archana Baideu from VRC had filled it up for me. One time I received Rs. 9000 for my hand. They called me in the night. When they called me I thought nowadays there are so many frauds. I got scared. Then I called Archana Baideu. She told me that I should go to the* [HKCT] *office and inquire as one more boy has received the money. Then I told my husband about the issue. Then he took me to the office and it is only then that I came to know about it.*

From the above narrative it can be seen that the person in charge of VRC had filled up Jeuti's form on her behalf, and Jeuti was not even aware about it. While Jeuti had received the money in her account, in the case of Hema it was found that she was not even aware about the existence of such an organization. As mentioned in the previous chapters, Hema did not share a very cordial relationship with her father and older brother. Hema said that while her father had paid for all her treatment expenses in the past, in the last few years he had started to behave as if she is no longer his responsibility. During the interview it was also found that Hema was not aware that someone had applied for financial assistance in her name. It was also found that it was her father who had applied for this assistance on her behalf, and it was he who had access to her bank account. During the interview, Hema said,

> *I have a bank account. But I do not know anything about it. It is Deuta* [father] *who operates it. It would have been better if I would have got some money. But if he is getting the money, he uses it. He does not give it to me. I feel that if I get some money from the government or some agency, I would be able to utilize that money for improving the sales of my shop. But he never thinks about these things. He just made the shop for me in the beginning and then he never upgraded it. It is just Ma who has helped me. She borrowed some money from someone. Deuta has not done anything for me. If he would have helped me, I would have been able to run my shop in a better way today.*

The above narrative shows that it is Hema's father who had applied for the financial assistance on her behalf. It is also clear that he never told her about the receipt of this money and it is quite probable that he had spent this money on himself. When I presented such a scenario in a hypothetical way to Palash, the president of HKCT, he said that they cannot account for such dysfunctional families.

> *The money is sent to the person's bank account. If he/ she does not have a bank account, then we send it his/her family members, such as mother, father, husband or wife. We do not give the money to anyone else. What if the person runs away with the money? ... If the mother or father does not feed the person and uses the money for other purposes, then we do not know about it.*

The above comment shows that the organization has a very ideal view of the family as a harmonious institution where each member looks after the needs of the vulnerable members. However, in reality certain families may not meet this ideal, and may in fact torture the person with disabilities. The organization, therefore, must make an effort to ensure that the money that is being provided for the person with disabilities is used by only him or her.

To sum up, this section tried to show how the women came into contact with disability organizations. It is clear from the above narratives that most of them came to know about the organizations through their social contacts, or in certain cases they were approached by the organizations directly. It is noteworthy that knowing about the organizations was a matter of sheer luck and should not be something that persons with disabilities as a group should be made to rely upon as there are not enough organizations to cater to their needs. These organizations only work for persons with disabilities under the jurisdiction of their own areas and do not usually entertain persons with disabilities belonging to other areas. This is very important to consider as in the absence of any kind of support from the state, it is only these organizations that persons with disabilities come to rely upon. Regardless of the drawbacks of these organizations, it is important to reiterate that the study participants have received various kinds of support from them. In the following sections we elaborate on these aspects of the organizations.

Support Received from the Disability Organizations: The disability organizations have provided different kinds of support to the study participants. The nature of the support obviously depended on the approach of these organizations. This section elaborates on the type of support that the women had received from the organizations that they were associated with.

Making the Disability Certificate: Under the Persons with Disabilities Act, 1995, a medical authority needs to certify that a person has a disability of more than 40 per cent in order to avail certain benefits from the government. These services are rendered to persons with disabilities who come from the poorer socio economic background. Several studies have criticized the procedure of making disability certificates because of its reliance on the medical model (Ghai, 2003) and also because of the cumbersome process of making the certificate (Klasing, 2007). Despite these criticisms, the Right to Persons with Disabilities Act 2016 has also upheld this 40 percent criteria in the issuing of certificates for persons with ‘benchmark’ disabilities. Furthermore, the process of making the certificate also varies from to state to state. In Assam, until 2013, persons with disabilities were provided with a disability identity card, which had to be renewed every two years. This created many hurdles for persons with disabilities because they had to depend on other family members to take them to the Social Welfare Office very two years to renew the certificates. Many times persons with disabilities have complained about experiencing misbehavior in the hands of the officers. In addition to this, it was also found that many persons with disabilities and their family members were not even aware about the kind of benefits that they are entitled to when they possess the disability identity card. Among the study participants, it was found that those who tried to make the disability identity card/ disability certificates without the assistance of a disability organization had to endure different kinds of hardships. On the other hand, when they sought the support of these organizations, the process was very smooth. Again it is important to note that the nature of the organizations facilitated them in making the certificates.

Table 8.1 gives an overview of the organizations with which the research participants are associated, whether or not they currently possess the disability certificates (DC) or the now redundant disability identity cards (DIC), and the percentage of disability as per their DC/ DIC.

Sl. No.	Name (in alphabetical order)	Organization(s) associated with	Whether they possess DC or DIC	Percentage of Disability
1	Anamika	Sanjeeboni	DC	45%
2	Ananya	Senehi	DC	60%
3	Bandana	Moromi and HKCT	DC	55%
4	Chitra	Sanjeeboni	DC	Does not know
5	Dolly	Moromi	DC	65%
6	Gargi	Sanjeeboni	DC	100%
7	Hema	HKCT	DIC	75%
8	Jeuti	Moromi and HKCT	DC	80%
9	Korobi	HKCT	DIC	55%
10	Lata	Sanjeeboni	DC	60%
11	Minakkhi	Sanjeeboni	DC	60%
12	Nayana	Senehi	DC	80%
13	Pronoti	Sanjeeboni	DC	65%
14	Risha	Senehi	DC	60%
15	Sobiha	Senehi and personal contact with Suchismita, founder of Sanjeeboni	DC	55%
16	Suchismita	Special Educator at Senehi and founder of Sanjeeboni	Did not ask	NA
17	Surabhi	Sanjeeboni	DC	45%
18	Uma	Sanjeeboni	DC	45%

From the above table it can be seen that all the women expect Hema and Korobi possess disability certificates. Let us now look at the problems they had faced while making the disability identity cards and disability certificates.

Minakkhi made her disability identity card before she came into contact with Sanjeeboni. Her family members came to know about the benefits of this identity card through a well-wisher. He asked them to go to a ‘medical’ (health facility) to make this document.

> *It was very difficult for me to make the certificate. It was a huge mess… I went to make the certificate with my family. At that time this office* [Sanjeeboni] *was located somewhere else, we were not aware of its existence… We went to the same office over and over again. People gave us wrong information about where to make the certificate. We would go to the office, and things won't get done there, and then we would go again. It was a lot of harassment… No one knew at that time that disability identity cards are made at the Pan Bazar Medical* [MMCH]. *They told us go to the medical* [health facility], *but we did not know which medical to go to. We went to many medicals, like the Guwahati Medical* [GMCH], *the Joonaki* [pseudonym used for the actual name of the place] *Medical* [PHC] *and so on. After many such attempts, one day we finally reached the Pan Bazar medical… It took me a long time to make the card. It was at least two years.*

From the above narrative it can be seen that Minakkhi and her family suffered from a lot of harassment when they tried to make the disability identity card without the support from a disability organization. Without any clear information, they had to go from one health facility to another until they reached the MMCH where these cards are actually made. On top of this, since the disability identity card had to be renewed every few years, it caused additional harassment to the women. Anamika's narrative gives a good illustration of this.

> *I made my identity card in 2005 when I was in Lakhimpur. After coming back to my village in 2010, I realized that the identity card has expired, and I need to renew it. I came to know about Sanjeeboni from my neighbor. So one day I came here along with her and spoke to* Suchismita *Baideu. I told her about my identity card. She asked me to go to Social Welfare office. When I went there, they told me it is made in Lakhimpur, and so it won't be renewed here. I was like what! What to do now? It is made in Lakhimpur, but my home is here. They told me to make a new certificate. So I took a new form and went to MMCH. I went there the first day, and I was told that it won't happen that day. Next day when I went again, they said we can't make it. I went again after two days. Then they told me that it would happen only on a Saturday. At that time the certificate was only made on Saturdays. Then I went to the Sodou Axom Bikolango Sonstha (All Assam Disabled People's Association), took a form from there, and submitted it in MMCH. After that they made the identity card.*

From the above narrative it can be seen that Anamika also faced a lot of harassment while trying to renew her disability identity card. It is claimed by the members of Sanjeeboni that all such problems have been resolved since 2013 when the organization became the nodal agency for making disability certificates for the entire Kamrup Metropolitan District. This is, however, not true for the research participants who belonged to other organizations. It was found that several of these women were not even aware that the disability identity cards expire after a period of two years, and that currently, in order to avail benefits from the government it is mandatory to have disability certificates. This was found to be especially true for the research participants who were contacted with the help of HKCT. Korobi and Hema's narratives bring out this point vividly.

Korobi's disability identity card had expired several years earlier as a result of which she has not been able to claim her disability pension. During the interview her husband said,

> *I have been to MMCH about four times to make the certificate. But the doctors are very bad nowadays. Every time they asked us to come back later… They have seen the patient, we had submitted the old documents, but they said this won't work. She will again need to get a checkup by a doctor. It is very difficult to take her there and bring her back home.*

This narrative reflects the kind of harassment persons with disabilities and their family members face when they try to make the disability certificate without the support of a disability organization. Like in the case of Korobi, it was found that in spite of going to the hospital several times, they were asked to come back later for a checkup later. Even though the doctors were just following their protocol, it needs to be remembered that many persons with disabilities need to depend on their family members for taking them to the hospital for making these identity cards/ certificates. On top of that they also face accessibility issues which make it difficult for them to go to the hospital facility again and again to make the certificate. Korobi, for instance uses a walker for mobility. She also cannot travel by public transport and needs to depend on her mother's car and a hired driver to take her to the hospital. Her husband is her primary caregiver, who not only looks after her, but also the entire household, which makes it very difficult for him to take out time to take her to the hospital. Her husband also pointed out that the money that is sanctioned from the government is so meager (Rs. 3000 in a year) that it is absolutely pointless to undergo so much strain to make the certificate. It is interesting that Korobi was able to apply for the financial grant from HKCT with her expired identity card, which shows that the trustees of the organization are not aware of the changed government policies.

In the case of Hema it was found that her father did not even allow her to touch any of her health and disability related documents including her disability identity card. During the interview when I asked her about her disability certificate, she said that it is her father who keeps all these documents with him along with a heap of her other documents. Only her father had access to these documents. When he brought out the disability identity card, it was found that it had expired several years earlier. Hema was not even aware that nowadays these identity cards have been replaced by the disability certificates. Her father, however, seemed to be aware but did not find it necessary to make her certificate. When I handed her the disability identity card, her father immediately snatched it away from her hand. As mentioned earlier, Hema and her mother did not share a very cordial relationship with her father. As a result of this, they are not aware about anything related to her disability including whether she possesses a disability certificate or not.

In the case of the women associated with Senehi it was found that the organization took the initiative of making their disability identity cards when they were young and also their disability certificates when the new rule came into place. Risha said that when she was young, her parents were not aware about the disability identity cards. Her first card was made when she joined Senehi for her education. She said that the school had organized medical camps at the premises for the benefit of the students. From 2013, when disability certificates became the norm, the school arranged transportation for the students to travel to Sanjeeboni office located at the Joonaki Block in order to make the disability certificates. Like Risha, Nayana, Ananya and Sobiha had also made their disability identity cards and later their certificate with the help of their Senehi.

In the case of the women from Moromi, it was found that they had made their certificates only a few months before the interview. They were told that only if they have the certificate they will be eligible to take a stitching course at the Vocational Rehabilitation Centre (VRC) located near their organization which would enable them to claim Rs. 15,000 after its successful completion. Jeuti had made her disability identity card earlier, but made the disability certificate recently after she heard about this scheme. She received the sum after successful completion of the course. Similarly, Dolly had made her disability identity card much earlier but she was not aware that it had to be renewed every two years. She decided to make her certificate in order to do the stitching course to avail the money from VRC. During the interview, she said that she was not able to successfully complete the course because she fell sick in between and had to be hospitalized. As a result she has not been able to claim the money.

In the case of Lata it was found that she had made the disability certificate only after she got her job at Sanjeeboni. She mentioned that prior to this when she had visited MMCH for making her disability identity card, she was humiliated by the officers responsible for making the certificate. She said,

> *I have the certificate now. I got it made only a few days back in a camp. I did not have it earlier. I went to make it one day. We do not know Guwahati much. I went to Pan Bazaar with my father. Actually in the beginning we went to the Social Welfare Office. They told us that in order to make the certificate I will need to have a checkup with a doctor. For that purpose they asked me go to MMCH in Pan Bazaar. We took the address and went to MMCH. At that time it was a different doctor. There I was asked to go to Room No. 18. I went there. I told them that this is my problem, I have come to make my disability identity card. When I was talking, one of them said, let us see, start walking. He said it with an attitude, let us see how you walk. He asked me to walk, so I started walking. Then he said, is this a difficulty? It does not fall under the government rules. It does not fall under any percentage. He said you won't get the card. I requested them so much, but he did not pay any attention. I came back home crying. I was studying in High School at that time. I had just passed my matric. If they cannot give me the certificate, what can I do about it? At that time I could not talk so much, I could not talk confidently. Now at least I can say something. Earlier I could not do it. Pita* [father] *also did not say anything. He also does not know how to talk to people. He was just standing there. That is why we came back. I cried the entire way back. I did not care that someone is watching me. I did not have that thing in mind. I was very hurt that I could not get the card. I was told that if I make the card, I would get some small job. I went to make the card so that I can do some work. But I was not able to make the card. I thought why is God like this? I cannot even get the card. I thought it would be better if I am not there in this world. It would be better if I die. I thought all of this when I was returning back home in the bus.*

From the above narrative it can be seen that Lata was very hurt that she was not able to make the disability identity card in her first attempt. This might seem strange considering the stigma surrounding disability, someone would be so keen to be identified as a person with disabilities. Singal (2010) attributes this shift, and rightly so, to the changing socio-political landscape of India especially after the implementation of the Persons with Disabilities Act, 1995 which has enabled persons who possess the certificates certain benefits. Although these benefits are insufficient, it has helped persons with disabilities in countering the stigma of disability (Singal, 2010). During her fieldwork Singal (2010) had even come across people who are listed as disabled, but were not actually so. This explains why Lata felt so hurt about not getting her identity card because she had high hopes that it would enable her to get a job in the future. But when she was told that she cannot get the card, she felt that there is no point in her life. It is important to mention here that the Persons with Disabilities Act did not explicitly mention dwarfism as a category under locomotor disability. Thankfully, this change has been made with the Right to Persons with

Disabilities Act, 2016 so that they do not have to face such humiliation again. It is also apparent from Lata's narrative that there is a lot of discrepancy among doctors while issuing the certificates. As Lata had mentioned, the first doctor told her that she cannot get a certificate because her condition is not listed under the Persons with Disabilities Act, the second doctor gave her a certificate with 60 percent disability. This certificate was given to her before the passing of the second disability Act.

From the above narratives it can be seen that without adequate support from a disability organization, it is very difficult for the women and their family members to make the disability identity cards/ certificates as they face different kinds of hurdles on the way. These include lack of knowledge, dependence on other family members, accessibility issues and so on. It was also found that several women made the certificates only to avail specific benefits such as the Rs. 15,000 from the VRC. Unlike Lata, very few of them were aware that persons with disabilities who have the disability identity cards/ certificates have 3 percent reservation in government jobs under the Persons with Disabilities Act, 1995 (now it has been increased to 5 percent under the Right to Persons with Disabilities Act, 2016).

The disability identity cards/ certificates also enable the women to avail disability pension, but very few of them seemed to be aware of it, and those were aware found it a very meager sum of money to actually run behind it (Rs. 3000 per year). The certificate also enabled the women to claim the unemployment allowance of Rs. 6000 per year. Again it was found that only a few of these women were aware about this scheme.

In addition to these benefits, the certificate also enables the women to avail train and bus concessions. Among the study participants only a few of them were found to avail public transport for travelling, and among these, many of them found it absolutely shameful to demand concession on their bus fares by showing their disability certificate. Dolly's narrative sums the hesitation certain women have in demanding bus concession.

> *I realize that if I show this hand, I will get some help. But for myself, showing this and getting the ticket for half the price, I do not want that. I want to live like a normal person. Would you want to give something to me in pity? I do not want anyone's pity. You can give me something saying that this girl can do it, but do not take pity on me.*

The above narrative shows that Dolly considers bus concessions for persons with disabilities as a form of pity and charity that she does not want. Similarly, Minakkhi also feels shy about showing the certificate and demanding for fare concessions while travelling in a bus. She said that sometimes the bus conductors themselves give her a concession by looking at her hand. Other women, mostly from the rural areas do not depend on government services for travelling as very few government buses run on these routes. So regardless of their disabilities and possessing a disability certificate, these women have to pay the fares which are much higher than the government-run buses. It was also found that while these women felt shy about demanding for fare concessions while travelling by buses, as shown in Chapter 7, they did not mind asking and sometimes even fighting for their seats in the government buses.

Access to aids and appliances: Aids and appliances play an important role in the physical rehabilitation of persons with disabilities by compensating for the loss of a particular body function. These aids can assist daily activities and lead to self-reliance enabling persons with disabilities to carry out tasks that would have been impossible without the aid (Klasing, 2007). The Government of India provides free aids and appliances to needy persons with disabilities under the "Assistance of Disabled Persons for Purchase/ Fitting of Aids and Appliances" (ADIP) Scheme that is administered by the Ministry of Social Justice and Empowerment. The aids are manufactured and distributed by companies and NGOs (Klasing, 2007). The following aids and appliances are provided for persons with locomotor disabilities under the ADIP scheme:

- All types of prosthetic or orthotic devices.
- Mobility aids like tricycles, wheelchairs, crutches/ walking sticks and walking frames/rolators.
- All types of surgical footwear and MCR chappals.
- All types of devices for activities of daily living (ADL) (Zutshi, 2004).

In practice, the benefits of aids and appliances are realized only by a small fraction of the population of persons with disabilities. This is because the organizations that distribute aids and appliances are only able to reach a small minority of the population of persons with disabilities due to limited funds (Ghosh, 2012) and also because many such organizations are located in urban areas, while a majority of persons with disabilities reside in the rural areas of the country (Ghosh, 2012; Joshi, 1992; Klasing, 2007; DEOC, 2009). When aids are available in rural areas, studies have shown that it is difficult to repair and maintain them (DEOC, 2009), and villages also may not have a repair centre due to which even minor damages can render the appliance useless for the owner (Klasing, 2007). Accessing aids and appliances were also found to be time consuming and bureaucratic because of which many people make do without aids (DEOC, 2009). Studies have also shown that the aids that are provided do not meet the requirements of persons with disabilities in their local contexts (Klasing, 2007; DEOC, 2008). In one study it was also found that the aids were stored in the parapets of the houses of women with disabilities without any use (Pati, 2011). This, therefore, suggests that the usability of the aids are not considered before issuing them to the beneficiaries (Pati, 2011). Other studies have shown that the ADIP Scheme has only a limited number of equipment which sometimes does not even cater to the basic needs of persons with disabilities (DEOC, 2009). Sometimes they are also of low quality and may even have a negative impact on a person’s condition if the right kind of aid is not provided. Many persons with disabilities have also not found the aids provided to them to be very useful for reasons like not having enough space in their homes to keep the aids; or they were not taught how to use the aids; and sometimes they are given these aids without considering whether they need them or not (Ibid).

The study found that some of the disability organizations facilitated the access to aids and appliances. This section elaborates on whether the study participants were able to access appropriate aids and appliances or not in order to mitigate their physical difficulties.

Table 8.2 gives an overview of the nature of the impairment of the research participants and the kinds of used they use. The last column also shows whether the women have received aids and appliances.

Sl. No.	Name (in alphabetical order)	Organization(s) associated with	Nature of Impairment	Mobility Aids Used	Whether they received any aids
1	Anamika	Sanjeeboni	Limb inequality due to a surgical intervention	NA	Elbow crutches and pair of shows to equalize her limb inequality
2	Ananya	Senehi	Cerebral palsy	NA	No
3	Bandana	Moromi and HKCT	Short Stature	NA	No
4	Chitra	Sanjeeboni	Cerebral Palsy	NA	Elbow crutches and Tricycle
5	Dolly	Moromi	Amputation of right hand after an accident at her workplace	NA	Occasionally she uses a prosthetic hand to match with her long sleeved dresses
6	Gargi	Sanjeeboni	Cerebral Palsy	Wheelchair	Wheelchairs
7	Hema	HKCT	Puncture wound that lead to amputation of her right leg	Crutches	Crutches, Wheelchair and Prosthetic limb
8	Jeuti	Moromi and HKCT	‘Typhoid’ fever (poliomyelitis)	NA	No
9	Korobi	HKCT	Head injury and later severe burns	Walker	Walker
10	Lata	Sanjeeboni	Short Stature	NA	No
11	Minakkhi	Sanjeeboni	Syndactyly	NA	No
12	Nayana	Senehi	Poliomyelitis	Wheelchair	Wheelchair
13	Pronoti	Sanjeeboni	Mysterious fever	NA	Tricycle
14	Risha	Senehi	Cerebral Palsy	NA	No
15	Sobiha	Senehi and personal contact with Suchismita, founder of Sanjeeboni	Cerebral Palsy	NA	Elbow crutches
16	Suchismita[171]	Special Educator at Senehi and founder of Sanjeeboni	Poliomyelitis	Walker or Elbow Crutches	NA
17	Surabhi	Sanjeeboni	Mysterious fever/ fall in infancy	NA	Elbow crutches
18	Uma	Sanjeeboni	Weakness in the left lower limb	NA	No

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[171] Suchismita’s case has not been included in this analysis because she is the person who makes these aids and appliances available to persons with disabilities who fall under the jurisdiction of Sanjeeboni.

From the above table it can be seen that only four study participants (besides Suchismita) use mobility aids on a regular basis. However, in total, 9 participants (besides Suchismita) have received aids and appliances. During the interviews with the research participants it came out clearly that many of the participants have received aids and appliances multiple times that they do not require. Four of these women fall under the jurisdiction of Sanjeeboni. As noted earlier in the chapter, both Suchismita and Lalit had said that about 99 percent of the people under the jurisdiction of the Sanjeeboni in the Joonaki Block have received aids and appliances for their mobility. The bigger question, however, is whether they need these aids and appliances, and if not, as the interviews have shown, why are these scarce but really valuable resources being wasted away. Let us look at some of the narratives to make this point more clear.

Anamika had received elbow crutches at a meeting from the hands of the then Chief Minister of Assam in the year 2012 or 2013. However, she does not use the crutches because she does not need them. During the interview she said that she might need them while walking through slippery roads in her old age. Anamika further said that in the same meeting, her feet were measured, and two months later she was given a pair of shoes to adjust for the limb inequality of her left leg. Anamika has never used these shoes because they are very heavy and makes it uncomfortable for her to walk.

Pronoti had received a tricycle in a meeting about two years after she had shifted to her village in the year 2000. She said that nobody was assessed in that meeting and everyone who was not able to walk were given a tricycle. She had used the tricycle earlier when she had difficulty in walking, but she no longer needs it after she started working for the organization, which necessitated her walking for long distances for work. She also said that now since it has been lying idle for such a long period of time, it is no longer functional.

Surabhi has also received several elbow crutches over the years, but since she does not need them, she gives them to others. Chitra had also received a tricycle and elbow crutches, but since she does not use them, it was given to someone else by the organization.

All the above narratives show that the aids and appliances have been distributed to the women without assessing whether they require them or not. It is only Gargi from this organization who uses a wheelchair for mobility. She was 3 years old when she got her first wheelchair from Sanjeeboni. Since that time she has received several wheelchairs from meetings organized in Guwahati. At the time of the interview, Gargi was using her third wheelchair. According to her mother, the wheelchairs are of good quality and last a very long time. At the time of taking the wheelchair they were explained that they should never repair a wheelchair, and should start using a new one in case the older one has some problem. Gargi said that they have a few extra wheelchairs in their home so that she can use them when the present one stops functioning. But over time they have stopped taking newer wheelchairs due to the paucity of space in their home.

From the above narratives it can be seen that the study participants from Sanjeeboni have good access to aids and appliances. However it was found that in many cases they received aids that were inappropriate for them or which they did not require because their disabilities were not so severe. This is a serious concern because a lot of governmental and non-governmental resources are getting wasted on providing aids and appliances to people which are then dumped into some corner of their homes. In many cases the research participants have also mentioned that these aids have been distributed to them multiple times, even though it is clear that they do not require them. In many cases the women were seen to accept these aids because they feel that they will require them at some point in the future. However, they do not take into consideration the fact that if the aids are not used for a long time, their condition starts to deteriorate. It is, therefore, mandatory to have a proper assessment of the needs of the people regarding whether they require aids and appliances or not and whether they would use them or not before making it available to them.

In certain cases it was also found because of their young age and also because they can fairly manage well without using aids, some of the women have refused to use aids and appliances such as elbow crutches for mobility. Sobiha's mother said that Sobiha was not able to walk till the age of 7 years. During that time it was her mother who carried her around everywhere. At the time of the interview, her mother said that now that Sobiha has grown up, it is no longer possible for her to carry Sobiha everywhere. Due to this reason, nowadays she pulls her everywhere. Her mother further said that when Sobiha was younger, Suchismita had bought her elbow crutches so that she would be able to walk without any difficulties. Sobiha, however, refused to use the crutches, asking, *"Am I old, that I would use this lathi* [stick]*?"* At that time Suchismita scolded her and made her use the elbow crutches. However, when she grew up a little more, she regained the strength in her legs, because of which she gave up using these crutches. Sobiha's mother said that now Sobiha is able to go almost everywhere without her crutches. She is even able to climb up to the second floor to Suchismita's apartment without any difficulties. It is only in the rainy season that she now faces certain difficulties, because of which her Mama (mother's brother) needs to carry her on his back up to the bus stop.

The study also found that the aids and appliances that are provided by the government agencies are usually of a poor quality, which makes it necessary for the women to avail such services from disability organizations who have better access to good quality aids and appliances. Nayana's narrative shows this clearly.

Nayana has been using wheelchairs for mobility since the time she joined Senehi as a student at the age of 8-9 years. At the time of the interview she was using her second wheelchair. Her father had got Nayana's first wheelchair from a rehabilitation centre, but she found it extremely difficult to use it by herself. She said,

> *The wheelchairs that are provided in rehabilitation centres, those are a bit rough. It is very difficult to use them. After using it, I started to have pain in my hands. After having pains, I cannot run my wheelchair. My hands would swell. I requested Zohan Da* [the Executive Director of Senehi] *to provide me a good wheelchair. He then got me this one from Russia.*

While the women from Sanjeeboni and Senehi had very good access to aids and appliances, it was found that the women who were contacted from HKCT had to purchase their own aids. This is because as an organization HKCT only provided financial assistance to persons with disabilities, and they believed that one can buy aids or any other essential items for themselves with the help of this money. From this organization Korobi and Hema were the two people who used aids and appliances, and in both the cases it was their family members who arranged it for them. Korobi said that her second sister, who lives in Canada, bought her the walker that she uses for mobility, on her last visit to India. She said that using the walker makes it much easier for her to walk. She has fallen down several times in the bathroom because she had kept it outside. Her mother and her younger sister, on the other hand, are of the opinion that Korobi is lazy and she is simply refusing to put any effort to walk without the help of the walker. Due to this reason she is often scolded by her mother who encourage her to walk without the walker, little realizing that her daughter is unable to walk without its help. Similar tension was also reported by Schneider (2016) in his study on the relationship between identity, disability and the family using the autoethnographic approach. He had noted that when he was a child he was often encouraged to walk with the help of a cane at this home, while he himself found it easier to crawl. Schneider (2016) wrote that he often got scolded by his parents due to this reason who asked him not to be lazy and to put some effort to walk with the help of the cane. He argues that this push to walk was because his parents had created this 'family script[172]' that considered walking to be better than crawling because walking is what 'normal' people do. Schneider (2016), on the other hand, liked to crawl because it was so much easier for him. This, according to him, was "*a tension between the rhetoric of our family script, and the physical reality of my impairment*" (unpaginated) that restricted him from walking (Ibid). Similar tension is also noticeable in the family script of Korobi's family who considered it better for her to walk without a walker than to walk with the help of a walker, even though the reality of her impairment restricted her from doing the same. It is noteworthy that Schneider (2016) in his paper was talking about this childhood where he was forced to walk by his parents. In Korobi's context, however, her mother and sister called her lazy for not putting enough effort to walk in her middle age. Regardless of the difference in age and the nature of disability (Schneider had cerebral palsy from birth), the underlying message in both of their experience is the same that one must strive to be as 'normal' as possible, and keep their physical inconveniences aside.

In the case of Hema it was found that she uses crutches for her mobility after her amputation in 2004. She said that up till the time of the interview she has used about 8 pairs of crutches that her father had brought for her. She said,

> *The crutches do not last very long. This is because I walk around a lot. It lasts for about a year if I use it properly. It also keeps on falling, so it breaks easily after that. I had also received a wheelchair, but I do not require it. I can walk around. But these* [crutches] *are very necessary. I need them. I cannot walk by using artificial leg. It pains a lot. That is why these* [crutches] *are required.*

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[172] Script is a device that helps people in deciding how they should behave in different social contexts (Schneider, 2016).

From the above narrative it can be seen that it is Hema’s father who had bought the crutches for her. As shown in Chapter 6, she suffers from body ache under her arms and both her legs from using her crutches. Her narrative also shows that she had also brought a wheelchair and prosthetic limbs, but they are just lying idle because she does not use them.

This section aimed to show the support that the women have received from their disability organizations in acquiring their aids and appliances for their mobility. It was found that the women contacted through Sanjeeboni and Senehi had good access to aids and appliances. However, in many cases, the women from Sanjeeboni received unnecessary aids from the meetings they had attended as part of the organization. These aids are never used by the women as they do not require them and are simply put aside by them. This can be considered to be a loss of valuable but scarce governmental and non-governmental resources and in the future more planning needs to be done before distributing them. In contrast to these two organizations, the women from HKCT had to arrange for their own aids and appliances, and for this they had to rely on other family members. Korobi’s narrative has also shown that sometimes the women have to struggle with their family members to be able to use their mobility aids.

Livelihood Opportunities: Apart from helping the women in acquiring their disability certificates and aids and appliances, some of the women were also given the opportunity to earn a livelihood by these organizations. The Persons with Disabilities Act, 1995 ensures that 3 per cent of vacancies in identified government and public sector jobs are reserved for persons with visual, locomotor and speech and hearing disabilities (Klasing, 2007). In the Right to Persons with Disabilities Act 2016, the reservation has been increased from 3 percent to 5 percent. In spite of this, according to the 58th round of NSS (2002) as many as 46 percent persons with disabilities are without work in both rural and urban areas of the country (Chaudhuri, 2006). Most people with disabilities are engaged in low profile jobs. One of the reasons for low levels of employment for persons with disabilities is lack of educational qualification and lack of access to the work place (Zutshi, 2004).

Table 8.3 gives an overview of the employment status of the research participants.

Sl. No.	**Name (in alphabetical order)**	**Whether employed or not**	**Place of employment**	**Previous job experience**
1	Anamika	Yes	Sanjeeboni	No
2	Ananya	No	NA	NA
3	Bandana	Yes	Self-Employed	Moromi
4	Chitra	Homemaker	NA	Sanjeeboni
5	Dolly	Yes	Moromi	At a printing press where she met with her accident that led to her amputation at the age of 14 years
6	Gargi	School student	NA	NA
7	Hema	Yes	Self-employed	NA
8	Jeuti	Yes	Moromi	NA
9	Korobi	No	NA	NA
10	Lata	Yes	Sanjeeboni	NA
11	Minakkhi	Yes	Sanjeeboni	NA
12	Nayana	Yes	Senehi	Senehi
13	Pronoti	Yes	Sanjeeboni	NA
14	Risha	No	NA	Senehi
15	Sobiha	School Student	NA	NA
16	Suchismita[173]	Yes	Founder of Sanjeeboni	Senehi
17	Surabhi	Yes	Sanjeeboni	NA
18	Uma	Homemaker	NA	NA

From the above table it can be seen that almost all the research participants who are employed, except Bandana and Hema, work for disability organizations. It is also

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[173] Suchismita's case has not been included in this analysis.

evident that except for Dolly who was compelled to work due to her familial circumstances that eventually exposed her to her impairment, most of the women either did not have any previous work experience, and if they did, it was also in a disability organization. Let us now look at their narratives more closely.

During the interviews with the organization members, it was found that they promote the idea of self-employment. Under the CBRF project, Sanjeeboni had provided skill based training within its livelihood programme. Suchismita said that the organization provides training to people with disabilities in various trades such as bamboo work, weaving, tailoring and crochet, so that they are able to live independently, by earning an income to support themselves and their families. None of the research participants from this organization, however, depend solely on these trainings for their livelihoods.

Pronoti has been working as a weaver for the organization for about 6-7 years. She learned to weave from her mother after she acquired her disability and moved to her village. Similarly, Minakkhi also learnt to weave at a very young age by just observing her older cousin. She had joined the organization one year before the interview as a weaver. According to both of them, joining the organization has been a big help for them, as they receive the treads for free, and are also able to sell their produce, which will not be possible otherwise because as women from the rural areas, they do not have any contacts with the market. Although the money they receive from their work is not a lot, it is sufficient for them for their own survival. Both of them come from relatively well-to-do families due to which they do not have to contribute financially to their families and can also ask for financial help if necessary. These narratives also show that these women already had the skill of weaving, and this facilitated their employment at the organization. Similarly, Anamika also got her job at the organization due to her knowledge of stitching and making crochet designs. She said,

> *When I was in Lakhimpur, my Pehi taught me tailoring and crochet designs. I also have a certificate in this. Then one day* [Suchismita] *Baideu asked me to learn tailoring at a training programme. I told her that I know it already. I told her that I know crochet also. Then she said I will bring you some designs for earrings, etc. Can you make it? I said yes. She got me the designs and I made it for her. Then we sold these earrings in different exhibitions.*

Anamika’s narrative shows that she got her first assignment with the organization because of her skill of stitching and making crochet designs. Eventually she was asked to join the organization as a CBR worker.

The insistence on self-employment was also found in the narrative of Rekha, who worked for Senehi. During the interview, she said that the emphasis of the organization has been on making the students self-dependent through self-employment opportunities with adequate help from the parents. However, in most cases these attempts have not succeeded. According to Rekha, this is due to the lack of vision of the parents about the futures of their children. The parents cannot even imagine that their children will be able to stand on their own feet, and this is more so in the case of women with disabilities.

Out of all the participants from this organization, Risha and Nayana are the only two participants who have been successfully employed. According to Rekha, Risha was a brilliant student even though she faces multiple physical problems. But her parents did not pay the same kind of attention on her capabilities, in comparison to her non-disabled brothers. According to her, Risha’s parents were able to find a scribe for their daughter with much difficulty during her matriculation exams, and it shows their reluctance in seeing a vibrant future for their daughter. After passing her exams, Risha was employed for a few years at the disability law unit of the organization as a research assistant. According to Rekha, even when she had started working for the organization, Risha was not able to come out of the time frame that she had followed when she was a student in Senehi. For instance, she still preferred to commute by the school bus, while the office hours extended far beyond the school timings. This also created difficulties for her in coming to the school during summer and winter vacations because the bus service to the school is not available during that period. Rekha said that during those days either of her parents accompanied her to the school, and waited in the lobby for her till she finished her work in the evening. Rekha said that it is her parents’ mistake that they did not instill the confidence in their daughter to travel alone. She also pointed out that when Risha was working for the law unit, she once got a chance to travel to Delhi for a seminar, but one of her parents had to accompany her during that period. Rekha said that her parents were not willing to take this responsibility and due to this reason Risha had to let this opportunity slip from her hands. She also said that Risha is a very understanding person and due to this reason she never complained thinking that it would cause pain to her family members. During my interview with Risha, she did not mention her difficulties in coming for work. She said that she really enjoyed working for the law unit, but unfortunately after her fall that led to her severe backache, she was not able to sit for a long time, due to which she had to quit her job. Risha found it very boring to sit at home, as her social circle revolved around Senehi. Due to this, when the organization started an ICT programme for old and new students she decided to join, even though she had earlier done a computer course and was aware of many of the things that were taught in the class. She often helped the teachers of the unit in teaching the younger children of the school. According to Rekha, her parents have allowed her to come to the school and teach the children for free in order to kill her time, but they would not help her in setting up a computer center for her where she would be able to teach children independently. She also said that her parents are getting old and she understands their difficulties, but they must have done something to secure Risha’s future, like they have secured the futures of her two younger brothers.

As has been mentioned earlier, the organization tried multiple ways to make the students of the school independent by also involving their parents. They promoted self-employment of the women, and expected their family members to help them in this endeavor. The organization, however, failed to acknowledge that the family members especially the parents have by now aged, while their siblings may have a life of their own which need not revolve around these women. When none of the initiatives were successful, according to Rekha, the school teachers decided that since most of them come from financially sound backgrounds, their parents would be able to take care of their futures. But the teachers decided to help Nayana as she came from a very poor socio-economic background, and her father, who was the sole breadwinner of the family, had also passed away during that period. Initially they gave her the responsibility of running the school mess, but she was removed from this post two years later. Rekha said while giving her this responsibility they should have considered her interests. It was clear that she was not interested in taking this responsibility. At the time of the study, Nayana was employed as the coordinator of the women with disabilities group. According to Rekha, Nayana was very hesitant in the initial period to take up such an important responsibility as she felt that she is not qualified enough. However, the Executive Director of the organization, Zohaan

Hussain, who also uses a wheelchair for mobility, did not pay any attention to her pleas, and asked her to do the job as expected. According to Rekha, it was his tough attitude that enabled her to start working at the organization and made her feel confident about her work. Nayana also said that whatever she is today is because of the support that she has received from the organization. In spite of this, it was observed during my interactions that the members of the organization, especially Zohaan, often infantilized her and did not consider her to be fully capable of handling all the responsibilities. He also accused her of being a laidback person who did not deal with things more proactively. During the interview with Nayana, she said that due to her sleeplessness (mentioned in Chapter 6), she has started to feel very sick, and due to this, she has not been able to concentrate much on her work. Rekha, who is very close to Nayana, did not mention this during the interview with her.

In my interview with Palash, the president of HKCT, he also emphasized on the importance of self-employment. He said that the primary motive of their organization is to provide financial assistance to persons with disabilities so that they are able to have food on their plates. He also said that if on top of this, persons with disabilities are also able to earn a living, then they would feel that have done a good job. From this organization, four women were contacted out of whom two were self-employed and one worked at Moromi. As cited above, Bandana had started working for Moromi from a very young age, despite the opposition from her mother. After her marriage she quit her job because she found it very difficult to commute to her workplace from her new home. Bandana said that she always dreamt of having her own business. With the right guidance from Archana, she took a loan to start her own shop. She also persuaded her husband to quit his job in a private company because the salary was very less. In the shop, Bandana works as a tailor, while her husband sells groceries. It was again Archana who had informed her about HKCT. At her insistence, Bandana applied for financial assistance but it took them a few months to receive the amount. According to her, this money has helped her a lot in the previous year, and she was very grateful to the organization for giving her that grant. She said,

> *I have received help money from* [HKCT] *once. That money was of great help for me. I had a lot of difficulties last year. I had a lot of difficulties in starting the shop. Even though Ma is in service, I did not tell her anything about my problems. He did not marry me by asking Ma, he has polai anise* [made her elope]. *That is why I find it very difficult to share everything with Ma. Then there is* [Archana] *Baideu in VRC, I shared my problems with her. She asked me to apply for the financial assistance from*

> [HKCT]. *She asked me to get my documents along with a full photograph of me to her office. She gave me the form, I filled it up and submitted it. Then I got the money.*

At the time of the interview, Bandana was not aware if she can apply for the grant for a second time. I found out about this from the organization and gave her the information that she can apply any number of times she wants to, but she will have to send them a utilization certificate specifying how she had spent the money the previous time. Bandana further said that even though she loved her business, it is her wish to get a government job so that her future is secured. She said,

> *I like doing business, but it is my wish to get a job. A government job. I don't care even if it is 3rd or 4th grade job. I would be just happy to get a government job. Now I have strength in my body, so I am able to work. If I fall sick tomorrow, I will not be able to work. That is why, I want a job. To secure my future. I have been looking for one.*

From the above narrative it can be seen that the money Bandana had received from HKCT helped her in her business because of which she did not have to ask for money from her mother. As cited in Chapter 7, Bandana had eloped with her husband which had resulted in a lot of drama in between the two families. Bandana feels the weight of her decision and said that she did not want to be a burden on her mother after her marriage. Due to this reason she was very grateful to HKCT for the financial support she had received. While Bandana loves her work, she realizes that there is no security in this line of work. In order to secure her future, she said that she wants a government job.

While the money from the organization helped Bandana in her business, it was not the same for everyone, and the following narrative illustrates this properly.

Hema's contact was also found from the files of HKCT. As mentioned earlier in the chapter, when I visited her home, it was found that Hema had no idea about the organization or if she had received the money. This was because it was her father who handled all her disability related issues, and because he did not have a very cordial relationship with his daughter, it is very likely that he had kept the money for himself. It is also significant that Hema's father does not provide for her expenses anymore. Seeing all of this and considering her future, Hema's mother used all her savings to upgrade the small shop that her father had opened for her in one part of the house. Due to lack of money, however, she was not able to buy more products for the shop. During the interview, Hema said that she was really in dire need of money, and if she would have received help from someone it would have been great. Even though her father knew about all this, he did not find it necessary to inform his daughter about HKCT. This shows that the dynamics in the relationships of family members may change over a period of time, and organizations that deal with families of persons with disabilities need to keep this point into consideration. On the contrary, the president of HKCT had a very generic understanding of the family, where all members look after the wellbeing of the other members, especially those who have been rendered more vulnerable by the society like persons with disabilities. The reality however can be something different, like what we have seen in the case of Hema.

As has been elaborated earlier, the founder of Moromi, Kishore Kamal Bora, had committed suicide in the year 2013. According to the brochure that Jeuti gave me, this organization was started with the sole motive to provide economic rehabilitation to persons with disabilities. In addition to providing them with employment, Kishore also provided different kinds of help to the people who came to work for him (this will be elaborated in the next sub-section). After his death it is not clear who has taken up the responsibility of the organization. According to some of the participants, the responsibility has been taken by a board of members, but who constitute this board, and when this board was formed, was not clear. Interview with the supervisor of the organization also did not yield much result, as he was unwilling to give time for a face to face interview. Instead a short interview was conducted on the phone where I tried to understand his views regarding the kind of work that is done at the organization. During the interview it came out that he had a very disabilist understanding about the lives of persons with disabilities. According to him, persons with disabilities have very limited capacity to work outside their homes due to their medical conditions. He felt that their organization provided persons with disabilities with a stipend (and not a salary) to sustain themselves so that they do not have to depend on others for their survival. He did not consider the backbreaking work done by them at the organization to be something that can be considered as worthy to earn a salary. It was very unfortunate that in spite of working with persons with disabilities for a considerable period of time, his views about the disabled community had not changed.

The women from this organization who were interviewed seemed to have a different opinion about their work status. Jeuti, who had worked at the organization for five years, said that she had never thought she would one day start working and earn a livelihood for herself. Even though the money that she earns is barely enough for her survival, she feels good that she does not have to depend on others for her survival. In the same way, Dolly said that after working at the organization she does not have to depend on anyone for her survival. She said,

> *After I started working here, if I want to do something for my home, if I want to buy something for my home, I can do it. I do not have to ask for money from anyone. I can do it on my own. That is the support that I have received.*

Although Dolly acknowledges that the pay is very less, yet she is grateful for the amount that she earns through the organization.

From the above narratives it can be seen that most of the women enjoyed their work at the organization, but lamented that it paid very less, and is insufficient to look after themselves, let alone their families. Most of these women aspire to be self-employed and have their own businesses, but the lack of capital hinders them from taking this step. It was also found that some of the women aspire to have government jobs because of the job security attached to it. However, lack of educational qualification hinders them from fulfilling this dream.

The study also found that the marital status of the women played a very important role in whether they wanted to continue with their work with the organization in the future. While unmarried women such as Dolly and Hema wanted to secure their futures through self-employment against any odds that might come their way, in the case of some married women it was found that even though they enjoyed their work at the organization, they also considered their jobs as secondary after their marriage, especially after they had their children. These points came out clearly in the narratives of Jeuti and Chitra.

Jeuti, who was married for a year at the time of the interview, said that she has continued to work after her marriage, and her husband does not have any problems with her work. But she is not sure if she would be able to continue later, hinting the possibility of motherhood, and the responsibilities associated with this role. In another instance, Chitra had to give up making doormats after the birth of her son because she was not able to juggle the responsibilities of work with her mothering responsibilities. This has resulted in reduced earnings for the family, as her husband is also not able to make the doormats without her help.

This subsection has shown the kind of livelihood opportunities the women have received through the help of the disability organizations. It was observed that all the organizations, except Moromi, have emphasized on the importance of self-employment for persons with disabilities. In spite of this, except Hema and Bandana, all the other women were employed in the disability organizations. This employment opportunity provided the women with the opportunity to stand on their own feet for the first time in their lives. As a consequence of this, most of them were able to develop their self-confidence to make their presence felt in the society, which had so far disregarded them due to their impairments. In spite of this however, most of the women were constantly looking for better opportunities elsewhere due to the low pay in this sector, even though they were not qualified for anything else other than self-employment, due to their lack of education.

<u>Other Kinds of Support from the Disability Organizations</u>: Apart from what has been mentioned above, in certain cases it was found that the founders of the organizations and other prominent members have gone out of their way and supported the women in overcoming their barriers and reaching their full potential, in their personal capacities. This includes helping the women to get admission at Senehi, to learn singing from a famous music teacher for free, emotional support to undergo a major operation and suggestion to buy prosthesis to overcome shyness in going out to public spaces. The following narratives illustrate these points clearly.

As cited in Chapter 4, Sobiha was referred to Senehi immediately after her birth by her mother's gynecologist. However, due to their familial circumstances, her mother was not able to continue her treatment. At the time of the interview Sobiha's mother said that she was introduced to Suchismita through the latter's driver who often came to her shop to buy *paan-taamul* [beetle leaves and beetle nuts]. She said,

> [Suchismita] *Baideu's driver, he used to come to my shop frequently to buy taamul-paan. He told me that Baideu works for 'such children'. He is the one who introduced me to Baideu. At that time Sobiha was about two-two and half years old. I*

> *met Baideu, and she has been looking after us from that time. Whatever needs to be done, she has done everything for us. She has taken us everywhere, for her treatment, for her exercises, she has done everything for us. After that she also got her admitted to Senehi. What happened was immediately after her birth she was referred to Senehi for the exercises. But I was not able to continue taking her there. I got pregnant, and later her father also passed away. After the birth of my younger daughter, I took her back to Senehi. But they did not take her in because she had grown up. Then we came back to Baideu. She said that her NGO is very far. So we got her admitted to another organization. Sobiha was there for three years. But they did not teach anything to her. So she used to cry. She used to say, everyone else get their results* [after exams], *why don't I get results? She was not able to understand at that time. When she was inconsolable, Baideu took her back to Senehi and spoke to the Principal Baideu. She got her admitted to Senehi five years back. Now also she is going to Senehi.*

Like Sobiha, the other women were also helped by the disability organizations in their personal capacities. Nayana said that she started singing for the first time when she had joined Senehi as a student. As mentioned in Chapter 7, Nayana was very thrilled about leaving her home and coming to the school where she met many other children like her. In the school she also participated in different activities. One of those activities was singing. She said,

> *When I first heard that there will be a function in our school, I was so thrilled. At first when I got up in the stage to sing, I was not scared at all. I was not even a bit scared. It was the first time I had sung a song. There were no mistakes in the taal* [beat] *of the song. But I make a lot of mistakes now. I was not worried at that time, I was just excited. Even though thousands of people were listening to me, I did not feel worried. I was very confident at that time. Now I do not know what has happened. After growing up, this confidence has lessened. Now if I am asked to sing in the stage, I am a bit scared. I feel ashamed. What if I make mistakes? It might be that at that time, the songs had just one taal, I sang songs with just one taal. Now if I have to sing, I have to sing in different kinds of taals. So to manage that is a bit difficult for me.*

Nayana said that in her school functions she often sang old songs of Dr. Bhupen Hazarika. These songs were taught to her in the school. With great pain in her voice, she mentioned that now she has given up all this. When asked to elaborate, she said,

> *The main thing is that I need practice. Actually, I do not have formal training with a music teacher. Whatever I can, I do it by myself. Or whatever I have been taught from the school. I do not have the classical base. One needs a classical base for singing. That is the thing. Even if someone gives me this opportunity, I should be able to seek it. That is one thing. To be myself, there are so many barriers in travelling. I cannot join in these activities.*

During the interview with Rekha, special educator at Senehi, she elaborated on Nayana's music education. She said that when she was younger she sang in almost all the school functions and impressed her audiences. These functions were attended by people who had a lot of contacts. During this period she got the offer of getting professionally trained from a renowned music teacher for free. It was only required for someone to take her to the music school. This beautiful dream did not turn out to be a reality for Nayana, as she faced accessibility issues in the school building. So she needed someone to lift her to her class, and back, which turned out to be difficult for both her parents and the organization to arrange. Rekha also said that her parents suggested that the teacher should come to their home and teach Nayana. But according to Rekha this was not feasible because they lived in a very small room, where they slept, cooked and ate. To expect a renowned teacher to teach in such an environment for very little or no fees would have been too much to ask.

This narrative shows that the organization recognized Nayana's talent in music and tried their best to provide her professional music education. But it should also be seen that what she was getting was nothing more than charity, as the school felt bad about her physical and socio-economic condition and decided to give her what her parents were not capable of giving her. In doing so, however, they did not try to reduce the accessibility issues which created an insurmountable barrier for her. This narrative shows that as recipients of charity, Nayana and her family had limited bargaining power to negotiate the terms for her music education.

In the case of the women from Moromi, it was found that Kishore had helped them in numerous ways in dealing with their difficulties. It was probably due to this reason that his death came as a tremendous blow to all the workers at this organization who have still not been able to overcome their grief of losing him. The following narratives of Jeuti and Dolly illustrate this point clearly.

Jeuti remembers quite fondly that Kishore gave her Rs. 1000 on their first meeting when he got to know that her sister is unwell. During that time she had not even decided that she would work for the organization. She also mentioned that Kishore was the first person who asked her if she wanted to go for a surgery for her impaired hand, after she started working for him. At that time she refused because she was scared as it was pointed out to her that it is going to be a major surgery. Later however, she changed her mind, when a *pujari* of the Teeni Jhandi temple, whom she deeply respected, gave her the assurance that she would get better after the surgery. When she told Kishore about her decision, he gave her his full support. Apart from her own family and her faith on God, according to Jeuti, it was only Kishore who stood by her side during her difficult time.

> *Sir who is no one for me, I just work under him. It was not needed for him to even call me. But he was calling the doctor to ask whether our girl is out of the operation room. How is she? He was trying to find out. He called me in the morning and told me that we would all pray for you so that you come out from the OT nicely. Sir is no more but he has done a lot for me.*

In the same way, Dolly also talked about the support that she had received from Kishore. Dolly had acquired her disability at the age of 14 years. Following this incident, Dolly tried to find work at many places, as she realized that her family was suffering without her economic contribution. However, it was very difficult for her to find work considering her disability and her lack of educational qualification. She decided not to give up as she realized that if she gives up, her family would be greatly pained. Much later when she came to the organization, it was Kishore who gave her the strength to keep her self-confidence intact.

> *Sir told me never lose your self-confidence. You try it by yourself; you will be able to do it. When Sir told me I can do it, I thought I can do it. I felt good. Many people said many things, but Sir told me you do not pay attention. Let people say whatever they want to, you do not believe them. I felt very good.*

From the above narrative it can be seen that Kishore's words gave her the motivation to survive her depression. Dolly also said that Kishore was able to understand that she felt ashamed about the visibility of her impairment. In order to reduce this visibility, he bought Dolly a prosthetic hand. Unfortunately, she finds it very painful to use the prosthetic hand, and due to this she does not use it for a long time. Dolly said,

> *Sir also gave me a hand, he bought it for me. He gave me a plastic hand. Even my relatives did not understand my problems as much as Sir understood them. He understood that this girl comes to work my hiding her hand. She feels shy, she needs a hand. I looked at Sir and felt at least Sir has thought so much for me, I was very grateful to him. He gave me a hand, a plastic hand. Sir paid half the money, and I returned him half of it by working here. Who would do so much?*

It is perhaps due to this kind of intuitive understanding that made these women lament his passing away even more. Dolly said,

> *Sir is no more now. When he was there it was like, when Deuta was there, it was like that with Sir. Sir is no more so I no longer like to work here. I am working well, I get along well with everyone, it is good. I am working with different people. But the kind of attention that Sir gave us, it is no longer there […] I miss him sometimes. Sir gave*

> *me a lot of support. Now there is no one to talk to. If I say things to someone, I do not know if I will get it or not. But I could talk to Sir as if he was my own. Now Sir is no more […] Sir was able to understand me. These other people also do not say anything to me, they also understand me. But the way Sir understood me, just like Ma-Deuta understands you and nobody else can understand you, it was the same with Sir.*

Like Dolly, Jeuti also praised Kishore for his dedication towards his employees. She said,

> *He never behaved with us as our employer. He also worked with us like an employee. He would also make a register entry for himself. Whenever he was not present, he would mark himself absent. That was one very good thing about him. And another was that he never displayed any ghrin* [disgust] *or othering towards us. Whatever we eat for lunch, he ate with us. The way we bring a plate and stand in the queue for our food at the organization, he also did the same. As our Sir, he never ate something good. Whatever we eat, if we are eating aloo pitika* [mashed potatoes], *Sir would also eat aloo pitika with us. In this way he was very nice. He was a very nice man. We pray to God that he is at peace in heaven now. We just pray for his soul.*

From the above narratives it can be seen that most of the founders of the organizations went out of their ways to provide for the persons with disabilities, which made them very popular among the beneficiaries. Unlike the other organizations, as mentioned earlier, HKCT did not have any personal contact with persons with disabilities. Due to this reason, the women who were contacted from here did not have much to offer in this regard.

The aim of this section was to show the kind of support that the women have received from the respective disability organizations. The section began with the description about how the women came into contact with the organizations through their personal contacts. It suggested that it was a matter of sheer luck that the women came into contact with these organizations. Following this, the section shows the specific kind of support that the women have received from their disability organizations such as in making disability certificates, in accessing aids and appliances and in getting the opportunity to earn a livelihood. The final section also shows how the founders of the organization have helped few of the women in their personal capacities. Regardless of the support that the women have received from these organizations, it is important to reiterate that it is a matter of sheer chance that they came into contact with these organizations. Furthermore, the organizations had their own limitations on the support that they were able to provide the women. The women also did not have the right to demand for things that they wanted from these organizations, but had to accept whatever little they received as a form of charity. Unfortunately the women were not aware that they could organize and demand for things from the government. Significantly, after years of failure from the state, the people of Assam, including women with disabilities had limited expectations from the disability organizations.

Section III

Impact of Support from the Disability Organizations

In the previous section we looked at the particular forms of support that the women have received from the disability organizations. Continuing the argument from there, this section looks at how this support has affected the lives of the study participants. It begins by discussing how the women had gained self-confidence and are now more aware about disability issues, followed by how the organizations helped the women to develop an identity as 'persons with disabilities' and how it enhanced their reputation in the family and the community. The section ends by discussing the unmet expectations of the women.

Gaining Confidence and Awareness about Disability Issues: In the previous section we saw that the women received different kinds of support from their respective disability organizations. Apart from these direct forms of support, it was found that the organizations helped the women in more indirect ways for which they were forever grateful. One of the key ways that the organizations helped the women was by boosting their self-confidence and increasing their awareness about disability issues. This is important because as noted in Chapter 7, many of the women had very low self-esteem in the early years of their lives, and it was not much facilitated by the environment that they lived in. Coming into contact with the disability organizations and meeting other persons with disabilities made them realize that they were not alone in their fight against the disablist attitudes of the society. Many of the women responded that coming into contact with disability organizations was a life changing event for them. The following narratives illustrate this clearly.

Anamika, who works as a CBR worker at Sanjeeboni, said that the organization has changed her life completely. This job gave her the experience of knowing the world around her, which was hidden from her all along. Anamika said that when she was young she had never travelled anywhere alone, not even to Guwahati. People in her village always scared her that Guwahati is a very big city and if she goes there alone, she would be lost. Joining the organization changed all of this for her. She said,

> *Through my work, I have been able to become independent. I have been able to earn a livelihood. I have been able to go wherever I want. I have been able to do things with my own income. I have been able to talk to others, how to introduce myself to others, where to go, I have received everything from* [Suchismita] *Baideu… Earlier I did not think that I will have to walk so much, I will have to go to so many villages, that I will have to talk to everyone, that I will know everyone. After getting to know everyone, I have been able to go to so many places, isn't it? I have been to Delhi, Bhubaneswar, Bangalore… earlier when I had just joined I went to Dimapur. I did not know that I would get to travel so much. I did not know earlier, what is there, and what is not there. I did not know anything. After coming here, I learnt so many things. I have gained knowledge about so many things. What to do after going to a particular place, I came to know about that also. How to talk to someone, I am also learning that. I am learning all this, isn't it? We village people do not know much. Earlier I did not know how to make a certificate. Now we make these certificates in our office. For the whole of Kamrup Metro. That is our biggest work. That is it. This is our biggest achievement in this organization. They have showed us the path.*

In the above narrative it can be seen that after joining as a CBR worker at the organization Anamika's life has changed completely. While growing up she had never imagined that her life would change so drastically. She is also amazed by the love and respect that she receives from the community where she works. Similarly, Surabhi, another CBR worker, also attributed the changes in her life to the organization. She said,

> *Things have changed after I joined here. Now I am able to do things on my own. I learnt to stitch, they took me out for training. They took me out for competitions, workshops. I passed in these tests. I brought back prizes from there. From that time things have changed for me… I have received many kinds of help from* [Sanjeeboni]. *Earlier I was not allowed to go out on my own. After coming here I have seen the world. I have learnt many things. I got to know about many things. Whatever I do,* [Suchismita] *Baideu is always with me. Or she would send someone with me. I have learnt so many things from here. I have been introduced to the Disability Commissioner. I also know all the important offices and doctors in hospitals. I have been introduced to them. Now we can do the work by ourselves. I can do the work for others also.*

Surabhi further said that in the past her mother restricted her from going out for the organization activities thinking that she would be troubled. This in turn angered her very much. She said,

> *While going to Guwahati, nowadays they do not say anything. But earlier they asked me if I would be able to go alone to a place like Guwahati! They used to say like that. Why they say like that? I used to get angry. If others can, I can too. I used to say like that. Then they remain quiet. Baideu* [her elder sister] *says to Ma you cannot win with her in an argument, so just keep quiet* [she laughs]. *Ma says I am saying this for her own good. I told them that my life would not work if I stay like this. I can understand now, that my life would not work. Whatever happens, will happen. What God has in stored for us, that will happen.*

Minakkhi, who had been associated with the organization since 2002, also said,

> *After coming here I do not feel that I am any different from others. I think of myself as bhaal* [non-disabled]. *When I was at home, I used to feel… I used to feel sad. After coming here, I have no such thoughts. I have seen so many people. I have travelled to so many places with* [Suchismita] *Baideu and all. So I do not feel sad anymore.*

The above narratives highlight that the women with disabilities who were contacted through Sanjeeboni were very grateful for the exposure that they have received through the organization. Similarly the women who were contacted through Moromi also talked about how the organization helped them in building their self-confidence. Bandana said that if she was not approached by Kishore to work for him, she would not have learned so many things about the world outside. She said,

> *If I had stayed at home probably I would not have learned so many things as I have learned after joining the organization. I also came to know about the outside world, how to speak in certain places, how to talk to people when you are running a shop. How to talk to people in an office… At that time Sir used to say, everyone has to be self-dependent. Whatever he has taught me, whatever he has explained to me, on the basis of all that I am living today.*

From the above narrative it can be seen that Bandana attributes whatever she has achieved in life to Kishore as he is the one who introduced her to the world outside. Similarly, Jeuti also said that she has changed a lot after meeting Kishore.

> *I feel that I have changed a lot after I started working at Moromi. This is because if I did not know some things, I learnt them here, I understood them here. Sir has taught us that never think about yourself as weak. Always think about yourself as a bhaal manuh* [non-disabled person]. *Be proud of the fact that you are standing on your own feet. From that we also think that we are not handicapped. He has also taught us that if someday we see a beggar on the streets, who is lying there and has got nothing to eat, always help him. Or help a person in the street who is kona* [blind] *and is not able to cross the street. Always help such people. Earlier I did not know many things like I should help such a person. I did not think that way. Now I feel that if I help this person then I will get punyo* [blessings]. *He always gave us bhaal gyan* [good advice].

From the above it can be seen that Jeuti realized that she is not weak when Kishore gave her the confidence which she had earlier lacked. Similarly she learnt the virtues of helping other people who are in need as she learnt that she would get blessings from them. These narratives show that the women have learnt a lot of things about life from their employer. These life lessons have helped most of them in dealing with their lives.

The women who were contacted through Senehi were also deeply indebted to the organization for whatever they have been able to achieve in their lives, or the friends they have been able to make at the organization. Nayana said her father wanted the disability organization to mold her life in the way they thought best.

> *I have received a lot of support from* [Senehi]. *Ma Deuta had the wish that after giving me admission in a school how to mold my life, only the people from the school would understand. We do not know. Deuta said that his economic condition is also not good. That is why Deuta requested Principal Aunty that I have given my daughter to you. How you can light up her future is up to you. Wherever I have to go, I will go. He said like that. Now whatever I am is because I am here. There is no point in denying it.*

Nayana feels that whatever she is today, it is because of the support that she has received from the disability organization. Similarly, Risha also said the same thing about the organization.

> *Whatever I have been able to achieve, whether it is in terms of education, or doing the work for myself, it is all because of* [Senehi]. *My parents have also received a lot of help from* [Senehi].

From the above narratives it is clear that both the women attributed whatever they have been able to achieve in their lives to Senehi and their special educators who have taken very good care of them since their childhood. It was found that unlike the study participants from Sanjeeboni and Moromi, the study participants from Senehi were severely dependent on their family members for their mobility. While one of the reasons for this was the nature and severity of their impairments (cerebral palsy for Ananya, Sobiha and Risha; and post-polio residual paralysis for Nayana), another important reason was the way they were brought up in a cosseted environment in the special school that hardly gave them any scope to intermingle in the mainstream society. According to Rekha, the organization had tried very many times to bring them into the mainstream, but because of the reluctance of their parents, this has not been possible. In her opinion things have only changed for Nayana in the last few years after she got her job as the coordinator for the women with disabilities network.

Even though she still asks the teachers of the special school for support, she is able to manage most of the things on her own.

It was found that all the women who attended the meetings that were coordinated by Nayana, liked it very much as it gave them the opportunity to meet their friends and share their problems with one another. However, none of those who were interviewed (except for Nayana) were able to tell in what way these meetings are beneficial for them. The following narratives provide a glimpse of this.

> *I like coming for the meetings. I do not like to miss any of the meetings. I want to keep coming to all the meetings till the end. Since I have joined this group I have come to know about a lot of things. The meetings are all about talking. We all talk about our feelings. Whatever I have in my heart I can share it with others, and others also do the same. I feel good when I am able to share my feelings with the others. I have shared my problems with Ma, Papa and Ba with this group.*

Ananya said that her elder sister often made fun of her because of her impairment. Earlier she had complained about these things to her parents but was not satisfied with their response. She said that after she shared her issues with her sister with the group, all the girls empathized with her problem. Some of them also asked Ananya to bring her sister to the meetings so that they can teach her a lesson. While Ananya says that it is not necessary, nonetheless she often warns her sister that if she does not mend her ways, she will let the group know about what she is doing to her. Ananya said that in this way she is able to keep her sister under control.

Similarly, Risha also shared that she likes the fact that she is able to share her feelings and experiences with the other members of the group. Other than this, Risha also feels that the workshops on gender, etc. have been very helpful in understanding her life circumstances. She feels that the knowledge of these things would be helpful for her in the long run.

The support that the women have received from HKCT has helped them in a different way. As has been elaborated above, Bandana said that the money from the organization has helped her when she had needed financial support the most. This money has helped her in setting up her store without having to ask anyone else for support.

To sum up this section, the support that the women have received from the disability organization has boosted the self-confidence and awareness of the women in multiple ways. This, however, is again dependent on the nature of the impairments of the women and the type of support provided by the organizations. Anamika and Surabhi, for instance, who work as CBR workers for the organizations have gained back their lost confidence after they were introduced to the wider world by the organization. Similarly, Minakkhi also started feeling proud of herself when the women around her started praising her for her travels outside of the village. These instances are important because as shown in the previous chapters, these women have grown up in an environment where they considered themselves to be inferior to others. Contact with Sanjeeboni changed their lives because due to their prior experiences they never imagined that they would be able to garner so much respect from the community. Similarly, the women who were contacted from Moromi also experienced a change in their attitudes towards themselves through the boost in self-confidence due to the words and actions of its founder, Kishore. For the first time in their lives somebody supported their abilities to work and this had an enormous impact on their self-image about themselves. In the case of the women from Senehi, the organization has been their only source of social contact since their childhood. As shown in the previous chapters, the women were rejected in normal schools earlier, while they received preferential treatment from their teachers at Senehi. Due to this reason they were very grateful to their school. In contrast to this kind of personalized treatment at the other organizations, the women who were contacted through HKCT were simply grateful for the money they had received as it enabled them to do their own tasks without having to depend on others for financial support.

Meeting other Persons with Disabilities*:* As mentioned earlier, women in general, and women with visible physical disabilities in particular, usually grow up with a negative self-image due to gendered notions about ‘normal’ physical appearance (Begum, 1992). Such an image is usually internalized by the women that can have a detrimental effect on their psycho-social well-being (Ibid). This is compounded by the fact that most persons with disabilities grow up isolated from one another, which sometimes makes it impossible to resist the disablism they experience in their day-to-day lives (Thomas, 2006; Scotch, 2009). In such a scenario, it is the disability organizations that provided the platform to the women to interact with other persons with disabilities for the first time in their lives. In the process, the women were able to question their own biases and form an identity as a person with disabilities. This subsection elaborates on their experiences of meeting persons with disabilities for the first time in their lives through their respective disability organizations. In many cases it was found that the first meeting with other persons with disabilities evoked different kinds of emotions, possibly because of the way these women had internalized the societal perception of disability and about persons with disabilities. Some of the women, for instance, felt angry with God about why s/he had created people with a range of physical and mental disabilities. Bandana said,

> *When I met another person with disabilities for the first time, I felt very angry with God. Why did s/he make people like us? […] Everyone else is bhaal* [non-disabled], *why are we like this? Even now sometimes I scold God. Why did you do this?*

Even though her anger with God continues to persist primarily because of the stigma and hardships that persons with disabilities have to endure, Bandana's perspective about their capabilities had certainly changed after joining Moromi. She said,

> *I tell my husband sometimes that there are such people with disabilities that when you meet them you will say that even bhaal manuh* [non-disabled people] *cannot do such kinds of work. Actually education or money is not important. People's knowledge should be big. It should be good. If people have outside knowledge, then they would understand everything. But if they are inside their homes or within their shops, they will see the money, but they will not understand who is like what in real life. That is why people should be acquainted with the outside world.*

From the above narrative it is clear that Bandana's perception about persons with disabilities had changed completely after joining the disability organization, Moromi. As mentioned in Chapter 7, occasionally her husband and his family members taunt her for her impairment. The above narrative shows that during such moments she reminds her husband that people with disabilities are not incapacitated by their impairments, which is a common perception in the society. As seen above, she tells her husband that it is only when people move out of their narrow spaces and interact with the world outside that they would come to know what persons with disabilities are capable of doing.

Surabhi also had her first encounter with other persons with disabilities when she started working for Sanjeeboni. She said,

> *After coming here, I saw* [Suchismita] *Baideu. In the beginning, I found Baideu to be just like me. She was better at that time. She walked with the help of elbow crutches at*

> *that time. I also met many other persons with disabilities… After meeting them, I felt good and bad at the same time. God made me like this, that is okay, but why them? I thought like that. I felt bad.*

The above narrative shows that Surabhi had a mixed reaction after meeting other persons with disabilities for the first time at the organization. On the one hand, meeting Suchismita made her feel better that in spite of all their other differences, they had their disabled status as common. On the other hand, she felt sad that there were so many persons with disabilities around her, many of whom had much severe disabilities than her. Seeing them she wondered why God created such people.

Similarly, Lata also felt very upset after her first encounter with other persons/ children with disabilities. She said,

> *I had met other persons with disabilities at a meeting organized by the Sarva Shiksha Abhiyan. One Baideu made me the volunteer of that meeting. I had attended 2-3 such meetings. I have these difficulties, but when I saw them, I felt very sorry for them. They had so many difficulties. Seeing them I had to leave my issues aside, and console them… Some of them were not able to understand anything. Some were not able to walk. They used a wheelchair for mobility. They brought it along with them in the camp. After seeing them I became more nervous. Why did God have to give them birth in this way? S/he should give them birth normally. I cried the entire night thinking about this. Why should they be given so many sorrows? Their Ma-Deuta were also very sorry about this.*

All these narratives show that when the women met with other persons with disabilities for the first time, they felt very sorry for the others. These narratives vividly show how the women had internalized the dominant social perception about persons with disabilities as victims of personal tragedy. In certain cases it was also found that women felt sorry for themselves that they were placed in the same category as other persons with disabilities. Sustained interaction with these people however enabled them to see beyond the disabilities and develop deep friendships with them. The following narratives of Jeuti and Dolly show this clearly.

Jeuti said that when she came to the organization for the first time and saw other persons with disabilities, she felt completely numb. Gradually, however, she came to realize that her colleagues are actually good people and now she spends her time in *hahi-furti* [having fun] and does not realize how her time passes with them.

> *Initially I felt what kind of a place I have joined for work. I had never seen anyone before* [another person with disability]. *Some have problems with their brains, some are not able to walk, and some do not have their hands. Seeing all this I had felt*

> *numb. I thought what kind of place I have joined to work. Gradually when I got adjusted to the place, I started feeling better. Now I spend my time with them, I laugh with them, I eat, I do everything with them… I have not seen such people earlier […] I had seen. I had seen them on the streets sometimes, but I had never interacted with them […] Now I feel better. Now I do not feel like coming back from the office. I have never felt that I would leave my job here and find a job elsewhere. Because all the people are now like my own. That is why I have started feeling good. Also because of* [Kishore] *Sir who had helped me a lot*.

In the same way, Dolly also said that when she first joined the organization she was very unhappy. But gradually she was able to find good friends among her colleagues.

> *When I first came here I thought where have I come? Have I also become like them? Have I also become a bikolango* [physically disabled] *like them? I thought like this […] When I first came to work I met another person. He had his hand till his elbow. Seeing him I closed my eyes. I felt what have I seen? Where have I come? After I reached home I cried a lot. Where have I entered today? Today I have joined with the handicapped. I thought how I would feel working with them. Whether they would understand me or not? How they would feel. But after working here for some time I realized that no, they understand me. It took me some time to adjust here. I did not understand what to do. Every time I reached home, I went to the bathroom and cried alone. If I cry at home, Ma would ask why I am crying. In the bathroom I would cry and I would wonder what kind of a place I have entered.* [Kishore] *Sir asked me to at least try. When Sir said this, I thought of giving it a shot. What to do it was written in my kopaal. […] Eventually I realized that it is very good. They are able to understand me. Other people cannot understand me but they can, they help me by holding my hand. […] Now all of them have become like family. I may not feel so good at home, as much as I feel good here. We all pass our days in hahi-furti* [having fun]. *At home I have so much tension about what to do and what not to do. How to help Bhaiti? I think about all these things. But when I come here to work with them, I feel good.*

From the above narratives it can be seen that both Jeuti and Dolly felt very disturbed in their initial days at Moromi. While Jeuti was never made to feel different at home, Dolly had acquired her impairment at the age of 14 years following an accident at the workplace. Due to these reasons, neither of them considered themselves to be impaired. It was only when they joined the organization that they realized that they are also classified at persons with disabilities. This came as a shock for both of them, and they took some time to recover from it. As they gradually mingled with their colleagues they realized that they were good people who made them forget about the worries they faced at home. Their employer Kishore had also helped them a lot in this process of finding peace within themselves.

In certain cases it was also found that after coming to the organization the women realized that they do not belong to the 'normal' world, and due to this reason there were special zones for people like them. As cited in Chapter 7, Nayana was denied admission to several 'normal' schools before she got admitted to the CSE, Senehi. She was very thrilled at the idea of attending school, and the fact that she will no longer have to sit idle at home. However, at the same time, she was also indirectly made aware about her place in the society. Through this experience Nayana realized that persons with disabilities are not welcome in 'normal' schools because of their inability to walk, hear or speak, and that is why they are admitted to impairment-specific special schools. In the existing literature, there is a strong debate regarding whether children with disabilities should be admitted to segregated spaces like special schools, or they should be included in the 'normal' schools (see Barnes & Mercer, 2003). While special schools for the blind and the deaf have tremendously helped in building up the disability movement and demanding for their rights (Chander, 2008), at the same time one cannot negate the negative influence such segregation might have in the young minds of children with disabilities.

In Anamika's case it was found that the she had met other persons with disabilities prior to coming into contact with Sanjeeboni. These people were from varying age groups with a range of disabling conditions such as mental retardation and cerebral palsy. Yet it never struck her that there is something in common between them. It was only after she joined the organization that she understood what disability means and that they all face similar discrimination and stigma from the society. She said,

> *I had met another person with disabilities for the first time in my village. One of them had MR, another had CP. They are much younger than me. They cannot speak, it is only their parents who can speak. So we could never share our experiences as such. Either they are much younger than me, or they cannot speak. It was only after I came to* [Sanjeeboni] *that we all started talking about what we go through in our everyday lives. Only then I came to know that there is something called disability.*

From the above narrative it can be seen that even though Anamika had met other persons with disabilities before coming into contact with Sanjeeboni, she never thought of them as having any similar concern. This is important because often persons with disabilities are often seen as a homogeneous group. Her narrative shows that age as well as the nature of impairment are two among many variables that create differences between persons with disabilities.

Regardless of this group identity, some of the participants were found to create a hierarchy between themselves, and those with other types of disabilities, especially cognitive disabilities. The following narratives give a glimpse of this. When Bandana was working with Moromi, she met several persons with mental disabilities. This is what she said about them.

> *I have worked with persons with mental disabilities. I have found that if we explain things to them with love, they understand everything. But if we explain to them with anger then they make a fuss and get very angry. […] The first thing is love. With love everything can be done. But if you are scolded all the time even a bhaal manuh* [non-disabled person] *would get angry. On top of that they are people who are facing problems. If they are given more problem, then they would be more hurt.*

In the above narrative it can be seen that Bandana talked about people with mental disabilities in a very patronizing manner. Similarly, Dolly also felt bad seeing persons with mental disabilities around her. She said,

> *When I feel sad, I think about them* [people with mental disabilities]. *They have so many troubles. But when others say bad things about them, that you are handicapped, then I say so what if s/he is handicapped? They are humans, respect them. No matter how big a person is, if they say something to me, I do not feel much, but if they say it to them… Why will they say anything? You stand in his/her shoes and see how it feels. They are going through a lot of hardships to earn Rs. 2000. Tie one of your hands and see how it feels. Work hard and see how it feels. You are educated, but that does not mean that you can demean others. No one has that right. All are humans, all are born equal. This is what I think.*

Dolly further said that after meeting her colleagues at the organization, she has realized how hardworking they are. After that whenever she meets other persons with disabilities who are not working, she considers them to be lazy. She said,

> *I feel very sad whenever I see my colleagues. This is because I have seen the hard work that they do. Now when I see other handicapped people, even if they have their hands and legs and they do not want to work, I feel like saying you have hands and legs and still you do not want to work. You should come to our office and see. There is no point in being lazy.*

From the above narratives it can be seen that the disability organizations have provided these women with a much needed space where they can interact with other persons with disabilities and share their problems with them without being judged. Even though some of the women had never considered themselves to be disabled and felt very sorry initially about being placed in the same category as other persons with disabilities, over time they made really good friends from among these people, and gave them the status of family. In spite of this, some of these women did create a hierarchy between themselves and others with mental disabilities. While such attitudes are really unfortunate, but similar findings have also been reported in studies conducted elsewhere. Deal (2003) had found that one of the common responses that wheelchair users give about what they find annoying is that sometimes they might he thought of as someone with a learning disability. Based on a review of literature, Deal (2003) has shown that impairments are hierarchized not only by non-disabled people who have differential attitudes towards different impairment groups, but similar attitudes are also found among persons with disabilities. Similar observation was also noted by Shakespeare et al. (1996) in their study on disability, sex and gender, where one of the research participants explained about how a ‘pecking order’ was established at his ‘special school’ for boys, where boys with hemophilia were considered to be the most desirable because they were closest to being non-disabled, while boys with muscular dystrophy were considered to be the least desirable. According to Deal (2003), one of the reasons why persons with disabilities as members of a stigmatized group compare themselves with others who are perceived to be less fortunate is to enhance their own self-esteem. He argues that it is very important that persons with disabilities hold positive self-esteem so that they do not discriminate against other persons with impairments, who are perceived to be lower in the hierarchy of impairments, out of fear for social stigma. According to him, such action would further isolate the latter group creating an additional level of social oppression (Deal, 2003).

While women from all the other organizations got a chance to interact with other persons with disabilities, the same platform was not available to the women from HKCT, due to which they often felt very isolated. Korobi’s narrative brings this out clearly.

Korobi said that she felt isolated at home because there is no one she can talk to about her issues. She likes to go out and meet other people, but because of her disability, she faces accessibility issues that restrict her mobility outside her home. She said,

> *I like to go out and meet other people. Because of my impairment I am not able to go anywhere. It is very difficult to get a driver. Due to these reasons I mostly stay at home. But I like going out. I like eating out at restaurants. Whenever my Bhonti comes back home from Canada, she takes me out. But otherwise I stay at home most of the times. When I stay at home, I get very bad thoughts. I also get very bored.*

Korobi had met another person with disabilities in her childhood. Later in her life she has met other patients with burn injuries while recovering from her own injury at the hospital. She has always felt very sad seeing them suffer. Her narrative suggests that she has never got the chance to interact with another person with disabilities under ‘normal’ circumstances where she could talk about her everyday problems. In one of my interviews with her she said that a few years ago she had attended a function organized by the VRC where she sang a song that was written by her maternal grandfather. She said that she received a lot of applause from everyone in the audience and really enjoyed the whole experience. She also said that there should be more such functions in the future for ‘people like her’ so that they get the opportunity to have fun with others.

Even though on the surface it seemed as if most of the women who belonged to these organizations had a very cordial relationship with one another, a few interactions with them reveal that most of them had their own insecurities. For instance, during one of my interviews with a woman from Moromi (who has not been included in the study), she seemed desperate for some kind of financial assistance in order to support her young daughter and parents. She asked me to help her in whatever way possible. In my next visit I took a form of HKCT for her and explained to her how she can fill it and where she should submit it. Seeing this, the other employees of the organization came closer to ask if they can also fill up the form and from where they can get it. Jeuti, one of the participants that I had contacted through HKCT knew everything about the procedure, but she did not share this information with the others. Similarly, a few more women from Moromi knew about the financial assistance that they can get from HKCT but did not inform the others about it. This observation made it clear that in the absence of resources, persons with disabilities, like any other marginalized community, do not like to share information with others which they feel that it would jeopardize their chances of getting the much needed but scarce resources.

In another instance it was also found that the women had rivalry with others related to their work. This seemed very apparent in the case of Surabhi who has been working with Sanjeeboni for nearly 10-15 years. During my interactions with her it was found that Surabhi was not very happy with the organization and her fellow CBR workers and DPO members. According to her, even when she made minor mistakes at work, her colleagues made it seem like it was a big mistake and scolded her for it. She said most of these people had joined the organization after her, and they have all now ganged up against her.

> *I was working in the new project, but they have removed me from there. That is why I feel bad. I worry sometimes because of this. Am I that bad? Everyone makes mistakes like me. But they see my mistakes more than that of others. That is why I feel bad. The amount of work that I do, the others cannot do so much work. Wherever I go for my fieldwork, I do my work with dignity. Yes, I do make mistakes. Everyone makes mistakes. Everyone should be penalized then. But others are jealous of me. They see me with their evil eyes. That is why I feel sad. I am thinking of leaving this work. I have come here today to submit my documents. I have to get some money from them. If they want to give me, I will take it, or else I do not care. I have just told them even if they do not give me the money, I have no problem.*

Surabhi feels that her colleagues are jealous of her and that is why they have removed her from the project. It was also clear that she was unhappy that other people who had joined the organization after her were now in better positions and were respected by all the other colleagues. When I discussed her problems with some of the other research participants, they said that Surabhi is an attention seeker who did not do her job properly and due to this reason she has been removed from the new project. During my interview with Surabhi's elder sister, she had said that Surabhi gets angry very fast, even for minor issues. She said,

> *Surabhi's sister: She gets angry very fast. Sometimes we do not even realize what she is angry about it. In such situations only she knows what she will do.*
>
> *Surabhi: She is lying [she laughs].*
>
> *Surabhi's sister: When she is not angry, she is very good. Now she is very good. But when she gets angry, isss! If you tell her about some fault of hers, then she gets angry. Otherwise she is good. But you cannot tell her about her faults. Why have you done this? It would be bad if you do this. All this she does not understand.*
>
> *Surabhi: Why don't you tell her why I get angry? I had fever. Typhoid. Since that time I have this anger.*
>
> *Surabhi's sister:* [Ignores what she said]. *When she gets angry all of us at home, we remain quiet. When she gets angry, we do not have another option. We say you only keep talking. The rest of us remain quiet.*

From the above narrative it can be seen that Surabhi does not like being told that she is wrong in doing something. It can also be seen that Surabhi justifies her anger issues as a residue of her childhood illness, but her elder sister did not give much attention to her explanation. As I have mentioned in a previous chapter, Surabhi's sister remained unmarried so that she can take care of Surabhi as she knows that no one would be able to handle her anger issues. Surabhi's narrative shows that she expects similar kind of treatment from her colleagues. When they refused to do so, she accused them of being jealous of her.

This subsection has tried to show the experience of meeting other persons with disabilities for the first time in their lives through the help of the disability organizations. It is seen that while most of the women have developed a sense of solidarity with other persons with disabilities, there have been a few cases where it is seen that they are not interested in forming such networks. Therefore it is necessary that we do not essentialize the relationships between persons with disabilities as amicable and sweet, as there can be many layers that remain hidden from the surface.

Enhanced Reputation in the Family and the Community: As can be seen from the above discussion, contact with the organization brought about a qualitative change in the lives of the women. They became more confident and articulate about their lives than before, and this consequently had a profound influence in their reputation within their families and communities. The following narratives bring out this point clearly.

Minakkhi recalled that when she was young her relatives often made fun of her saying mean things that her hands would deter anyone from marrying her. With tears in her eyes, she said that such incidents left a deep impact on her mind to the extent that she had completely stopped talking to them as seeing them reminded her of the mean things that they had said. But all this has changed after she started working at the organization. She said that now all her neighbors praise her for the work that she is doing at the organization, and for getting the opportunities to travel to distant places through the organization.

> *Now my Bou* [sister-in-law] *and other women in the village, they say, you are very fortunate. Since you are like this you have been able to see so many places… I feel good when they say so. They say even after being bhaal we have not been able to see any of these places (She laughs).*

In the above narrative it can be seen that after Minakkhi joined the organization the people around her started seeing her through a different lens as she has been able to do many things unlike other people around her. Seeing them appreciate her achievements has boosted Minakkhi's self-confidence.

Lata also said that since the time she has started working for Sanjeeboni, there has been a tremendous change in the perception of the people of her neighborhood towards her. She said,

> *From the time I have started working here, the kind of people that I have met, they have only encouraged me. Earlier people never paid any attention to me. But now they listen to me. The people in my field area, most of them adore me very much. I also feel good about working here because of this reason. When I talk to people, I can win their hearts. I can make them interested.*

From the above narrative it can be seen that after working at the organization, Lata has earned a good reputation in her community, which in turn has boosted her self-confidence. This is important, because as shown in the previous chapters, Lata has grown up feeling isolated all her life because of her impairment.

Risha's physical difficulties have increased quite a lot after her fall that injured her spinal cord. After this even though she had to quit her job, she still continues to go to the organization for volunteering at the ICT centre. Even though her parents sometimes show concern towards her health and restrict her from going to the organization, for the most part they have been very supportive towards her because they realize that the school is the only source of social contact for her. Risha feels that seeing her struggle with her difficulties and yet not giving up on life, could be a source of inspiration for the young girls in her neighborhood who would also want to do something in their lives. Although an article in *Everyday Feminism* mentioned how disabled people are tired of hearing that they are inspirational to others for their minor feats because they find it condescending (Tatum, 2015), in this study it was found that there could be some persons with disabilities who might want to feel happy about their lives by thinking that they are an inspiration to others. This, therefore, necessitates that we do not categorize persons with disabilities as homogenous who would identify with a certain way of being.

It was also found that being a part of the organization and earning a livelihood has increased their worth in the eyes of other family members. Anamika said that after she joined the organization, her family members now include her in family discussions and value her opinions, which was not so earlier. She said that this could be because earlier she was young and had lived in a joint family with many adult members. After the separation of her family from her uncle's family she is now one of the adults, besides her father and step-mother, who is earning a livelihood and contributing substantially to her family. In addition to this, she is also very popular in the community because of her CBR work, and people from her village often ask her about *Panchayat* schemes which they may not be aware about. She said that all this has made her very proud of her achievements.

In the above narrative it can be seen that Anamika's life has changed drastically after she joined the organization for work. Through her experience with non-disabled people, she has also come to realize that people with disabilities are not as weak as people think them to be. She said that she makes it a point to go out for work every day except Sundays because she gets very bored by staying at home. She also said that other women cannot come out of their homes to work outside because they have to maintain their *xonxaar* (conjugal life) and do their household chores. On the other hand she does not have any such responsibilities and due to this reason, she is able to come out of her home, even though she has to cover a distance of 4 km on foot one way. She said,

> *Everyone tells me, you can walk so much! It takes about one or one and half hours to walk for 4 km. The bus stand is 4 km from my home. Every day in the morning I have to walk for 4 km and then go back 4 km. I walk every day. They say you can do it! You can walk so much, don't you feel tired? Even if I am tired I will have to walk. I tell them that instead of sitting idle it is better to do some work. It is not just about money, I also get an experience. If I come out of home I am able to learn and hear many new things. If I sit at home, I get bored. I cannot do this. The girls who are non-disabled or the women who are non-disabled, their biggest problem is laziness. They are very lazy. I am not lazy. If I have to come I will.*

According to her, she is not lazy like non-disabled women and that is why she is able to walk all the distance without getting tired. From her narrative it is clear that she wants to emulate what is called the *SuperCrip* image in disability studies literature, that is a person who does not have severe disabilities, and whose only problem in life is the physically inaccessible environment (Morris, 2001). Anamika's disability is comparatively milder than most of the other study participants, due to which she is able to walk as much as 8 km every day for her work. However, being in the field of disability service provision, and saying that she is able to walk all the distance because she is not lazy completely obliterates the struggles of women who have severe forms of disabilities that restrict their mobility and increases their dependence on other members of the family.

In other cases, however it has been found that neighbors have been jealous of the achievements made by persons with disabilities and their families and due to this reason they try their best to crush them. In the case of Nayana it was found that her neighbors were very jealous of her because of her association with Senehi. She said that when she was growing up, she lived in a neighborhood where people were jealous of the things that she had been able to achieve through her association with the organization. For instance, whenever she went for a singing competition and won a prize, her neighbors would pass nasty comments on her. They also felt jealous of her when she went out of the city to attend different competitions and workshops. Nayana’s parents were well aware of these reactions. While her mother felt worried about her, and father took such comments in a positive way and said that people are talking about her only because she is doing something that is worthy of being talked about. She said that during the time she lived there, she had a terrible time as the neighbors spread venom against her and her family.

In this subsection we have seen that association with the disability organization enhanced the reputation of the women within their families and the wider community. This is a very significant change because many of these women have grown up in an environment where they have considered themselves to be less fortunate than others. Through their association with the organization when they went out of the cocooned environment, travelled to far off faces and gain more knowledge about governmental provisions, etc. this led to a definitive improvement in their position in the community. In certain cases all such developments also resulted in jealousy. However, it is important to note that the positive changes have mostly occurred in the case of the women who were contacted through the help of Sanjeeboni, primarily due to the nature of the organization. Through the efforts of the special educators of CSE, Senehi and Kishore, the women who were contacted through Senehi and Moromi had a better self-image, but this was not necessarily followed by a change in the attitude of the society towards them. This is because they as such did not have to work at the level of the community like the CBR workers from Sanjeeboni. In contrast, contact with HKCT did not have any impact on the reputation of the women within their families, although they did feel financially secure for a short duration of time.

Expectations of the Women from the Organizations: The above sections have shown the different kinds of support that the women have received from the disability organizations. However, some of them had certain expectations from the organization which have not been fulfilled. This subsection elaborates on the kind of support that the women and their family members had expected from their disability organizations and in what way the organizations had failed them. In most cases the women had problems with the less pay that they received from the organization which is insufficient for their upkeep in the future.

Surabhi said that she is satisfied with whatever she has received from Sanjeeboni from her youth, but she feels that the organization must recognize her contribution and increase the travel allowance, as she can no longer travel in the limited allowance provided by them. At the time of the interview she was determined to quit working for the organization because of the low salary they paid her.

> *I will have to be concerned about my own life. My family members would not live with me forever. One day, they will move away. That is why for my own livelihood, I will have to find some work. I will have to find something* [with emphasis]. *I will have to complete my degree somehow. If I am not able to find any work, that would also remain incomplete. From where will I get money? After the results are declared, I will need more money for admissions. I need books. They will give books from the university, but what about pen and paper? I will have to do my practical. I will have difficulty. If I do not get a job, I will have so many difficulties.*

Surabhi’s narrative points towards the fact that even though the organization gives them a source of livelihood and the means to interact with other people with disabilities, the money that they receive from there is insufficient for them. As Surabhi said, that at the moment her family is supporting her financially, but this support may not be there forever, as all of them are individuals who may have their own needs in the future and feeding another person may not be possible. Lack of adequate educational qualification is another problem that makes it difficult for these women to look for an alternate source of livelihood. In order to fill this gap, Surabhi is trying to study from an Open University, but in the absence of adequate income, she finds it difficult to complete her education.

It is because of the lesser pay in such disability organizations that several women aspire to start their own businesses so that they would be able to stand on their own feet in the future. Dolly’s narrative brings this out clearly.

> *Now I am working here and getting some money, but I feel that if I can start my own business. Even if I start my own shop it would be good. I want to stand on my own feet. How long can I work like this? I cannot work long with such less money. I feel that to run a family I would need some money.*

From this narrative it can be seen that even though Dolly is very happy in Moromi she realizes that she will not be able to work there for a very long time. This is because of the less amount of money that she is paid which is insufficient for her to help her brother in running their household.

Similarly, Jeuti also talked about the low pay in the organization which is not even sufficient for her to survive. She said that she has been looking for a government job, but unfortunately due to her lack of educational qualification, she has not been able to find one.

In the case of some of the women from Senehi, as has been mentioned earlier, their social interaction is limited to the school. After turning 18 the students of the special school are no longer allowed to come to the organization. This leaves a big void in the lives of the women most of whom have nothing else to do in their homes. Ananya is one such student who terribly misses her time in the school. During the interview she said that she does not want to leave the school and wants some excuse to get back to the school routine.

> *I want to stay in the school. But they would not keep me here. Once the* [ICT] *class gets over they would not allow me here. When the class gets over, I will miss it badly. I cannot tell you how much I would miss the classes […] I want to continue my bond with the school. I do not want to break the bond. [She laughs].*

Ananya said that after leaving school she spent most of her time watching television as there is nothing else she can engage in at home. Due to her restricted mobility she cannot even go out with her friends and have to depend on her father who hardly has time for such activities. So one day when she got a call to be a part of the women with disabilities project she was more than happy to join. The project conducts meetings once a month, and she was very happy to meet the other women in the project, including her childhood best friend. In this project she also came to know about the ICT classes, that she insisted on joining. The classes were held twice in a week, and she waited the entire week for those two days. Ananya however realizes that these classes would get over one day and then she would have to again sit at home and do nothing.

Similarly, Risha also does not want her connection with Senehi to break off and expects some kind of job at the organization, so that she does not have to sit idle at home.

Other women expected money or other material things from the organizations. According to Gargi's mother, Sanbeejoni had paid Rs. 500-1000 to her every year in order to take care of Gargi's education. However, they have not given the money after she was promoted to class 9. Her mother said that they need the support especially now because she was in a higher class and needed home tuitions. She said that the money would have really helped them, but for some reason the organization had stopped paying that amount.

In the case of Korobi, who did not have any other source of livelihood, and depended on her mother for her and her family's upkeep, expected HKCT to pay her 50,000-1 lakh of rupees so that she can treat all her ailments at a time. Her family members did not take her seriously, and laughed at her when she made this proposition.

In the case of Uma, she felt that even though she has been attending the meetings organized by Sanjeeboni since a very long time, she has not received anything from them so far. On the day of the interview, she said that she would ask them for a sewing machine. She said that if she has a machine she will be able to work from home, and will not get bored in the afternoons when her husband and son go out for their work and school respectively.

The aim of this subsection was to reflect upon whether the disability organizations were able to fulfill the expectations of the research participants. It was found that the women expected different things from the organizations. All of these expectations are ultimately connected to the nature of their impairments, their social class and the support they receive from their families.

Conclusion

The aim of this chapter was to understand the kind of support women with locomotor have received from disability organizations. As has been noted earlier, understanding this aspect is very necessary given the lack of any form of state intervention to ameliorate the difficulties faced by the disabled community. The chapter was divided into three sections. The first section elaborated on the case studies of the three disability organizations, Sanjeeboni, Senehi and Helen Keller Charitable Trust. It was found that the three organizations have different ideologies and were set up by people having different backgrounds, due to which all of these organizations have very different visions about persons with disabilities. Sanjeeboni started off by providing only medical rehabilitation, but over time through the funding they received from CBRF, they were able to provide community based rehabilitation, which had brought about a definitive change in the self-perception of the persons with disabilities as well as the perception of the wider society towards them. Senehi also started off as a rehabilitation centre and special school for children with cerebral palsy, but with the changes in the policy context they have brought about significant changes in the structure of the organization. HKCT, on the other hand, is a more recent organization which has started off as a charitable institution to provide financial assistance to persons with disabilities and critically ill people from the poor sections of the society. It has the most regressive vision regarding persons with disabilities as beggars, unproductive and dependents on other family, who have no other option but to depend on the benevolence of the able-bodied society for survival. Although such kinds of narrow-minded thinking has been critiqued extensively in the British disability studies literature as well as some of the Indian disability studies literature, it has not had any effect on the society of Assam. While all the three organizations are very different in their outlook towards persons with disabilities, what is common among them is that they are all unsustainable as a source of support for persons with disabilities. None of these organizations were found to have stable funds to continue their work unhindered. While Sanjeeboni and Senehi depended on the donor agencies and CSR projects, HKCT depended on the general public for funds.

The second section in the paper elaborated on how the women came into contact with these organizations and the kind of support they have received from them. It was found that contact with the organization was a matter of luck, which is why such kind of support is problematic as it is not available for everyone to claim. Disability organizations have their own inclusion criteria and cater to needs of the people only within these narrow criteria. In spite of this problem, almost all of the research participants maintained that they have received considerable support from their disability organizations. The support ranged from help in making the disability certificates, availing aids and appliances and livelihood opportunities. It is worth mentioning that the narratives have shown how difficult it is to make the disability certificate without the support of the disability organization. Additionally, even though aids and appliances are distributed by the government in the rehabilitation centres, several research participants have reported that their quality is extremely poor, which is why they prefer getting the aids from the disability organizations. In terms of livelihood, even though the government provides for reservation in government jobs, none of the research participants were able to avail them either because of lack of qualification or due to corruption. These three examples clearly show that the benefits given by the government are extremely inadequate and more research must be done on this aspect. Persons with disabilities also reported getting personalized help from the founders or other members of the organizations, which again is a matter of luck and cannot be evaluated as a legitimate source of support.

In the third section, I tried to understand in what way the support that the women had received from the disability organizations had helped them. It was found that in most of the cases the contact with the organizations have helped them in indirect ways such as in gaining self-confidence and awareness in disability issues, developing self-image by meeting other persons with disabilities, which in turn have helped in enhancing their reputation in front of their immediate families and communities. In the last part of this section I had also elaborated on the unmet expectations of these women. It is important to note that most of these women are from poor socio-economic backgrounds. Due to this reason, even though they are very happy with whatever they have received from the organization, the poor pay in the organizations make them look for other better livelihood opportunities elsewhere.

In the absence of a disability movement in Assam, it is the disability organizations that attempt to cater to the felt needs of the women. However, most of the services are unidirectional and does not take into consideration the voices of the persons with disabilities. The concept of social capital is very apt in understanding this relationship. As defined by Coleman, social capital is defined as direct and indirect resources that are a result of social networks and social systems amongst family, friends or community members (cited in Hawkins & Maurer, 2009). The particular type of social capital in the context of the women and the disability organizations is *linking* *social capital*, that is, the extent to which individuals build relationships with institutions and individuals who have relative power over them (Woolcock, 2001, cited in Hawkins & Maurer, 2009). In spite of the benefits of social capital, its limitations are also necessary to understand, which is that it can and does exclude certain groups completely.

Chapter 9

Discussion and Conclusion

Persons with disabilities constitute about 15.6 to 19.4 percent of the global population (World Report on Disability, 2011). This figure is gradually increasing worldwide due to various factors such as wars, ethnic conflicts, HIV/AIDS, industrial injuries, road traffic accidents, population growth, medical advancement and increasing life expectancy that make people more susceptible to old age related, chronic illness induced disabilities (United Nations Enable: Development and Human Rights for All, n.d.; Addlakha, 2010). Additionally, due to demographic transition, the number of persons with disabilities who are surviving till old age has also significantly increased over the last few decades, which can be attributed to advances in medicine, rehabilitation, public health and technology. About 80 percent of this population has been estimated to live in the majority world countries (United Nations Enable, 2008). In spite of this, the discipline of disability studies has mostly concentrated on the experiences of persons with disabilities in the minority world context (Grech, 2009). On the other hand, the focus on the majority world has been considerably limited (Priestley, 2001; Barnes & Sheldon, 2005; Grech, 2009), which has resulted in the exportation/ importation of ideas from minority world to the majority world (Ibid). As a result of this *scholarly colonialism* (Meekosha, 2008) and *cultural arrogance* of European and North American disability scholars (Ingstad & Eide, 2011), the influence of the heterogeneity of contexts in the majority world countries on the lived experiences of persons with disabilities largely remain unacknowledged (Grech, 2009). Majority world theorists have also critiqued minority world theorists for ignoring the specificities of colonialism and the effects of globalization on the lives of persons with disabilities (Meekosha, 2008). This research has used this framework to understand the lived experiences of women ageing with locomotor disabilities acquired early in life (below 20 years) in the Kamrup Metropolitan District of Assam. The context of Assam is intriguing given its unique socio-political history from pre-colonial period to the present period as has been shown in Chapter 3. In the last quarter of the 20th century especially, Assam has witnessed numerous instances of insurgencies, ethnic movements and unchecked foreign infiltrations which have further hampered the economic development of the state (see Chapter 3). Research in other similar contexts has shown that poor people and persons with disabilities usually suffer the most in such instances of socio-political instability (Muderedzi & Ingstad, 2011; Muyinda & Whyte, 2011; Taksdal, 2011). In Assam, however, much less is known about the lived experiences of persons with disabilities. The present study has been an attempt at fulfilling this gap.

As stated above, the study was conducted in the district of Kamrup Metropolitan, which is one of the 33 districts in Assam. It was carved out in the year 2003 out of the erstwhile Kamrup district. In the predominantly rural state of Assam, this district is an exception as out of the total population of 1.2 million, an overwhelming majority of 1 million individuals reside in the urban areas of the district. Available statistics show that out of the total population of persons with disabilities in India, a vast majority reside in the rural areas under extremely poor conditions with little access to services (Klasing, 2007). It was felt that the rural-urban differentials of the district would give a unique picture of the experience of disablement of women with disabilities. In addition to this, the presence of several established disability organizations made it easier to recruit the participants for the study.

The study was conducted among 18 women with different locomotor disabilities in the age group of 18-57 years. These women were contacted with the help of four disability organizations, three of which are working in the city of Guwahati, while the fourth is working in the Joonaki (a pseudonym) Block in the vicinity of Guwahati. The main inclusion criteria for the study were the occurrence of locomotor disability below the age of 18 years, and their ability and willingness to talk at length about their lived experiences. Since most of the disability organizations cater to poorer sections of the society, a majority of the study participants also belong to poorer families with a hand-to-mouth existence. Life history interviews were conducted as the primary tool for data collection. Apart from the 18 women, wherever it was possible in-depth interviews were conducted with their family members, especially mothers and their sisters, to have a better understanding of the women’s lived experiences. In-depth interviews were also conducted with the members of the disability organizations in order to understand their ideology and the kind of services they provide to persons with disabilities. Lastly, a few short interviews were also conducted with Orthopedics, Physiotherapists and doctors from the Medicine department to have a general understanding about the kind of treatment that is provided to persons with locomotor disabilities. In total, I have spent approximately 15 months in the field.

The broad objectives of the study are to understand the lived experiences of women ageing with locomotor disabilities acquired early in life. The specific objectives are to understand the subjective explanations of the occurrence of impairments among the women; their sources of social support; their corporeal experiences of living with disabilities; the influence of significant life events on their mental being; and the intersection of disability with other forms of identity. The major findings of the study have been elaborated from Chapters 4-8. Although the chapters have used the overarching framework of the majority world perspective on disability, each of the data chapters have used a different framework to understand the micro details about the lived experiences of the women more deeply. In Chapter 3 I have elaborated on the socio-political context of Assam in order to have a better understanding of the lives of the study participants.

The present chapter discusses the major findings of the study in the light of the existing literature on disability studies. The chapter concludes by elaborating on the contributions made by the study in the interdisciplinary field of feminist disability studies. It also provides a commentary on the limitations of the current policy framework and the directions for future research.

Subjective Explanation of Disability: Understanding the Oft-Repeated Refrain about Kopaal and Bhagyo

One of the major points of tussle between medical sociologists and disability scholars is the way disability has been conceptualized in both the disciplines. As noted in Chapter 1, medical sociologists have primarily tried to understand the experience of chronic illness from the perspective of the individual and have negated the influence of the larger social structure in which chronic illness takes place (Pierret, 2003). This approach has been critiqued by disability scholars for individualizing the experience of disability by emphasizing that ‘disability’ is primarily caused by ‘impairment’ while ignoring the social and cultural factors completely (Thomas, 2004c). In contrast, disability studies provides a structural analysis of disability based on the notion that persons with disabilities are an oppressed group (Shakespeare & Watson, 1996). Medical sociologists have critiqued this perspective for severing any connection between impairment and disability (Thomas, 2004c).

In this study, one of the major objectives was to understand the women's subjective explanations about the occurrence of their impairments. Chapter 4 has elaborated on their experiences by using both the approaches noted above. It tried to understand the individual perspective of the research participants along with the broader structural context within which disabilities these disabilities were created and sustained. The chapter identified four different themes based on the narratives of 11 study participants. It was found that the women made sense of their impairments depending upon a multiplicity of intersecting factors. One of the major findings of the chapter was that the women with congenital impairments and their families did not receive any information about the cause of their impairments from the health services system. Due to this reason, they developed their own reasons about causation that correspond with cosmological factors. In contrast, those women who had received proper medical explanations about the cause of their impairments were found to be better adjusted to their impairments. The study also found that in certain cases disability, poverty and ill-health form a vicious cycle that was not easy to break. Finally, in certain cases the women blamed their doctors for providing them wrong treatment that they perceived was the cause of their impairment. While these were all individual explanations of the women, they provide valuable insights about the broader socio-political context of the society in which these women were brought up. As noted in Chapter 3, from the time of independence, Assam has suffered from numerous ethnic movements for reorganization of state and recognition of Assamese language as the official state language vis-à-vis other ethnic languages. These movements reached its climax with the six years long Assam Movement from 1979-1985, which took an insurgent character towards the latter half of the 1980s. This movement, along with the insurgency outfit, ULFA, became the model that was later emulated by other ethnic communities of the state to demand for their rights. Although the situation is considerably under control at the moment, there are still sporadic outbursts of violence in different locations of the state even to this day. Within such a context it is not difficult to imagine the setbacks that the health services would face, even though such studies have not been conducted in the context of Assam. Due to these factors, it was found that the concepts of '*social suffering*' and '*structural violence*' were relevant for this study. Social suffering is defined as *'collective and individual human suffering associated with life conditions shaped by powerful social forces'* (Benatar, 1997: 1634, cited in Muderedzi & Ingstad, 2011). On the other hand, structural violence is the negative impact of social structures that are beyond the control of individuals and groups (Muderedzi & Ingstad, 2011). These two concepts are important in the study of disability because they take politics to the level of the individual as well as the household (Muderedzi & Ingstad, 2011).

It is important to note that none of the research participants or their family members have reported being directly affected by the conflict situation of Assam, although from the narratives one could understand that all of them have been affected in one way or another indirectly. Besides, most of the research participants of this study were Assamese-speaking, due to which they were not affected by the clashes. However, among the study participants, Anamika (Nepali) and Sobiha (Bengali Muslim) were the only two women who belonged to communities that were being persecuted during the Assam Movement. Neither of the women or their family members (in the case of Sobiha) talked about the problems they had faced due to their ethnic identities. Anamika had mentioned that her parents were scared of the city people, which is why they did not take her back to the hospital for treatment or to confront the doctor who had severed her nerve. According to Anamika, this was due to the lack of awareness of her parents and their general fear of the city people. She did not mention that this fear was due to their ethnic identity. Perhaps I would have got a clearer understanding of the situation if I had conducted an interview with her father, but unfortunately I could not schedule a meeting with him. In the case of Sobiha, it was found that by the time she was born in the late 1990s, the situation had relatively calmed down. As a result of this, neither she nor her family members faced harassment at the hands of the majority community, although in their narratives they did mention about being harassed by people from their own community for educating her daughters, especially Sobiha's younger sister. Sobiha and her family received great amount of support from Suchismita and her husband from the time of her childhood, and this could be one of the major reasons that she never faced any drastic situations in her life. It was only in the case of Korobi's mother who had stated that they had witnessed the Assam

Movement and the ensuing violence at the time of Korobi's burn injury but they were not affected by it because her father was in the police force and they were able to traverse smoothly from Guwahati to Dibrugarh, a distance of 439 km, without any difficulties due to this reason. She mentioned that she does not know if another family who did not have such connections would have been able to travel without any difficulties in a similar situation. Thus, belonging to a particular ethnic community as well as their social class enabled few families to access healthcare unhindered which may not be so for other people belonging to other ethnic communities, especially those who have been systematically othered by the system. Perhaps a more focused study on ethnic identities of persons with disabilities and the vulnerabilities they face within a chauvinist majoritarian Assamese society would yield better insights upon this aspect.

Another major finding of the study was that accessibility to healthcare was particularly limited for the study participants either due to lack of awareness of the parents, the physical distance to the health facility, or due to certain unavoidable circumstances in the family. In many cases it was found that the delay in healthcare seeking had a definitive impact on the health conditions of the women. As a result of such helplessness, the research participants and their family members often used the refrains of *kopaal* (fate) and *bhagyo* (destiny) to be responsible for their impairments and for all the other adversities they have faced in their lives. As has been elaborated in Chapter 1, in the Indian context, the religious/ moral model is one of the most widely used models to understand disability. Within this model disability is considered to be the divine retribution for past sins committed either by the individual or his/ her ancestors. Thus persons with disabilities are considered to be suffering from the wrath of God (Ghosh, 2012). Another related explanation within this model is that disability is part of God's plan which must be respected. The major motive of this plan is to test the resilience and inner strength of a person (Dalal, 2002). Therefore, both the explanations about disability within the religious model are at two different ends of the spectrum, but the major similarity between them is that nothing is done to ameliorate the suffering of the person with disabilities (Dalal, 2002; Mehrotra, 2013). In the current study, it was only Minakkhi's mother who considered her daughter's impairment to be a result of her *beya kormo* (bad karma). She considered herself to be responsible for her daughter's impairment, one of the primary reasons for which was that she never received a medical explanation about Minakkhi's condition. Apart from her, all the other research participants considered their impairments to be something written in their *kopaal* (fate) or *bhagyo* (destiny), which eased their process of accepting the impairment as a part of *Bhogoban'or Issa* (God's plan), which would have happened no matter what they had done to prevent it. This way of making sense about their impairments eased the process of adjustment (Pakenham, 2008) to their life circumstances.

Such beliefs about the causal factors might give the wrong impression that persons with disabilities and their family members in the context of Assam are 'irrational' and 'passive', but this would be to completely negate the social context within which persons with disabilities live. From the narratives above one can see that the primary causes of impairments of the women include poverty, lack of accessibility to healthcare facilities, and lack of support from the government. As a result of these unfavorable circumstances, the attempts of curing the disability or ameliorating their sufferings prove to be useless. Due to these factors people learn to accept the impairments in a spirit of resignation (Dalal, 2002). In contrast, to the other research participants, the ones who had received a medical explanation for their conditions were much at ease about their life circumstances. Such instances, therefore, show that the binary distinction between impairment and disability as espoused by the social model of disability does not hold any relevance in the majority world settings where healthcare needs are out of reach for a vast section of the population.

Social Support: Importance of Family and Disability Organizations

The second objective of the study was to understand the social support available for women with locomotor disabilities. This aspect was considered to be important given the lack of state support for persons with disabilities in the majority world setting and the general stigma, disdain and apathy that this community suffers from at the hands of the society. In the course of the study, it was found that two of the major sources of support for persons with disabilities in the study area were the (natal) *family* of the women and the *disability organizations* with which they are / were associated. Let us now look at each of these forms of support in detail.

Support from the Family: In disability studies literature from the minority world, the importance of family support across the life course of persons with disabilities has not been much emphasized. One of the reasons for this could be the preponderance of individualism and the virtues of independence in this context (Brisenden, 1986; Morris, 1995). Such values, however, are in sharp contrast to the collectivistic values that are predominant in the majority world context. Family is one of the major sources of support for people with disabilities in this context (see Dalal, 2002; Ingstad, Baider & Grut, 2011; Grut, Olenja & Ingstad, 2011; Muderedzi & Ignstad, 2011; Muyinda & Whyte, 2011; Taksdal, 2011). In fact, in many cases the very survival of persons with disabilities is dependent on the support they receive from their families (Grech, 2009). Due to this reason, majority world theorists have questioned the universal application of the social model in social and cultural contexts which are not premised on western values and norms of individualism and autonomy (Sheldon, 2005; Grech, 2009).

In India, traditionally, all children, regardless of their impairments, are taken care of by the family. Usually, they were considered to be dependent, immature and incapable of making their own decisions (Dalal, 2002). In such a context, the family has played a major role in the rehabilitation of persons with disabilities, even though the general attitudes of the family members towards them was paternalistic and were not taken seriously. In addition to the love, care and support of the family members, the economic and caste status of the family and their social networks also played a major role in the well-being of persons with disabilities (Dalal, 2002). With the gradual breakup of the joint family system and rising individualism among people from the younger generation has resulted in increased vulnerabilities for persons with disabilities, as well as other vulnerable members in the family such as widows and elderly men and women (Vatuk, 1995; Lamb, 2000; Khan & Handa, 2006; Mathur, 2006; Raju, 2011).

In this study, the family support for women with disabilities has been elaborated in Chapter 5. It has been shown that the women had received considerable support from their families throughout their life-course. The chapter begins with the initial reaction of the parents towards their daughter’s disabilities. It was found that the initial reaction of the parents of the study participants was not that of grief as has been shown by existing literature on the family's initial reaction towards children with developmental disabilities (Chakravarty, 2002; Barbosa, Chaud & Gomes, 2008; Dhar, 2009). Instead, the parents were able to easily accept their daughters' impairments due to a number of factors even though they did lament their own and their daughters' *beya kopaal* (bad fate) and *beya bhaygo* (bad destiny). This is an encouraging finding that suggests that children with disabilities do not always face discrimination within the family or treated as unwanted by their families as shown in some other studies (Mehrotra, 2004; 2013). This finding is particularly important because certain minority world theorists have suggested that persons with disabilities are hidden away by their families in the majority world out of shame and embarrassment (Stone-Macdonald, 2012), although such a claim has been refuted by majority world theorists (Ingstad, Baider & Grut, 2011; Grut Olenja & Ingstad, 2011; Muderedzi & Ingstad, 2011). The findings of this study also indicate that persons with disabilities have not been hidden away by their families.

In the literature, another theme that is very prominent is the rigid gendered division of labor in the family, whereby mothers have to take the entire responsibility of caring for their disabled child, while fathers usually remain distant from the mother-child dyad (Chakravarti, 2002; 2012; Mehrotra, 2004; 2006; Vaidya, 2010; 2015; Ghosh, 2016). In the current study also it was found that the mothers were overburdened with care work as well as domestic work, which was very trying and unrewarding at the same time. In such matters social class helped sometimes, as it enabled well-off families to hire cheaply available live-in domestic workers, who could somewhat ease the burden on the mother. For poorer families, however, there was no respite for the mother as they had to do all the work by themselves, including sometimes earning a livelihood. It was also found that many of the research participants and their mothers talked very fondly about the care that their fathers had provided for them in their childhood. However, it is very difficult to comment upon this, as most of them had lost their fathers in their childhood, and we as a society tend to avoid talking ill about a person who is no more. When one looks closely at their narratives, however, it can be seen that the women and their mothers have imbibed the prevalent gender ideology whereby even the minutest care work done by their fathers is praised because such work is not expected of them. What is even more worrisome is that the disability organizations have also imbibed such an ideology whereby they only provide the home-based training to the mothers of the disabled children and not to their fathers. While this is done keeping in mind the work schedule of the fathers, there is no acknowledgement on the part of the organizations that by doing this, they are ultimately distancing the child from his/ her father, both physically as well as emotionally.

The study also found that some of the women were resentful of their fathers as they did not fulfill the responsibilities of the breadwinner of the family. For instance, it was found that even though Jeuti praised her father for taking care of her pain and other difficulties in her childhood, she resented him for his alcoholism and for being inconsiderate towards the needs of his wife and children. As shown in Chapter 5, it was her mother who fulfilled the responsibilities of a breadwinner, even when her father was alive. Similarly, Hema also appreciated her father for arranging for her treatment in the initial years of her physical suffering. However, over time she found that her father has sided with her brother and sister-in-law who have been scheming to throw her and her mother out of the house. Due to this reason, she expressed her resentment towards her father, again for not fulfilling his duties as the head of the household by protecting her against her harassers.

The study has also found that family is the only major source of support for the women as there is no other institution outside of the family which could take care of them. This has been shown with the help of Sobiha’s narrative that her mother was so overburdened by her caring responsibilities as well as the responsibility of earning a livelihood for the family, that she considered leaving Sobiha at a residential institution for children with disabilities. However, the condition of the institution was so poor that she could not leave her daughter at the institution. Her narrative shows the urgent need for better-equipped residential institutions for children with disabilities from the poorer households, so that the parents of such children can get some respite. The literature on disability studies in the minority world context have advocated the right of persons with disabilities to remain in the community (Hunt, 1966; Brisenden, 1986; Morris, 1995). In countries such as India, there is evidence that sometimes poor parents have to leave their severely disabled children alone in their homes when they go out for work. Such instances also increase the dangers of sexual abuse of children with disabilities (Ghosh & Banerjee, 2017). In order to avoid such extreme situations, residential institutions for persons with disabilities must be given due importance to ease out the burden on the parents.

These findings from the study have also illustrated the importance of support from extended family members in order to help the parents, especially the mothers, to look after their disabled children. It was found that among the middle class families that were settled in Guwahati, the mothers received considerable support from their extended family members. However, there was still a difference between the support they received from their natal families vis-à-vis their affinal family. Suchismita's mother talked about the support she had received from her own mother in looking after her daughter during the first three months after Suchismita fell sick. During that period she did not have to think about anything and could concentrate on taking care of her daughter. In contrast, when Korobi was taken for treatment to Calcutta by her father and *Aita*, her mother was so worried that she could hardly talk. Instead of allowing her to rest, her husband's family asked her to cook during that period thinking that this would be a cathartic exercise for her. Such instances clearly reflect the differential treatment that is meted out to daughters and daughters-in-law in Assamese society, which sadly continues up to this day (Bhattacharyya, 2009). In the case of families who had only recently shifted to Guwahati, it was found that parents had no one else but each other for support. In other cases it was found that only the mother's relatives provided support, while no such support was forthcoming from the father's family. In contrast to the urban areas, it was found that in the rural areas since all the brothers lived contiguously to one another after marriage; a lot of people were available to look after the disabled child. Even in such cases it was found that it was usually the mothers who were their primary caregivers. It is only in cases where the father was the head of the household that other members of the family provided the mother and child with support. In the absence of the mother, or when the mother is busy with other activities, in such cases other female relatives such as grandmothers take up the responsibility of the child. In the case of Anamika who had lost her mother at a very early age, it was found that her aged Burhi Aita (great grandmother) looked after her and her younger sister, while her father whiled away his time drinking with his companions. Due to this reason, Anamika and her sister had to learn to do domestic and agricultural chores from a very early age. In the case of Lata, since she was her Aita's only grandchild, Lata was partially brought up by her. These findings corroborate with Mehrotra (2013) had said that it is usually women from the extended family who replace one another in taking care of the disabled child.

In their childhood, the women with disabilities did not usually experience any difference between themselves and their nondisabled siblings. This was because much like their siblings, the women with mild to moderate disabilities were brought up in a way to make them capable of their adult roles as wives and mothers. On the other hand, not much emphasis was given to their education. This lack of emphasis on education was not found to be peculiar only in the case of women with disabilities, as it was found to be true even in the cases of their siblings of both genders. Unfortunately, unlike their nondisabled siblings, most of the women with disabilities did not find marriage partners. As a result of this, women with disabilities find themselves to be 'roleless' in their natal families in their adulthood. Due to their lack of educational qualification, the women also fail to get employed in better paying jobs. These women, therefore, are brought up to be dependent on their natal families throughout their lives, or their husbands, in case they manage to find a marriage partner. In most cases, till the parents are alive the women felt secured about their futures. However, many of them were concerned about their futures because they were not sure if their siblings and their spouses would look after them after their parents have passed on. During the interviews with the women it came out clearly, that the women without brothers would have to look after themselves anyhow. On the other hand, the women who had brothers could still depend on them. However, with the growing nuclearization of families and emphasis on values of individualism, the women were scared that their brothers, their spouses and children may find it burdensome to care for them in the future. Additionally, even though legally women are now eligible to property rights, they often find it shameful to ask for it. If parents are giving a share of their property to their daughters, women are made to feel privileged about it, and not that they are eligible for it in any case.

Women's lifelong dependence on their families makes it clear that the occurrence of disability in the household affects all other members of the family. Due to this reason, the concept of *'disabled household'* (Ingstad, 1997 cited in Ingstad, Baider & Grut, 2011) is very useful to explain the situation of the family. It means that when there is an impaired individual in the family, the entire family has to reorganize their resources in order to accommodate the needs of the impaired person. This further means that it is the family that becomes disabled, due to which rehabilitation of person with disabilities should also take into consideration the needs of the family unit (Ingstad, Baider & Grut, 2011). Thus suggests that when poor ‘disabled families’ in the majority world context do not provide the opportunities to their disabled family member, it is not necessarily because they do not want to, but usually because they are not able to or they do not have the required information and options to support their children (Ibid). It is because of such reasons that the social model of disability with its emphasis only on the individual with disabilities is incompatible with the lived realities of persons with disabilities in the majority world. Unfortunately, the policy framework in India is also much influenced by the western discourse on disability rights, and do not take into consideration the context-specific realities of those living with disabilities.

Support from Disability Organizations: Apart from the family, another important source of support for the women is the disability organizations. In Chapter 8 I have elaborated about the support that the women have received from the disability organizations that they are/ were associated with. In disability studies literature disability organizations have been heralded as the ultimate voice for persons with disabilities (Finkelstein, 1991). However, disability scholars have distinguished between organizations *for* persons with disabilities and organizations *of* persons with disabilities. In the former, organizations are generally run by nondisabled persons, while in the latter, the organizations are run by persons with disabled (Barnes & Oliver, 1993; Finkelstein, 2007). According to them, it is only the organizations *of* persons with disabilities that deal with the real struggles of persons with disabilities (Ibid). In the context of the study it has been found that such a distinction between organizations is untenable, due to which what we have are organizations *for* persons with disabilities. This was found to be true even when the people who are sitting at the helm of affairs of the organizations are someone with disabilities. There are several reasons why this is so. First, there is very little awareness among persons with disabilities in Assam that the problems that they are facing are not individual issues, but are issues that the entire community of persons with disabilities experience. Due to this lack of awareness, there is no urgency among persons with disabilities to come together and form an organization to fight for their rights. As a result of this, organizations *for* persons with disabilities have occupied this space, and they provide services in a top-down approach rather than a bottom-up approach. Grech (2009) has also commented on the issue of representation in disability organizations of the majority world context. According to him, the large organizations in the urban areas may not be in touch with the poor persons with disabilities who rarely get the opportunity to participate due to basic constraints such as inability to afford transportation and to attend meetings, power relationships within the organization and little, if any, contact with other persons with disabilities. Additionally, disability organizations may have imbibed some of the slogans of the disability movements of the west, in order to keep ensure that the money keeps on flowing from the North to the South, even though this process may itself have many implicit hierarchies (Grech, 2009). Some of the other reasons why it is difficult to mobilize persons with disabilities are due to differences in the nature and severity of impairments, as well as the other differences among persons with disabilities like that of caste, class, gender, ethnicity and so on. Due to such differences, to expect a person with disabilities to work for the community of persons with disabilities would be farfetched as s/he might not find any commonalities between his/ her own experiences and the experiences of other persons with disabilities.

In the case of this study, Suchismita's life course has been considerably different from the life course of all other research participants, primarily because she is from an affluent family that had the means to overcome all the hurdles that came on her way to achieve what she is today. Unlike her, most of the other participants did not even have the bare minimum for survival. It is primarily due to this deprivation among persons with disabilities in the rural areas that made Suchismita work for them. However, in the process her work got dominated by the demands of the donor agencies that fund her organization, Sanjeeboni. As has been noted in Chapter 8, the donor agencies fund the organization only for a stipulated period of time after which the organization, along with the persons with disabilities within its jurisdiction, are expected to fend for themselves. At the time of the interview, Sanjeeboni was actively applying for other projects under CSR schemes of different companies.

Apart from Sanjeeboni, the other organizations have also started to depend on CSR projects of companies for funds in order to initiate different projects for persons with disabilities. During my interview with Rekha, the special educator at Senehi, it was made clear that these organizations cannot depend on the government funds because it gives priority to newer organizations. As a result older disability organizations are left with no other options but to depend on CSR projects. In the case of Helen Keller Charitable Trust, however, it was found that the organization is not eligible for applying for funds under the CSR projects. Due to this, they depend on the general public for the funds. All such activities ultimately show that the power does not lie in the hands of persons with disabilities but in the hands of either the organization founders and/ or their funding agencies to find out what is it that persons with disabilities require. As the narratives have shown, the women with disabilities have gained certain invaluable forms of support from the organization. These include making the disability certificate and getting access to aids and appliances. These are important because persons with disabilities and their families usually find it difficult to make their disability certificates without the support of an organization, and the organizations also have access to better quality aids and appliances than the ones provided by the government rehabilitation centres. It was also found that a few of the women got employed at the organizations. In a few cases the women have also received certain favors from the organization founders. Contact with the organizations, therefore, is a form of *social capital* for the women as it helped them in getting a number of benefits that others without this support were not able to get. All such forms of support have helped the women in a number of ways. This includes improvement in their self-image and becoming more aware about disability issues. The organization also provided the women with the opportunity to meet other persons with disabilities for the first time in their lives which enabled them to understand about the problems that persons with disabilities as a group experience. Association with the organizations also enhanced the reputation of the women within their own families and communities. However, in spite of all these opportunities, unfortunately the organizations have not been able to satisfy the felt needs of the women which is to find a better paying job so that they will be able to take care of themselves and their families. Since their needs were not met at the organization, most of them were always on the lookout for newer opportunities elsewhere. These organizations, therefore, do not qualify as organizations *of* persons with disabilities, as persons with disabilities from these organizations hardly have the say to point towards the things that they require. The study also found that the support received from the organizations is not sustainable in the long run. Furthermore the organizations do not encourage universal claims for the services they provide. Due to these reasons it is necessary that instead of the organizations, the state must provide for the felt needs of persons with disabilities.

Corporeal Experience of Impairment and the Response from the Health Services System

The third objective of this study was to understand the women's corporeal experiences of living with disabilities. This was considered to be important because in disability studies literature, medicalization of disability has been criticized for giving undue emphasis on clinical diagnosis. Several disability scholars have argued that this approach not only determines the kind of treatment that is suitable for persons with disabilities, but also the form of life that they are supposed to lead (Brisenden, 1986). Oliver (1990a), who had developed the social model of disability, argues that disability is a social state and not a medical condition, due to which, medical intervention and control over disability is incongruous. While he does not deny the role that doctors play in the lives of persons with disabilities, he argues that it is absolutely wrong when doctors use their medical knowledge and skills to treat disability rather than illness, which, for him, are two different things (Ibid). Such a conceptual distinction between disability and chronic illness has been critiqued by feminist disability scholars such as Wendell (1996; 2001) and Wolfe (2002) for concentrating only on the 'healthy' disabled at the expense of others who are 'unhealthy' disabled. Majority world theorists have also critiqued disability scholars for promoting a universal discourse about disability and impairment, which is contextually and culturally inappropriate in the majority world setting. Grech (2009) has argued that even though the social model has been critiqued for not taking into account the experiences of functional limitations and pain, such issues have rarely been debated across cultures. In countries of the majority world, the distinction between impairment and disability is difficult to maintain. This is because healthy body is a necessary concern here as poor livelihoods and even survival depends on whether or not someone can engage in hard physical labor. Additionally, as noted above people with disabilities in the majority world countries do not have access to health and social protection systems. Due to these reasons Grech (2009) has argued that it is imperative that we engage with the body in the majority world context.

In the present study, I had discussed the study participants' corporeal experiences in Chapter 6. It was found that the parents of women with disabilities seek cure from all possible avenues in order to normalize their daughters' physical conditions. This includes seeking both biomedical treatment as well as treatment from folk healers and spiritual gurus. This was found to be true in the context of the women in both rural and urban areas of the district. It was also found that the parents of women with disabilities from the urban areas continued their treatment for a considerable amount of time. This is in sharp contrast to the experiences of the women from the rural areas who had to discontinue their treatment due to lack of accessibility to healthcare and rehabilitation services in their vicinity at the time when they were growing up. One point that needs to be mentioned here is that most of the study participants from the rural areas had comparatively milder forms of disabilities, except Gargi, whose mother did talk about visiting doctors for a considerably longer period of time. This difference is an indication that the place of residence (whether rural or urban) played a big role in seeking healthcare in the 1970s and 80s when the women were growing up. Unfortunately, the situation in the district has not changed much even today as people from the rural areas still prefer to seek treatment from the tertiary centre directly which is about 40 km away from the Block. Another important finding of the study is that some of the women never received proper prognosis for their condition from their doctors. Gradually they left seeking treatment out of frustration, and sometimes also out of the realization that the treatment was causing them more harm than good. The promise for cure was also found to be psychologically debilitating for some of the women (Barnes, 2003). Due to these reasons it is necessary that instead of focusing on curing for the condition, efforts must be made to explain about the health condition and to provide appropriate counseling and physical rehabilitation services to persons with disabilities and their family members.

In this chapter I have also elaborated on the secondary conditions of the women. It was found that the women suffered from a number of health conditions that were related to their primary conditions. This includes seizures, experiences of pain either directly from the impairment, or due to using aids and appliances for long; pressure sores and phantom limb pain. In spite of these experiences, it was found that the women were hesitant about visiting a doctor out of fear, due to their past experiences. In certain cases it was also found that the women suffered from health conditions that were associated with their occupations, while others experienced body ache due to inaccessible barriers. This suggests that there are considerable overlaps between the physical reality of the bodies of persons with disabilities and the infrastructural barriers present in the society that create unique hurdles for them. Due to the multifaceted nature of health problems that persons with disabilities experience, it is important that along with demands for addressing the accessibility to the built environment, disability studies literature should also addresses health issues and lack of access to healthcare that persons with disabilities in the majority world experience.

Finally the chapter also discussed the other health problems faced by the study participants that were not directly associated with their impairments. These included general physical health conditions, mental health conditions and dental health conditions. It was found that throughout much of their younger lives most of the women considered themselves to be relatively healthy. It was only towards their late adulthood and middle age that the women began to face different kinds of health issues that made them worry about their deteriorating health. Among the study participants, it was only Korobi, who suffered from a multitude of health problems and probably due to this reason she showed much eagerness in talking about her health problems explicitly. Her narrative shows us clearly that disability studies must look beyond the ‘healthy’ disabled to include those people who are ‘unhealthy’ and require cure for their conditions.

The chapter has also shown that mental health issues are not given much priority by either the women themselves or by the families and disability organizations. It is important to understand that mental health issues in general are also a stigmatized topic in the context of India, due to which many people do not wish to acknowledge it in the first place. This was seen to be true in the case of Nayana. Therefore, it is necessary that taboo against mental health is broken so that people are able to seek healthcare for such conditions more openly. It is also important to note that the women who had taken psychiatric drugs for their mental health issues (Nayana and Korobi), started facing other physical problems such as weakness and incontinence. While such drugs may also be problematic for nondisabled women, for women with disabilities, who need to depend on others for their care, it increases their difficulties manifold. As a result of such problems, both the women stopped taking the medicines eventually. During the interview, both the women had talked about aggravation of their physical conditions due to this reason. Hence, it is very necessary that doctors must share the possibility of side effects with their patients.

The study also found that dental health was much compromised among the majority of the study participants. It was found that they only visit a dentist if their toothache becomes unbearable. In cases where they have had to extract their teeth, it was found that the women had not replaced them with caps, even the front teeth. This is an important finding because such behavior was typical only among women with disabilities. In contrast, nondisabled women in the age group of 18-40 years would not be found without their front teeth. The primary reason for this could be that women with disabilities are considered to be unattractive to men, because of which they were not encouraged by their families to wear the caps after the extraction of their teeth, as the procedure would be much expensive.

The above discussion clearly indicates that negating the issue of medical needs of persons with disabilities in the majority world context for taking forward the demands of the disability movement can be extremely dangerous. Additionally, due to lack of focus on disability issues and the inaccessibility of the built environment, functional limitations pose a greater threat for the survival of persons with disabilities in these countries (Grech, 2009). Due to these reasons, it is mandatory that disability scholars must engage with the health services system in the majority world context, and in fact, demand for better health services for all, so that no one, regardless of their impairments are deprived of appropriate healthcare.

Psycho-Emotional Dimensions of Disability

The fourth objective of the study was to understand the influence of significant life events on the mental wellbeing of the women. This was considered to be important because one of the major critiques of disability studies by feminist disability scholars is that it does not provide the space to persons with disabilities to talk about their personal experiences (Morris, 2001; Miceli, 2010). According to Finkelstein (2001b), such an approach is nothing but to accept the nondisabled view of disability that having a disability is akin to a personal tragedy. Feminist disability scholars such as Morris (2001) and Thomas (2004a), however, disagree with such a viewpoint to argue that if persons with disabilities do not discuss about their personal issues then it would negate key dimensions of their experience. Keeping this viewpoint into consideration, Thomas (2004a; 2004b) had introduced the concept of *psycho-emotional dimensions of disability* to understand the experiences that persons with disabilities have to endure on the 'inside' that is along psychological and emotional pathways. This perspective shifts the focus away from macro level of the economic to the micro-politics of the individual (Thomas, 2004a).

In this study, I had used this concept to understand the women's experiences of mental wellbeing throughout their life-course in Chapter 7. True to the concept, this chapter primarily looks at the personal and intimate experiences of the study participants that may have left a mark in their minds. It was found that the women experienced different kinds and degrees of discriminatory behavior from their friends and neighbors throughout their life-course. Their experiences, however, cannot be homogenized, as one could find a lot of differences in their experiences depending on the nature of their impairments, the severity of their impairments, the age at which they acquired their impairments, place of residence and the level of support they received from their families. It was found that the women with mild to moderate impairments were not treated much differently and they had nondisabled friends when they were young. However, their impairments were often treated jocularly by their peers. In contrast, the women with severe impairments were never made fun of, but they were subtly excluded from mainstream society. It was also found that the women who had acquired their impairments in their teens found it very hard to adapt to their impairments, unlike the other women who had no memory of themselves as nondisabled. The study had also found that the women in the rural areas did not face much difficulty in being accepted in their adulthood primarily due to their association with the disability organization, Sanjeeboni, while similar support did not exist for the women in the urban areas. The study also found that having a friend or a family member who understood them and supported them helped the women a lot in facing the world bravely.

The study has also found that the women had faced numerous hindrances on their path to attaining education. It was found that a few women faced outright denial of admission in 'mainstream' schools in the urban areas, which forced them to seek admission in a special school. Even though they received considerable support from their special educators, it was found that the quality of education in the special school was so poor that it permanently marred their possibility of getting employed anywhere. In contrast, several of the women with milder disabilities from the rural areas could not complete their education due to a number of hindrances such as geographical distance to the school, lack of public transportation facilities, lack of proper guidance at school and also at home and their responsibilities of completing their household and agricultural responsibilities before going to school. In certain cases, the women from both rural and urban areas had to dropout from their schools because of circumstances in their families. Due to their lack of qualification, it became very difficult for the women to seek employment when they grew up. As a result of this, some of the women blamed their *beya kopaal* (bad fate) and *beya bhagyo* (bad destiny) for their predicament.

The study also found that the women often had to endure questions about their unmarriageability from the wider society, which hurt them very much. Due to the widely prevalent notions about attractiveness, most of the women were found to have internalized the notion that they will not be married. It was also found that the women were actively encouraged by their mothers to think in this way. Some of the reasons why the women considered marriage undesirable are the possibility of domestic violence, fear that they might have to compensate their impairments with sufficient amount of dowry and to fulfill their duties of looking after their parents in the absence of a brother. Some of them also said that they were interested in getting married in their younger age, but lost interest over the years, while others evoked their *kopaal* and *bhagyo* for not being able to get married. It was also found that some of the women were very keen to get married, and found inspiration when they saw other women with disabilities married. Out of the 18 women that were part of this study, only five of them were married, and one was widowed. It was found that almost all of them had faced discrimination from their husband's families, regardless of whether it was a love marriage or an arranged marriage. The study also found that there are clear cut differences on the way the women are treated by their husbands depending on their disability status. It was found that the women who were married to disabled men were living more peacefully than the women who were married to nondisabled men. One of the reasons why this could be so is that for the former category, the women did not have to overcompensate for their impairments because their husbands also faced similar difficulties and did not expect them to outdo themselves (Uma and Chitra). On the other hand, the women who were married to nondisabled men were not exempted from their responsibilities, and sometimes had to work doubly hard to overcompensate for their disabilities (Bandana). The study also found that the place where the couples set up home after marriage also matters a lot in the way the women are treated by their husbands. In this study it was found that the women who lived with their natal families, or lived close to their natal families, under the watchful eyes of their mothers, reported to be happier in their marriages (Korobi and Jeuti) than women who lived far away from their natal families (Bandana). Additionally, women who chose their own partners also put themselves in a difficult situation as after marriage they were not able to talk about their worries with their natal family members (Bandana). Thankfully, unlike other studies on married women with disabilities (Ghai, 2003; Klasing, 2007; Daruwalla et al, 2013; Sarma, 2014), none of the research participants narrated about instances of domestic violence. Out of these 5 women, only three of them had children (sons). It was found that the women had faced a lot of physical difficulties in raising their sons. It was only Korobi, who lived with her natal family, who received support from her family. The other two women had to bring up their sons with much difficulty.

The study also found that the ability to do household chores was an important qualification for the women. This ability was much emphasized in the rural areas where the women learned to do household work from their cousins, while in the urban areas there was not much emphasis. The study also found that it was only the women who had mild disabilities that were expected to do household chores, while the women with severe disabilities were never expected to do such work. After marriage, the women were found to have no other option but to work and they did not expect their husbands to support them in such work.

The study also found that the women were much concerned about their futures, and their concerns varied according to their marital status. While the unmarried women were concerned whether or not their siblings would look after them in the future, the married women were concerned about their son’s futures. All the women were also found to be concerned about their own health and whether or not they would be able to work in the future as they did not want to depend on other people.

The chapter, therefore, has shown that the women have had to encounter negative and discriminatory behaviors from different people throughout their life-course. Such interactions have often left them feeling worthless, unattractive or as a burden. As seen from the discussion, persons with disabilities often internalize such notions and accordingly restrict their own movements. According to Thomas (2006), this is a form of *disablism* that limits persons with disabilities from being what they want to be by shaping their inner worlds and social behaviors. In addition to this, the women with mild to moderate impairments were also found to have internalized the gendered notions about what it is like to be a woman in the society of Assam. Due to these reasons, most of them wanted to assume the traditional feminine roles of marriage and motherhood at least in some point in their lives. However, as they grew older they realized it is not marriage but economic stability that they require.

Disability and Other Intersections

The fifth objective of this study was to understand the intersection of disability with other forms of identity. It was important to understand this because critiques of the social model is that it homogenizes the experiences of all persons with disabilities without giving due importance to other aspects about their lives. They have pointed out that apart from disablism, other forms of oppression such as racism, sexism and homophobia have not been adequately addressed in the social model of disability (Oliver, 1996; 2004; Shakespeare and Watson, 2002). Oliver (2004) acknowledges this flaw in the social model and has mentioned that just because the intersections have not been taken into consideration earlier does not mean that such experiences cannot be taken into consideration in the future as well. Feminist disability scholars have pointed out the differences that women with disabilities experience additional hardships because of their gender and also because of their social class (Morris, 1991; 1995; 1998). This study also sought to understand the different intersections in the lives of the study participants.

In this study, I have employed the intersectionality framework to gather insights about the internal dynamics in the lives of the study participants in all the data chapters. The findings of the study illustrate that the experiences of women with locomotor disabilities vary according to a number of intersecting factors. Some of the important axes of difference were found to be class, age, rural/ urban difference, nature and severity of the impairment, age of onset of the impairment and marital status. It was found that class plays a very important role in the way parents accessed information about their child’s impairment, which in turn affected the way they brought up their daughter and how the daughter saw herself as she grew up. This was particularly evident in the experiences of Suchismita and Korobi who belonged to relatively affluent families. However, their experiences with their families were varied due to the nature of their impairments. In the case of Suchismita it was found that since her impairment was only physical in nature (post-polio residual paralysis), her parents were able to provide her the most congenial environment for her to achieve her dreams. Even though she also faced hurdles along her life’s journey (Raimedhi, 2015), these problems were to a large extent ameliorated by her supportive family. In contrast, Korobi’s impairment was not only physical but also cognitive, due to which she was brought up in a cosseted environment that made her all the more dependent on her family members for support as she grew up. Due to the complicated nature of her impairment, her family found it hard to come to terms with her physical condition. In her narrative it is seen that her mother blames her for the severity of her condition. Similarly, Risha has also received considerable support from her family, even though the nature of her impairment and the progressively deteriorating condition of her health have made it very difficult for her to live her life as per her wishes. In contrast to these women, all the other study participants had faced constraints in their lives as a result of their class background. While for some poverty exposed them to their impairment, for others poverty made it difficult for them to access healthcare for alleviating their condition. Class, along with its intersection with the nature and severity of the impairment played a great role in shaping the life-course of the women.

Age was also found to be an important factor. It was found that the women who were younger in the sample had access to much better health and rehabilitation services, than the women who were born in the 70s and 80s. The reasons for this include the socio-political situation in the state during this period, along with the policy changes that came about in the 1990s and 2000s, that made life easier for the younger women. Yet the women were not able to access the services because of their familial circumstances that restricted their mothers from continuing their treatment.

Apart from class and age, the place of residence and the marital status of the women also played a big role in shaping the experiences of the women, as has been cited above.

Summing Up

The aim of this study was to understand the lived experiences of women ageing with locomotor disabilities acquired early in life in the Kamrup Metropolitan District of Assam. It was found that different factors have affected different facets of the lives of the women and due to this reason different concepts are necessary to understand their lived experiences. The social model of disability has been used as the reference point in this study to critique its universalist discourse and to argue that it is not applicable in every social setting. The study clearly shows that in a context where there is widespread poverty, lack of access to healthcare and rehabilitation services, educational qualification and employment opportunities and dependence on family members for their upkeep, the binary distinction between disability and impairment as espoused by the social model is irrelevant. Additionally, the political consciousness that is necessary for applying such an understanding in the lives of persons with disabilities is completely lacking in the context of Assam. There is no active disability movement in the state. There are just disability organizations that are providing services for persons with disabilities from a top-down approach. As a result, most persons with disabilities individualize their problems instead of blaming the society for their lack of accessibility.

To understand the lived experiences of persons with disabilities in such a context, therefore, a more structural understanding is necessary. The majority world perspective on disability was found to be very relevant in understanding this context. This perspective, however, robs people off their agency, as it is a commentary of the structure, without any mention of how individuals can bring about changes in the structure through their own efforts with the help of family members or organizational support. The study has shown that although the majority world perspective gives a glimpse of the life situations of persons with disabilities it does not show how these relationships are changed by other favorable or unfavorable conditions as well as how the change of time affects people’s lives. The lives of individuals are far more complex than what can be dictated by the structure of a society. Due to this reason, the study also made an attempt at understanding the micro details in their lives from the concept of psycho-emotional dimensions of disability as espoused by Thomas (2004a), life course perspective and the intersectionality paradigm.

The study has shown that women with disabilities are vulnerable in a number of ways. This vulnerability is accentuated by a number of deprivations in their lives. In comparison to women with disabilities, it is said that men with disabilities enjoy certain privileges because of their gender. However, more studies must be conducted on them to make a definitive argument on this regard. The study has also shown that the experiences of women with locomotor disabilities vary according to the exact nature of the impairment, the degree of the impairment and the age at which the women had acquired their impairments. This indicates that in the future more studies need to be conducted on the differences among women/ persons with disabilities in order to design better policies. The current policy framework, as shown in Chapter 1, is more medical oriented, which needs to be changed in order to accommodate more people. The Rights of Persons with Disabilities Act, 2016, has expanded the number of disabilities within its ambit to include 19 more health conditions as opposed to the seven impairments considered earlier under the Persons with Disabilities Act, 1995. However, the criteria for defining a person with ‘benchmark’ disabilities is still 40 percent, which completely obliterates the pain and suffering that persons with disabilities experience as a result of their the social context in which they are living. Additionally, within the health system more emphasis should be given to counseling and rehabilitation of persons with disabilities, rather than only providing the hope of cure as has been seen in this study.

Contribution of this Study and Directions for Future Research

This study has contributed in enhancing our understanding at how broader structures shape the lived experiences of persons with disabilities. Unfortunately not much research has been conducted by taking this perspective into consideration. Besides, this is the first of its kind study conducted in the context of Assam. So it provides valuable insights about how parents and the community at large deal with persons with disabilities in the state. This is significantly different from the way persons with disabilities are treated in the context of other states. This draws our attention to the fact that even within the same country the experiences of persons with disabilities vary considerably.

This study has also opened up different avenues into which research can be conducted:

1. Future studies need to be conducted on persons with other forms of disabilities, both visible and invisible, to understand how people with different disabilities are treated separately in the society.
2. In the future more studies need to be conducted on the health of persons with disabilities for the whole of India.
3. More studies need to be conducted on men with disabilities because virtually nothing is known about their lived experiences.
4. Future studies conducted in Assam must make it a point to consider persons with disabilities from different communities of the state to understand if their experiences vary.
5. Future studies must also have a direct understanding about how persons with disabilities have been impacted by the years of ethnic violence and insurgency movements in the state.

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