# DISABILITY AND SEXUAL INTIMACY: SEXUALITY OF PERSONS WITH CEREBRAL PALSY

*Dissertation submitted to*
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## MASTER OF PHILOSOPHY

### MEENAKSHI MUND

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## DECLARATION

This is to declare that the dissertation entitled "Disability and Sexual Intimacy: Sexuality of Persons with Cerebral Palsy" submitted by me in partial fulfillment of the requirements for the award of the degree of Master of Philosophy, at Jawaharlal Nehru University, New Delhi, is my own work. The dissertation has not been submitted in part or full, for any other degree or diploma, either at this or any other university.

**MEENAKSHI MUND**

## CERTIFICATE

We recommend that this dissertation be placed before the examiners for evaluation.

**Prof. NILIKA MEHROTRA**

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Supervisor

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# <u>INTRODUCTION</u>

## DISABILITY

Disability has been a universal experience since time immemorial. The term connotes a hindrance in the performance of functions and activities by individuals as members of society thereby, circumscribing their participation in socio-cultural, political and economic aspects of their community life.

Disability has been defined primarily in terms of medical deficit and connotes 'a lack' or 'a deficiency' whether mental, physical or sensory. In almost all societies of the world, people with mental and physical anomalies have been presumed to be by the very nature of their condition as 'inferior'. In all societies the experience of disability is mediated by the socio-cultural constructions that give meaning to impairment and influence the experiences of people with disabilities in different socio-historical context. Disability scholars and activists have long questioned the medical definitions of disability and have greatly emphasized on the social and cultural interpretations of disability that define the power relations between the non-disabled and the disabled which results in the disabled, being stigmatized and ostracized.

## SEXUALITY

Sipski and Alexander (1997) describe sexuality in the broadest sense. They asserted that: "*sexuality is not merely an act of copulation or an activity to derive sensual pleasure rather it also includes different ways in which people present themselves to others. It is an act of expression to convey love and companionship. It is a way to exhibit different aspects of personality and emotional existence that expresses the femaleness and the maleness*".

Sexuality is one of the important aspects of everybody's life. In a research conducted by Felce and Perry (1997) revealed that in most of the people with or without disability, sexual desires and its expressions are natural and are important for the emotional well being and to improve the overall quality of life. Extending this proposition further, Sipski and Alexander assert that since sexuality is deeply connected to self-esteem and body image, it is also an important part of rehabilitation. Development in sexual maturity is essential for any individual as it is considered as a necessity, since the developmental success or failure in the sexual systems influences the transition into adult life (Greydanus& Omar, 2008). People with developmental and physical disabilities report greater sexual and reproductive disparities as well as sexual distress than the non-disabled people (Stein &Tepper, 2015).

## DISABILITY AND SEXUALITY

Census reveals that people with disabilities form a significant percentage of the total population across the globe. Despite such large numbers of disabled people, various facets of disability and the problems associated with it are ignored. One such issue pertains to the sexuality of people with disability (here people suffering from Cerebral Palsy). Not much work has been done on sexuality with respect to persons with disability. This ignorance indicates the invisibility of people with disabilities from mainstream research on sexuality, implying that these people do not count. Hence, the desire of persons with disability for expression and pleasure are neglected. The myths associated with them that they are asexual beings and therefore, they do not need any awareness and information on sexuality and sexual health play a significant role in problematizing the scenario. Apparently, the lack of research on the sexuality of persons with disability has led to a gap in planning intervention programmes and services for them. Disability

and sexuality together have not been addressed from a social justice or a human rights perspective and persons with disabilities continue to be marginalized.

## STATEMENT OF THE PROBLEM

As discussed above, the marginalization of people with disability has been addressed in many academic discourses but not much emphasis is given to the interpersonal experiences of people with disability in terms of their desires and sexuality. The apprehensions and the negative attitude of thenon-disabled people towards the people with disability which is shaped by both social and structural relations affect the construction of a positive self of disabled people. The dissertation aims to focus on cerebral palsy, a life-long developmental disability, a condition due to brain damage, during or within five years after birth that profoundly impacts the social, communicative and imaginative capacities of an individual. It aims to examine the vicarious impact of the social processes of felt and enacted stigma associated with disability on people with disabilities and their families. The study further explores whether the stigmas attached with disability impact the formation of sexually intimate relations between people with disability and others.

## RESEARCH QUESTIONS

The present study aims to answer the following research questions:

1.) How did parents and guardians of children with Cerebral Palsy come to terms with the child's problem and to explore the experience of disability following the diagnosis?

2.) How people with cerebral palsy negotiate and perceive their sexual interaction with others and do they consider marriage as feasible option to establish sexually intimate relations?

3.) What role do the family, friends and medical care givers play in making the people with cerebral palsy understand about their possibility of a sexual life and marriage as adults?

## RESEARCH OBJECTIVE

The objectives of the present study are:

1.) Exploring the social and the cultural impediments that make it difficult for the people with disability to establish sexual intimacy with others (non-disabled).

2.) To ascertain, the reasons for the culturally constructed undesirability for people with disability through a critical analysis of different models of disability.

3.) Chronicling the process of symptoms, recognition and diagnosis of cerebral palsy.

4.) Examining the current state of anthropological research on disability, general research on disability and sexuality, and anthropological research on disability and sexuality.

## CONCEPTUAL FRAMEWORK

Broadly locating itself within a symbolic interactionist framework, the study uses various concepts that enable a better understanding of social reality. Few scholars, who placed disability and sexuality in a particular context, critiqued that current social attitudes and cultural meanings of disability and sexuality affected and influenced the lives of people with disability. People with disability have a self-conception about themselves which is usually negative.

Their negative attitude towards them is derived from the social interactions in a society that negatively views disability. This position was clearly reflected in the work of Erving Goffman and his concept of stigma. He argued that an individual seen as having attributes of disability

would be "reduced in our minds from a whole and a usual person to a tainted or a discounted one" (Goffman, 1963). The Goffmanian concepts of discreditable and discredited identities are used for better understanding of disorder like Cerebral Palsy.

The concept of liminality by Murphy is referred in order to enable a better understanding of cerebral palsy and its manifestations. Through the socio-cultural concept of labeling, stereotyping and separation the study attempts to understand the vicarious impacts of theses social processes on the lives of people with disability. The study will also refer to Foucault's work on deviance and sexuality for a better understanding of 'normality'. Foucault's study of 'governmentality' will also be used which attempts to describe the production of the body as an object of professional practice in the post-structural tradition.

The study employs anthropological techniques and theories to understand the relationship between disability and sexuality. The present study also highlights a theoretical lacuna that exists in anthropological research on disability as the field of disability in anthropology has been conceptualized on few theoretical notions like liminality and stigma. There are not many studies in anthropology that examines the way cultural values and belief system, social structure and gender expectations impact the chances of people with disabilities in sexual and marriage relationships which are incorporated in the present study. Another main concern of the study is the analysis of the impact of child's disability on his/her family and the dynamics that operate in middle-class families under difficult circumstances. With the social-psychological concepts of coping and resilience the study attempts to understand that why some families are better than others in coming to terms with the child's disability. The present study aims to contribute to the existing literature on disability and sexuality in both disability studies and medical anthropology. The study extracts its content from inter-disciplinary literature in the fields of disability studies,

psychology, anthropology and sociology of culture. It further refers to different models of disability to understand the interplay between disability, sexuality and community. In other words the study goes beyond the medicalized view of disability which extends to not only the affected person but also to the family and community at large.

## METHODOLOGY

The study employs qualitative research paradigm to understand the perceptions, attitude and perspective of informants (both disabled and the non-disabled persons) towards disability. Both primary and secondary data were used to compile data for the present study.

Different data collecting techniques like interview method and observation method were applied to obtain information. The first hand data was collected by employing the unstructured and semi-structured interview techniques with different informants. I used to engage myself in informal conversation with local people during my field visit for supporting my formal interviews. The present study is a qualitative, ethnographic engagement with 10 families having children with Cerebral Palsy and 7 people with disabilities (CP) aged between 16 to 35year and two doctors (one neurosurgeon and one orthopedic surgeon). These individuals and families were interviewed at Kalawati Saran Children's Hospital and at Amarjyoti Charitable Trust both of which are located in Delhi. The informants were selected on the basis of their willingness and availability. Further, observation method was used to gather information. I had enrolled myself for physiotherapy session at Amarjyoti Charitable Trust (since I am suffering from PPRP in my left lower limb). Through this way I could make comfortable relations with persons affected with Cerebral palsy and their families. I was involved in participantobservation as I used to observe

the everyday activities of persons with Cerebral Palsy and their attendants who accompanied them to the physiotherapy sessions.

Secondary data was significantly used to develop a conceptual and theoretical framework for the present study and to substantiate the first hand observation gathered from interviews and observation. Peer reviewed articles, books and other related published and unpublished materials along with the electronic sources were reviewed for relevant materials as per the requirement of the study.

## CHAPTERIZATION

This work consists of four chapters along with an introduction and conclusion.

The first chapter deals with the theoretical, historical and political perspectives on disability. It is based on the major themes of the present study which is disability and sexuality. It discusses the history of disability, the socio-cultural process by which disability has attained meaning in different cultures in western societies and non western societies. Models of disability are analyzed to understand the normative gaze and other evaluative processes based on the ideals of desirability. Policies and practices of disability are analyzed to understand the political stance of disability.

The second chapter is largely based on primary data wherein doctor, patients and family were interviewed on the processes of symptom recognition, diagnosis and it's after effects on the affected person and on family and friends.

The third chapter examines the general research done so far on disability and sexuality. It further dwells into the anthropological research on disability and sexuality. In the said chapter, it is argued that research on sexuality has ignored disability and works on disability has marginalized

issues of sexuality. The chapter is concluded with some current anthropological work done on the said field.

The fourth chapter examines a wide range of social and cultural barriers that people with disability come across in establishing sexually intimate relations with others. The chapter is concluded by an argument that the myth of asexuality of people with disability has cultural connotations that largely affects the construction of a positive self.

The concluding section has the key findings of the study. It discusses the role and responsibilities of the family, friends and medical care giver with respect to people with disability. Finally, some suggestions will be given on how to combat the desexualizing context that people with disability face in their day to day lives.

## RELEVANCE OF THE STUDY

There is limited research into the sexual lives of people with disabilities. Therefore, the present study will academically help us to understand the reasons for stigmatizing disability which negatively impacts the formation of sexually intimate relations between the non-disabled people and the disabled people. The study also uncovers the reasons responsible for the negative attitudes towards the disabled people. Also the study provides an insight into the lives of people with disabilities and their families and the interpersonal issues related to the sexual preferences of such people. Thus, the study will provide inputs and assist various stakeholders like Government agencies, NGOs, hospitals to designs policies, counseling sessions, rehabilitative programmes based on the need of people with developmental disabilities like Cerebral Palsy.

# LIMITATIONS OF THE STUDY

The present work is a qualitative study which aims at breaking down the "hierarchical and potentially exploitative relationship between researcher and researched "considering the sensitivity of the topic. Due to my location as a patient/sufferer, reflexivity was an essential aspect of the research design.

However, during the course of research the roles of 'researcher' and 'patient/sufferer' gradually came to be demarcated and separated. My belongingness to a certain group was a critical factor in ensuring that the research relationship was a non-hierarchical meeting of 'equals'. However, while compiling the data and during the writing phase, I confronted with the issue of power. I was vigilant in the presentation of the stories narrated to me by the informers as the personal details shared by them were presented in a tactful manner and the identities were kept confidential. During the course of my study I often felt and was quite apprehensive about the fact that another person's pain was the source of my academic advancement.  I used to pacify myself by explaining that I too along with my family have experienced a similar pain not so grave though. The researcher in me motivated me to think that analysis and scrutiny of the content and making it available for others was a part of my academic training. I always worked with the intention that there is an urgent need to bring the experience of persons with cerebral palsy and their desire for sexually intimate relationship in an academic discourse and make it available for lay audiences, and that I was qualified to accomplish this task.  The very theme of the study is deeply personal and emotive. I sometimes experienced feelings of annoyance and impatience with some respondents. I had to restrict myself from giving unsolicited advice or passing judgments. Sometimes I used to get so carried away by the emotional turmoil some families were going through that I would seriously consider giving up altogether. At the same time, I had to

exercise caution and self-restraint in order to avoid getting "over-involved" with my participants. Despite all this I was alarmed at the way I could manage to study the events clinically like a conventional, dispassionate researcher from an involved empathetic insider. I eventually managed to "rise above" my emotions in order to represent my experiences as a researcher. How this reflects on my human qualities is a different matter entirely. Also, I had to restrict to consider every interaction with my informant as a research opportunity. There were occasions when I had to remind myself that I have to be like a friend sometimes to avoid looking things from a researcher's perspective every time.

The time I had spent on the field was both exhilarating and exhausting. It was exhilarating, because on one hand I was doing something which I liked and on the other hand it felt that one was unlocking an aspect of social reality that had not received much attention in Sociology, and that there were narratives of people which urgently needed to be told; exhausting, because of the toll it took on one's physical and emotional energies. It was sometimes difficult for me to relate to the emotions of the parents and the affected person who were recounting their past experiences. Many families encouraged me by saying that they were reliving the pain of their past experiences by discussing it with me.

Overall, the study helped me to understand the liberative aspect of social science at the level of my own experience. It helped me to understand that how culture and society shape our emotions, our constructs and definitions of the situation. Going to the field was an enriching experience not only as a researcher but also as a human being as I learned to view life as part of the 'bigger picture' and began at last to understand how the personal is the political.

# CHAPTER ONE

## DISABILITY: THEORETICAL PERSPECTIVE, HISTORY, POLICY AND PRACTICES

Disability is a complex category. It is not a homogenous category as it encompasses different kinds of bodily variations, physical impairments, sensory difficulties, mental and learning impairments which may be either congenital or acquired. Disability theorists and scholars differ with regard to the appropriate terminology of disability in variety of ways. For instance, disability has been conceptualized in terms of community responses and obligations (Ingstad, 1995; Goffman,1963) or in terms of circumscribed economic and productive roles (Stiker, 1994; Focault, 1967). British scholars have a different connotation of disability and term it as a restriction of activities caused by the society that takes little account of people with impairments and thus excludes them from the mainstream activities. Therefore, disability is like racism and sexism, resulting in discrimination and social oppression (Oliver, 1990; Finkelstein, 1980; Shakespeare, 1996).

The thesis aims to focus on cerebral palsy, a life-long developmental disability, a condition due to brain damage, during or within five years after birth that profoundly impacts the social, communicative and imaginative capacities of an individual.

Cerebral palsy was first described by the English physician, Sir Francis William Little in 1861. Cerebral palsy was known as a little's disease for a long time. Initially, it was not thought that this condition was caused by neonatal asphyxia. The little's idea was later challenged by Sigmund Freud and other scientists who proposed that a variety of reasons during pregnancy

could damage the developing brain. Apparently, it is accepted that around 10% cases of cerebral palsy can be attributed to neonatal asphyxia. The majority occurs during the prenatal period and in most of the cases, a specific cause cannot be identified (Berker and Yalcin, 2010). The knowledge and awareness amongst the medical care givers, mental professionals and lay public is limited. As few medical professionals are conversant with its symptoms and diagnostic criterion, the diagnosis is usually difficult (Berker and Yalcin, 2010).

The World Health Organization (WHO) concept of disability is differentiated by three conditions viz., impairment, disability and handicap. It developed International Classification of Impairment, Disabilities and Handicap (ICIHD) in 1980 and the International Classification of Function, Disability and Health in 2001. According to WHO, impairment denotes loss or damage of physiological, psychological or anatomical function or structure, example: limb deformities, loss of hearing or sight etc. Disability is defined as a functional limitation in performing day to day activities that are considered age and gender appropriate. It denotes the interrelationship between the impairment and the environment that impacts the individual functioning, example: locomotor, cognitive, communication disabilities etc. Handicap as per WHO is a limitation experienced by individual with impairments and disabilities to take part in the life of the community and to prefer their social roles within society.

 The United Nations Convention on Rights of Persons with Disabilities (2006), Article 1 says, "*Persons with Disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others*."

According to, the Persons with Disabilities Act (Equal Opportunities, Protection of Rights and Full Participation), 1995, (India) "*Person with disability means a person suffering from not less than forty percent of any disability as certified by a medical authority*." The definition laid in the PWD Act 1995 was criticized by many theorists and activists on the ground that it is very limiting and narrow in focus and leaves out various conditions and factors from the purview of disability.

Ghai in her work (Dis) Embodied Form: Issues of Disabled Women (2003) critiques the definition given by both the WHO and the PWD Act of 1995. She asserts, both the definitions "*do not reflect the definitions propounded by disabled people themselves. As early as 1976, the Union of the Physically Impaired Against Segregation (UPIAS), expressed a need for an alternative definition of disability*."

According to the UPIAS concept of disability, it can be defined as "*the disadvantage or restriction of activity caused by contemporary social organization which takes little or no account of people who have physical impairments, and thus excludes them from the mainstream of social activities*".

However, it can be questioned that whether the notions of impairment, disability and handicap are analytically separable; whether it is desirable to create a divide between the impaired body and confine it to the domain of biomedicine and define disability and handicap in socio-cultural and political terms. This can be understood after analyzing the key features of different models of disability.

## 1.1 THE MEDICAL MODEL OF DISABILITY

The medical model is the historical consequence of the tremendous advances in the field of modern medical sciences in the western world and the opening up of the human body and its functioning to the medicalized gaze. The emergence and the subsequent growth of the concept of 'normalcy' which prescribes certain standards of functioning of human body and mind which resulted in deviation and the difference were labeled as abnormal or disabling. A range of physical, mental and sensory conditions came under the medical scanner.

As per the medical model of disability, disability is viewed as a negative variation from the physical norm that impairs the functional capacities of the disabled person. The medical model attaches diagnostic labels to people with disabilities, and they are categorized into a group of people whose bodies do not work, or look different, or act differently or who cannot do productive work (Shakespeare, 1996). The task of 'normalizing' the impaired body is handed over to the medical care givers and other specialists by using medical technologies. The underlying assumption of the medical model is that of a universalized, uniform biomedical body which is measurable and whose functions and limitations are defined concretely which is generalizable over time and space. This ignores the complexity of lived experiences of people with disabilities and obscures the role of society in giving names to these bodily states. The clinical definition of disability becomes the administrative tags for controlling the disabled people's access to financial and other assistance thereby, stigmatizing the labeled persons by suggesting deviance from the norm.

The medical model was critiqued by the disabled people themselves because of the lack of lived experience of disabled people and its inherently biological determinism. The medical model

completely overlooks the role of obstructive environment in creating dysfunctionality by tracing the built and arranged environment as invariable. From the perspective of a person mobilizing on wheelchair, disablement is experienced not as the absence of walking but the absence of access to the public facilities. Thus, the medical model ignores the subjective social experience of disabled people and focus only on the medical dimension of difference (Shakespeare, 1996).

## 1.2 THE REHABILITATION MODEL OF DISABILITY

Rehabilitation or functional model is an extension of the medical model and at the same time a precursor to the social model. With the advances in medical science and with the need to reintegrate those citizens who had acquired disabilities during two world wars into a more or less normal life, a shift was taking place in the perception towards disabled people. The functional model perceived the disabled people as needing assistance through services and supports aimed at making the individual as functional as possible (Kaplan, 1998). This understanding of disability brought an era of rehabilitation programs like physiotherapy, skill training, occupation therapy etc. The new advancements in medical technology was harnessed in research to manufacture assistive devices for people with disability with a purpose to assist them to lead a normal life. The rehabilitation model paved way for people with disabilities to question the authority and dominance of the medical model. A paradigm shift took place when disability was conceptualized as the barriers which the society imposed on people with disability through their attitude, stigmatizing disability etc. The rehabilitation model paved way for the social model which was primarily a critique of positive science which posed a dominant discourse.

## 1.3 THE SOCIAL MODEL OF DISABILITY

The social model was a reaction to the medical model which conceptualized disability as an objective phenomenon in the individual (Diedrich, 2005). The social model was developed as a result of the disabled people's movement both in U.S.A and Europe in the 1970s and 1980s. It is built on the premise that disability is not the outcome of bodily pathology but is socially produced by systematic patterns of exclusion that are built into the social fabric (Shakespeare 1994, Hughes and Paterson 1997). The social model of disability focused on the ways in which disability is created through social, political, psychological and cultural exclusion of people with impairments. Hence, disability is imposed on people with impairment through restrictions ranging from institution discrimination to individual prejudice; unusable transport systems to inaccessible buildings (Oliver, 1990, 1996). Goodley and Lawthom (2006) describe disablement (the exclusion of people with impairments) as a form of apartheid of the21st century. In the U.K., which is the birthplace of the social model, it took almost years for people with disability to receive some legal rights. Finally in the year 1995, the Disability Discrimination Act was established for the disabled people to receive some form of legislative protection. Unfortunately, the disabled people are still facing life on the margins of society despite, many legislative reforms. Disability is thus, clearly a political phenomenon as well.

The social model served as an effective tool in repairing for the injustice faced by people with disability and by removing the barriers so as to enhance their participation in the mainstream activities. The model brought about a structural change in the developed countries in which it was developed by insisting on anti-discriminatory policy and citizenship rights. It demanded for better services, higher benefits, more provision for education and employment etc.

One strand of the social model suggests that society creates a negative social identity for people with disabilities which is usually identified as 'deviant' (Fine & Asch, 1988). Disability is emulated with helplessness, dependency and incompetence at all social interactions and disabled people are subjected to isolation and lack of social support. Although, social model has shifted the focus from the disabled individual to social structures yet, it has failed to take into account the subjective and bodily experiences of people with disabilities (Morris 1991, Tregaskis 2002). It fails to recognize the rejection of lived experience of impairments with respect to social barriers thus, creating a separation between the body and culture, impairments and disability. The body-society dualism inherent in the model also confounds the problem of identity politics (Hughes and Paterson, 1997).

Having situated the 'body-society' debates in disability studies through the above brief examination of the models of disability, we now focus upon some major sociological and anthropological approaches to the understanding of disability.

## 1.4 DISABILITY AS SOCIAL DEVIANCE AND STIGMA

The relationship between disability and deviance can be understood with respect to the freedom from social obligation which is evident in the rigid role construct and in the negative connotation that is attached with impairment in industrial and post-industrial societies (Becker, 1963). The functionality of these societies is based upon the liberal ideals of individual responsibility, competition, productiveness and employment. Thus, any deviation from these ideals or any kind of freedom from social obligations for people with impairments must be discouraged as asserted by Becker. The analysis of social reaction towards the people with impairments was central to sociologists in the 1960's who were working within the traditions of symbolic interactionism.

Their emphasis was to understand the meaning, identity and the process of labeling to explore the relationship between disablement and socially prescribed behavior. Lerment (1962) divided deviance into two categories: 'primary deviance' and 'secondary deviance'. He asserted that primary deviance has marginal implications for the individuals concerned while the secondary deviance is associated with the ascription by others of a socially devalued status and identity.

Sociological analysis of stigma by Erving Goffman (1963) is regarded as foundational in theorizing disability. His elaborate explanation and application of symbolic interactionist framework laid a conceptual ground for understanding stigma. Symbolic interactionism according to Blumer centers on "processes actors use to constantly create and recreate experience from one interaction to the next" (Blumer, 1962:179). For Blumer, symbolic interactionism views human beings as pragmatic yet reflexive actors who perceive and act of symbolic meanings of actions and of other actors.

Goffman observed that the major aspects of disability experience while focusing on the interaction between the disabled and the non-disabled was the constant struggle to turn away the devaluation caused by labeling as 'less than normal' at best and 'less than human' at worst. Goffman further detailed the ways in which public noted deviance is highlighted in the society, for instance, a noticeably impaired individual may be subjected to insensitive comments, curious gaze and are in a way denied privacy that the non-disabled people are accorded in public. At worst they may be denied a status of a 'person' and are thought to be people devoid of feelings, ideas and responsibilities unlike the normal people. The disabled people who are stigmatized may 'pass' as socially acceptable by proving their competence, using humor etc. in other words, minimizing the effect of social discreditation caused by stigma by adopting various means. If the

stigma is not managed successfully then the individual is ostracized and the individual often internalizes the spoiled and stigmatized identity.

Further, Goffman focused on the dilemma of the discreditable person i.e. the person whose impairment is not visible and therefore, has a non-visible stigma that could be potentially discovered in future and the discredited person i.e. a person with visible impairment and the one with an obvious stigma. Goffman theorized that while the demand of visible stigma is the management of the tension encountered, by employing strategies such as proving competence, disguising difference etc. and in the case of hidden stigma, it was the management of information about oneself to avoid discreditation (Albrecht, Seelman& Bury, 2001).

One of Goffman's contemporaries, Fred Davis (1961) studied the strategic behaviors adopted by the disabled person to "disavow deviance" and also to establish their common humanity in interactions with others. He further asserted that social interaction is threatened by public's perception of disabled people as odd, different and not normal.

Davis interviewed adults with different types of disabilities which included blindness, orthopedic conditions and facial conditions asking how they handled social relationships affected by societal attitudes towards disability. Based on the responses he got from the interview, he concluded that new relationship between disabled and non-disabled people move through sequential stages of deviance disavowal model. The first stage in deviance disavowal model is known as the fictional acceptance. In this stage the non-disabled people superficially treat the disabled people as equals. This kind of exterior acceptance may become an end in itself. If the first stage proceeds smoothly the disabled person may then start revealing sufficient personal information to the non-disabled persons with a purpose of challenging the stereotypes attached with them. Fred called this stage

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as the breaking through stage which is an attempt to build bridges that will enable the non-disabled person to identify in terms of shared interest and perspectives. If the breaking through stage succeeds, the non-disabled people start relating to the disabled people as one of them i.e. non-disabled which Fred presumes to be most desirable to many disabled persons. This is the last stage of deviance disavowal model and is called institutionalization of normalized relationship. Both Davis and Goffman considered the case of disabled people who opt to forego the struggle for acceptance by the non-disabled people but neither of them presented this possibility in a positive light.

Robert Scott in his powerful work, 'The Making of Blind Men (1969), offered a more complex and nuanced understanding of stigma and analyzed disability as a social role. He in his work exposed how the blind are conditioned to become dependent because of stereotypes and because these are the attitudes expected of them by service professionals who hold the key to powerful blind services system. Scott also described various forms of resistance put forward by the blind people who rejected the docile role they were expected to perform. But eventually, these attempts results in the alienation of blind person from himself/herself. Although, the disability theory became more profound and sophisticated in the following years the early theories and works retained their resonance. In this connection, we may recall a Bollywood movie Margarita, With a Straw. It is a story of a young college going girl Laila, who is grappling with cerebral palsy. The title of the movie refers to the time when she orders an alcoholic drink for the first time, after she has made her way from Delhi to New York University to undertake a writing course. The protagonist of the movie is Laila played by KalkiKoechlin who does her best and strives hard not to let her identity of a disabled girl get in the way of student lifestyle like any other non-disabled individual. In order to make herself a part of the main stream and to enjoy her

youth full years, she tries and does everything which a normal individual of her age (here a college going youth) does to explore and live life to the fullest. She (Laila) like any normal teenager write lyrics for a rock band, has a crush on rock-star who is her classmate, deals with heartbreaks and surfs for erotica on the internet.

Although, Laila is a physically challenged girl but that is just one aspect of her personality. She also has to contend with several other 'minority' identities i.e. she is a woman in a man's world. Laila's sexual orientation (being a bisexual) is not obviously deemed 'normal' by those who know little or not at all about it. Therefore, it can be said that Laila, prefers carrying an identity of a normal youth of today who is playful, determined, goal oriented, witty, curious, and impatient and want to live an independent life without any supervision of her parents. She does not see herself dependent on someone despite severe disability. She denies embracing the identity which is ascribed to her by society i.e. of a disabled girl and loves to explore herself with every passing day and is evolving as an individual with the passage of time.

## 1.5 DISABILITY AND EMBODIMENT

Turner (2001) in his work seeks to locate disability using a 'sociology of the body' that combines the phenomenology of the 'lived body' on one hand along with the Foucauldian tradition that examines external social and political structures that regulate and govern bodies and populations.

Wendy Seymour's work (1998) is a good example of phenomenological approach which asserts on how individuals manage social relations and personal role through management of their bodies. In her fieldwork where she interviewed people who suffered from paralysis due to spinal injury, Seymour's brings out the ways in which day to day task such as cleaning, bathing, washing, grooming, eating, etc. engage embodied individuals in the production and reproduction

of their bodies. Hence, the body is made meaningful in a phenomenological as well as social sense through appearance, sexuality, intimacy, routines, embarrassment etc. Seymour in her work assesses the reflexive task of making and remaking one's embodiment through day to day activities associated with these social categories.

The Foucauldian approach has been summarized as the study of 'governmentality'(Rose 1989:5). Governmentality attempts to describe the production of the body as an object of professional practice in the post-structural tradition. Foucault's critical writings can be extended to demonstrate how social and political institutions operate in the regulation and governance of disabled bodies. The process of rehabilitation, regulates and discursively producing the rehabilitated person through the orchestration of medical and social practices (Turner, 2001).

Rajeshwari Sundar Rajan, through the analysis of the widely reported cases of hysterectomies performed on mentally retarded women in Pune in February 1994, brings out the issues confronting institutionalized women against the worries produced by the unregulated sexuality. The experts in favor of the procedure dwelt upon the rise of unwanted pregnancy and the dirtiness of the menstrual cycle. The experts further argued that "the institution offer protection to women from the outside world just like a familial home because women are vulnerable; and they offer protection to the society from women because of the threat and danger they represent" (Rajan,2005: 142).

The cruel procedure of hysterectomies, therefore, 'disciplined' the uncontrolled sexuality of these women in its more visible manifestations viz, the danger of unwanted pregnancy and the 'pollution' of menstrual bleeding. On the Foucauldian view that suggest that institutions by their very constitution are regulatory, Rajan asserts that "*vulnerable Indian women.....caught in*

*travails of a rapidly changing society are desperately in need of the services of institutions like shelter , hostels, old age home and vocational training centers that only the state can provide and hence, are deemed to be regulated*".

The increasing valorized role of bio-medicine in the recent times has had a profound impact on the lives of disabled people all around the globe. By being stereotyped and labeled as a separate population on the basis of their impairment, the disabled people's very right to life has been challenged. Further, the recent advances in different field of medical sciences example, genetics is seen as a potential source to eliminate the difference at the foetal stage itself. Rainbow (1996) in his analyses of Human Genome Project, predicts a shift from socio-biology to bio-sociality i.e. the remaking of nature through technique such that nature will become artificial just as culture will become natural.

The above view of various scholars and theorists brought out some important perspectives on disability which emphasizes that how the non-disabled people or the 'normal' society construct those with impairments as damaged or even less than human to regulate non-normative populations in need of normalizations. These perspectives also highlight the varied experience of people with impairment to adapt and sometimes to confront and challenge these dominant discourses.

## 1.6 PEOPLE WITH DISABILITIES IN DIFFERENT PARTS OF THE WORLD

As discussed above, people with disabilities are not a homogenous group because of many kinds of disabilities. Taking about India in specific, the law recognizes seven types of disabilities based on a narrow medical context. The experience of disability varies from person to person and

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hence is unique to every individual. The difference in experience is based on many factors like culture, gender, caste, class, age and the presence of more than one disability For example, people with intellectual disabilities, those with visual, hearing and speech impairment and those with loco-motor disabilities all encounter different barriers, and have different ways of dealing with them. Also, two people possessing the same type of disability may have different experiences based on their socio-economic status, gender, age etc.

Persons with disabilities are degraded and devalued because of their restricted capabilities, societal participation and on other aspects of day to day activities. According to the World Bank Report titled People with Disabilities in India: From Commitments To Outcomes (2007), the negative attitudes and stereotyping about the capability of people with disability and the apprehensions towards them as the effective and productive members of the workforce is a bigger deterrent towards their development than the disability itself. Physical and mental disabilities that are visible are more stigmatized than invisible disabilities like hearing or speech disability, thus reflecting a hierarchy of stigma faced by persons with disabilities. We will now understand that how disability is conceived in different parts of the world.

## 1.6 a) WESTERN CONCEPTION OF DISABILITY

Roeher (1969) in his work asserts that the attitude of non-disabled people towards people with disabilities suggests that societal perception and treatment of persons with disabilities are neither homogeneous nor static.

Among the Greeks, people with impairment and the sick were considered inferior. Plato, in his republic recommended that the impaired or deformed offspring of both the superior and the inferior must be put in 'mysterious unknown places' (Goldberg and Lippman, 1974). The early

Christian doctrine established the notion that disease is neither a punishment of sin nor a disgrace but is a means of purification (Barker,1953). However, during the 16th century Christians such as John Calvin and Luther stressed that people with disabilities were possessed by evil spirits (Thomas, 1957).

Historically, the portrayal of disabled people on the basis of their bodily deformity in the mainstream culture has stressed their significant abnormalities (Barnes and Mercer, 1996).Gerber in his work The Careers of People Exhibited in Freak Shows: The Problem of Volition and Valorisation (1996), brings out that during the middle ages of Europe, the main stream people (normal people) had fascination towards the perceived bodily deformity or abnormality of people (disabled people). He further elaborates that many royal courts in Europe, specially retained people of short stature as "court jesters" or kept a complement of "fools" including people with cognitive impairments to provide amusement to normal people. It was also a ritual where people with any kind of abnormality (physical or mental) were put into display at village fairs, festivals and holidays. Gerber in his work, further asserts, that the parents of the infants born with defects toured the countryside and earned money by displaying their abnormalities.

In ancient Greece and Rome, almost every household had sprinkling of dwarfs, mutes, hunchbacks whose duty seemed to have been to undergo painful humiliation and degradation in order to provide amusement to normal people at festive occasions and get together (Garland, 1995: 46)

By the nineteenth century, the informal displays of people with abnormalities, developed into "freak shows" which was a formally organized exhibition to exhibit the people with alleged physical, mental and behavioral deformities at fairs, carnivals, amusement parks, circuses etc.

The practice of freak shows flourished in Europe and North America for a long time i.e. nineteenth century and early twentieth century.

The freak shows were undoubtedly the site for extreme exploitation and degradation of people with abnormalities. Although, some disabled performers gained a lot through this platform and enjoyed the celebrity status and really earned well but largely it was a site of humiliation. The subjugation and degradation of the people with abnormalities was further fuelled by the invention of "Ugly Laws" in the United States of America, which placed social restrictions on those whose physical appearance might offend or frighten the 'normal people'(Bogdan 1996, Gerber 1996).The popularity of freak shows declined in the early twentieth century and was presided over by other cultural forms. These practices continue to reflect and confirm the negative stereotypes about people with deformities and provided ample rationalization for treating them as defective (Barnes and Mercer, 1996)

**Lukeoff** and Cohen ( 1972) bring out that some communities ill treated the blind while others accorded them special privileges. Lippman (1972) in his analysis bring out that the people with disabilities in European countries such as Denmark and Sweden are more accepted than in U.S.A. He further observed that the degree of acceptance of people with disability is directly proportional to the financial resources of a particular society. These countries provided better and more effective rehabilitation services.

## 1.6 b) NON-WESTERN CONCEPTION OF DISABILITY

Study conducted by Hanks and Hanks (1948) suggests that in non-occidental countries people with disabilities were completely rejected by some cultures while in others they were considered as economic liabilities and by compulsion were kept alive by their families.

In Africa variations in the treatment of persons with disabilities is evident. In east Africa among the **chagga**people with impairments were considered as pacifiers of the evil spirits and therefore, a lot of care was taken to not to harm physically handicapped. Among the Benin is West Africa, constables were selected from the group of people with obvious physical impairment (Amoako, 1977). However, among the Ibo in Nigeria, people with disability were completely rejected (Wright, 1960).

In Ghana too, diversification in the perception of non-disabled people towards people with impairment exists. Among the Ashanti of Central Ghana, the traditional beliefs prohibited men with physical impairments from becoming chiefs whereas the children with obvious disabilities were also rejected. For instance, an infant born with six fingers was killed upon his/her birth (Rottray, 1952).

In the Indian context, disability as articulated in epics and scriptures can be explained through the karma theory. Dr. G.N.Karna (2001) brings out that in the Hindu doctrine of 'karma phala' disability in this life is a consequence of past misdeeds. He further asserts that in a third world country like India, where majority of people are illiterate and are narrow minded in their outlook, illness and disability is associated with disobedience to religious and natural principles. In the Hindu world view on disability, disability happens to a person because of his/her sinful life and as a result is subjected to wrath and avengement of God and Goddess.

Finkelstein brings out that the lower class people in the Indian society believe that the misfortune or ill fate in their lives is caused due to their association with the disabled individual living in their family. He thus, asserts that disability is not only associated with bad luck of the disabled person but also every person in their family.

Usha Bhate asserts that in primitive societies, the Darwinian concept of 'survival of the fittest' existed. The primitive tribe often abandoned their children with any sort of disability. The tribal chiefs supported the killings of these unfortunate children. In the primitive societies mere illness or any deviation from the expected normal behavior of an individual was thought to be disability. Ghai in her work (Dis)Embodied Form: Issues of Disabled Women (2003), brings out that the assumption associated with disability as a deficit is rooted in the dominant Hindu Mythology where two most important epics Ramayana and Mahabharata portrays people with deformity (Manthara, ' the hunchback in Ramayana and Shakuni 'the lame man' in Mahabharata) to possess a negative character. Therefore, it can be said that any kind of deformity, impairment, ugliness and disability associated with an individual was thought to be incarnation of something bad or evil. She also discusses examples to highlight that people with disabilities are considered to be the children of the almighty. She quotes the example of Ashtavakra who was a renowned scholar and suffered from eight deformities and the great poet Surdas who was visually impaired who possessed immense strength and had the ability to fight oppression through their work and intellect. Also in the ancient period Lord Vishnu's appearance as a Dwarf (The Baman Avatar) was to destroy the evil power of the raksas. Even Goddess Durga who possesses ten hands which symbolizes the additional strength and power to destroy the demon. Thus, it can be concluded that there is abnormality and supernaturalism that is associated with the deviation caused from the normal behavior and is often regarded as either the evil spirit or special powers bestowed by God and Godesses.

Throughout the globe, many changes have taken place in the status of people with disabilities and the treatment towards them but the remnants of the past beliefs do influence the present day practices (Wright, 1973). Also from a cultural point of view, there are many instances that have

influenced the living conditions of people with disabilities. History is witness to the neglect, ignorance, superstition, fear, hatred because of which many societies have categorized people with disability as 'deviants' rather than inmates by the society (Lippman,1972:89).

## 1.7 POLICIES AND PRACTICES

Disability has always been and still is a fragmented category due to the complexity and diversity associated with it. Disability cuts across race, caste and class divisions and therefore, the likelihood of framing groups was not easy.

The emergence of disability rights movements all across the world was the result of suppression that the disabled community has faced since time immemorial. These movements were the result of collective expression of people with disabilities. Disability rights movements like other movements in the post 1960's consisted of several conglomeration of individuals and groups with disabilities that came to be organized in the 1980s under a cross-disability umbrella representing the interests of the disabled as a group. The DRM all across the globe shifted the focus of disability from an impaired body and its medical construction to a matter of subjugation and social oppression where cultural value and social structures were seen as creating a disabling environment for people with disabilities and socially engendering and undermining their psycho emotional well-being. The DRM questioned "*the taken-for-granted notions which construed persons as able or disabled and uncovered the knowledge and power politics inhering in these discourses*" (Mehrortra, 2011).

Across the globe the polices laid for people with disabilities has evolved from the perspective of rehabilitation to the equalizing principle where more emphasis is given to equal opportunities for the people with disabilities to enhance their participation in the mainstream society. The right

based approach aimed at empowering people with disabilities in political, economic, social and cultural life in a way that is respectful and accommodating of their differences. 1970's is marked as an era where human rights approach gained huge prominence internationally following which the year 1981 was declared as the International Year of Disabled Persons by the United Nations General Assembly. It took more than a decade to acknowledge the sexual concerns and desires of people with disabilities and finally, in 1993 the UN General Assembly of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities raised their concerns under Rule No. 9 of the Standard Rules onEqualization thatdiscusses the right to family life and personal integrity of people with disabilities.

The rule states, "*Persons with disabilities must not be denied the opportunity to experience their sexuality, have sexual relationships and experience parenthood. Taking into account that persons with disabilities may experience difficulties in getting married and setting up a family, States should encourage the availability of appropriate counseling. Persons with disabilities must have the same access as others to family-planning methods, as well as to information in accessible form on the sexual functioning of their bodies.*"

For the very first time in the history, disability issues and the problems associated with it was dealt at a global forum at the United Nations Convention on the Rights of People with Disabilities (UNCRPD) in 2006. The convention gained huge popularity and came into force with the active participation of people with disabilities. Many countries including India became a signatory to the UNCRPD and pledged to provide all rights and services as stated in the convention.

Article 30 of the convention states the right to cultural life, recreation, leisure and sports. It is an important right with reference to sexual and reproductive health. Loneliness and isolation caused by structural and attitudinal barriers is one of the main obstacles for people with disabilities to be able to form relationships and friendships with people of a different or same gender. The realization of the rights in Article 30 would provide a person with disabilities the opportunity to be able to mingle with both non-disabled and disabled people in mainstream society.

India was no different when it came to policy making for the disabled. Although India is a signatory to the UNCRPD, its provisions are yet to be translated into national laws and policies for people with disabilities. The attitude of the Indian state was guided by medical and the rehabilitative model where people with disabilities were construed as dependents and were considered as the beneficiaries of the state. They were deemed to be incapable of formal employment and their responsibility was invested with their families. Post Independence, the National Council for Handicapped Welfare was established to frame guidelines for people with disabilities and to priorities disability programmes. The council comprised of central and state ministers and rehabilitation experts who regulated the activities of the central and state governments and of voluntary sectors. Disability was perceived as a diseased state and thus, emphasis was given to curing and to the rehabilitation services where the hospitals and primary health centres played a key role. The rehabilitation centres were responsible of education and vocational training of people with disability. The initial developments and work on disability was carried out in a vacuum with a little or no interaction with other groups and hence, were operating in a relatively apolitical context. (Malhotra 2001).

The Disability rights Movement in India started in the 1990's with the launch of the Asian and Pacific Decade of Disabled Persons which played as a catalyst for further developments

concerning people with disability. Following the start of APDDP in 1993, Government of India organized a national seminar to discuss the various issues concerning disabled people in India. The main need that emerged from the seminar was for a comprehensive legislation to protect the rights of PWD. However, it was only after intense lobbying of the Disabled Rights Group that the crucial legislation, the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, was passed in 1995 (Hosamane, 2007). The Act is considered as a watershed development in the history of the Disability Rights movement in India. Though the Act talks about rehabilitation and other services that must be given to people with disabilities but there is no mention of sexual or reproductive rights of people with disabilities.

Succeeding the Persons with Disabilities Act, 1995, many such Acts were enacted in India with reference to disabilities. The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, also known as the National Trust Act, 1999, was an important legislation. The Act aims at empowering people with disabilities to live independently and encourages them to participate in the mainstream society. It talks about providing support to the families of people with disability to ensure their care and protection. The broad provisions laid down by the Act can be extended to cater to sexual and reproductive health and rights. For instance the health aspects can be extended to include sexual and reproductive health services and information.

The disability-rights movement claims to take cognizance of the rights of the disabled with diverse impairments. But the women with disabilities who seem to suffer from multiple disadvantages have raised several issues and have argued that the disability rights movements are male-centric and the women have been largely ignored in the process (Ghai 2003) Feminist disabled women have also accused women's movements of not paying attention to their

concerns. Today many women disability rights activists have accepted prominent positions not only in the DRM but also with Government bodies, and even in the private sector. Undoubtedly, DRM have made a huge difference in the lives of people with disabilities and has pushed for a more disabled friendly environment in the country but in India it is still trying to make its presence in the public sphere.

The DRM's all across the world has played a crucial role in constructing the disabled as a political category and has promoted their right to live life with dignity, free from stereotypes and stigma and as regular or "normal" people. In the Indian context the change in the terminology, i.e. from "crippled" to "handicapped" to "physically challenged" or differently abled to finally "disabled" to designate persons with impairments reflects the politics of the time. People who have a certain level of awareness and consciousness would proclaim themselves to be disabled. In some contexts the term "differently abled" also came into usage but it has not found much acceptance among rights activists for its ableist connotations. Mehrotra in her study in rural Haryana states that "*most women with impairments did not see themselves as disabled as in their cultural terms it translates as being "dependent" an identity they refuse to embrace*". Disabled as an identity has a limited reach owing to its common sense understanding of being "incapacitated", "dependent" and also due to the stigma it seems to carry (Mehrotra, 2011).

There is no doubt about the fact that the disability rights movements has touched the lives of masses of persons with disability and pushed for a more disabled friendly environment yet it is still trying to register its presence in the public sphere in India. Given the enormity of the country like India, the provision for accessible environment or disabled-friendly infrastructure, job reservation, rehabilitative and support services for people with disabilities have to be contextualized within the larger picture of deprivation and marginalization. Unlike the West

where the State and the International agencies are completely responsible for the rights and development of people with disability in a country like India with poor social security mechanisms, much is left to families and communities as they have traditionally been responsible for taking care of their disabled members.

In the recent years the shrinking of community and family support mechanisms has reminded the State of its responsibility towards its disabled citizens. The State has played a crucial role in formulating acts and policies, initiating disability prevention and rehabilitation programmes and promoting organizations affecting the lives of millions of disabled in the country.

With the changing scenario there are enormous challenges before the DRM's. To build a strong and an influential movement it is essential to recognize the diversities, historical, social structural arrangements, fast changing social, political and economic dynamics in the Indian context.

# CHAPTER TWO

## LIVING WITH CEREBRAL PALSY: SYMPTOM RECOGNITION, DIAGNOSIS AND LIFE AFTER DIAGNOSIS

Cerebral palsy is a commonly used name for a cluster of conditions characterized by motor dysfunctions due to non-progressive brain damage caused early in life. It is one of the most common causes of childhood disability. The severity associated with CP can range from total dependency and immobility to bewildered behaviour expressions with clumsy actions that threaten the cultural conventions regarding child rearing practices and developmental expectations. Te brain damage results in disorganized development of neurological mechanism that results in abnormal postures, poor isolated movements and biomedical difficulties whereby, everyday experience of child rearing which is taken for granted experience is shattered when confronted with such an unexpected 'natural' reality (Levitt,2003).

The overall functional delay and the abnormal performance of the child impacts social, communicative and emotional functioning (Wing, 1988). It is only around the second year of the child's life that some of the parents involved in this study became aware that there was something unusual about their child. A further inquiry of the illness narratives uncovers the conflicts that a particular illness evokes in a society and indicates political and moral processes that operate within that community (Lewis, Fernandez and Kleiman, 1995). The narratives discussed below reveal how the notions of 'normalcy' is subverted by behaviour that initially seems to be confirming and easy to explain but gradually coalesce to form a pattern that defies common sense explanation.

## 2.1 SYMPTOM RECOGNITION: IDENTIFYING ATYPICAL DEVELOPMENT

In the initial days of child rearing it is extremely difficult for parents to identify signs that may indicate that the child has cerebral palsy and to acknowledge the fact that their child is not 'normal'. Built into this proposition is a cultural understanding of what constitutes 'normal development'. Studies conducted on symptoms of related development disorder brings out that the symptoms that elicited most concern was lack of social relatedness (Daley, 2004).

Savita is mother of Harsh and Preeti. Her younger son Harsh who is eight years old is affected by severe CP and is quite different from his regularly developing elder sister who is twelve years old. Savita recalled one incident when she took Harsh to Preeti's school to pick her up. She met an old friend who had come with her younger son to receive her elder son from the same school. Savita narrated that her friend's younger one reacted with so much excitement on seeing his elder brother coming from the school but her son, Harsh did not show any emotions...... '*Harsh did not seem to care that Preeti was back!*' Savita was in a state of uneasiness on noticing her son's behaviour. Just like Savita many parents were confused about their child's apparent obliviousness towards the people and the world around them.

Delayed speech was another major concern for parents. Parents were concerned about the inability of their child to speak. One of the parents recalled a visit to a birthday party with her daughter then aged two. The mother Janvi was unsure about her daughter's problem then. On seeing her friend's child who was of the same age, her comparison ended there. Janvi was shocked to see the things her friend's daughter could do like, following her mother's command..... 'darwaza band kar do (close the door), dodo lo lekarao (Get dodo (her toy) along

with you) and she obeyed all her other commands and was so talkative. But her daughter was unresponsive to anything she did or say……….. '*Not only my daughter was weak and was unable to walk, she was also inactive in comparison to other children of her age. She hardly spoke anything.'* Even after so much, Janvi was not convinced that her daughter was not 'normal'. And quite often convinced herself by saying 'seekhjayegi' (She will gradually learn).

Manav is ten years old and looks fine unless one sees him on his wheel chair which is always wheeled by someone. He has CP and autism. His father Prakash told about Manav's strange behaviour like sudden inexplicable display of fear since quite an early age. One evening their entire family was sitting and watching a movie on the television. The fighting scenes and the loud noise disturbed Manav to such an extent that he gets frightened every time he comes to the TV room. '*He is extremely sensitive to loud noises and fears them'* said his father. Although his parents are trying to desensitize him by exposing him to music and making him familiar to different sounds but unfortunately he has not shown any progress yet.

The above mentioned family narratives of the early years of their children's behaviour and episodes were a cause of concern that something is wrong somewhere with their child. However, it was difficult to pinpoint the reasons for such odd behaviour of their children. They could not exactly understand what was "wrong" as they were doing many other things that parents look forward to; they were reacting while seeing a toy, exploring the environment and showing positive gesture on seeing their parents. During the early years of parenting, many parents within the sample were negotiating with their own self by convincing themselves that the children's strange behaviour was due to lack of maturity (abhisamajhnahihai), due to small age (abhibahutchottahai), obstinacy (ziddihai). But as the unusual behaviour persisted and became difficult to 'excuse' or 'condone' (because the child was expected to learn self control) the

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parents started to worry about the unusualness in the child's behaviour. In some cases the absence of any physical stigma and the usually attractive appearance of their children did not mark them as 'abnormal' and mislead parents in understanding the problem of their children.

The narratives discussed above reflect the experience of families whose children development was atypical from the beginning. Four families in the sample recounted that their children developed normally for the first one and a half year to two and then started regressing.

A fifteen years old girl Saumya whose early development was reported to be 'normal' by her family members appeared to regress after a prolonged fever at the age of one and a half years. Her mother Pooja recalls and shares……… '*Saumya turned into a robot. She almost lost interest in playing and stopped responding to the stimuli, she used to stare at the wall ceiling continuously for hours*.' Initially, her parents attributed these symptoms as the side effects of the medicines she consumed for fever but they soon realized that she has lost all abilities of returning to normal. Since then she is on bed and needs help for everything.

In yet another case of Rohit now aged twenty one is the only son to his parents after two daughters. He was born in Kota in Rajasthan through normal delivery. When he was six months old, the family went to Haridwar on a pilgrimage. Upon their return to Rajasthan, Rohit had developed high fever and remained unconscious for almost two days. The local doctor suggested Surendra, father of Rohit to immediately take him to Delhi. The fever subsided after medication in Delhi and they returned to Rajasthan. Rohit showed no signs of abnormality till the age of three years. However, the parents were alarmed when Rohit did not start walking at the age of three. His parents finally took him to Delhi's Kalawati Saran Children's Hospital. It was there that the doctors informed that there was no cure of Rohit's condition and he should be admitted

to a special school. Their son's condition led Rohit's family to permanently shift to Delhi. Rohit who is now grown up has stiff arms and fingers. His lower body does not function at all. He has an enlarged tongue due to which his mouth does not close properly.

In both the above discussed cases the children already had regular developing siblings. Hence the parents were well versed with the practices of child rearing in normal development scenario and could have picked up signs of atypical development but the notions of normality and denial towards abnormality and disability led to the non recognition of symptoms by parents which were evident.

## 2.2 RECOGNITION OF THE PROBLEM AND HELP SEEKING

Mechanic (1978) writes about help seeking behaviour in the context of illness and disability. He talks about social selection of symptoms wherein much emphasis is given to the unusual characteristics of individuals and groups that makes them different in some way or the other. Most of the literature on illness brings out that people are likely to take action for symptoms that disrupt usual functioning. Mechanic identifies the following determinants affecting response to disability/illness which is based on the 'health belief model' proposed by Zola:

1) **The visibility, recognisability and perceptual salience of deviant signs and symptoms**: With respect to early signs and symptoms of CP like muscle and tendon stiffness, trouble crawling and walking, delay in reaching developmental milestone, poor manual coordination, speech difficulties, lack of social relatedness and lack of emotional reciprocity, parents of the affected children found it hard to conceptualize them as symptoms of a medical or clinical condition. Very often symptoms mentioned above were viewed to be lack of maturity in the child, obstinacy, nutritional problem and bad

parenting. Symptoms like child's withdrawn and aloof behaviour were not viewed as symptoms at all rather it was associated with the character of the child. The affected children were often related to relatives in the extended family who were 'late developers' but usually turned out to be talented or gifted. Since there was an absence of awareness about Cerebral Palsy as a developmental disorder, the perceptual salience of signs and symptoms was not very significant.

2) **Estimating present and future possibilities of danger**: Since the families of children with CP had difficulties in recognizing signs and symptoms and in conceptualizing the odd behaviour of their children as symptoms of a disorder, they were thus, unable to accurately assess the possibilities of danger.

3) **Frequency of recurrence of symptoms**: The above discussed cases bring out that families of children with CP reveal that the symptoms of their child increased and intensified over the first few years of their life. By the average age of three to four years, all children in the sample, displayed were decidedly different from the norm. Some families reported atypical developmental patterns from the beginning while others reported regression after a certain period of comparatively normal development. However, even though the children looked like any other 'normal' child but they were lagging behind in the areas of communication and social development.

4) **The extent to which family, work etc get disrupted because of symptoms**: Parents of children with CP resorted to help seeking as a result of disruptiveness of their child's symptoms. Some of the behaviours displayed by children like numbness in social relations; lack of communication etc. causes immense distress in the family. Parents were sometimes hesitant to be accompanied by their child in social gathering with the fear that

the child might feel uncomfortable and might get uncontrolled. Hence, family outings and routine activities like shopping, visiting friends and relatives were reduced to a great extent.

5) **<u>The tolerance threshold of individuals exposed to symptoms</u>**: The tolerance threshold of families for many symptoms took a heavy toll of the family's physical and psychological reserves. Cultural beliefs like boys start speaking late and many other made families gloss over these symptoms. The signs and symptoms were usually considered as a product of reduced opportunities for interaction rather than a development deviance.

6) **<u>Available knowledge, information and cultural assumptions</u>**: The complexity and lack of knowledge amongst both the lay and the professional people about the condition/disorder contributes immensely to early symptoms not being 'picked up' by parents and clinicians. The notion of 'normalcy' and cultural assumptions about child development allude to the non-recognition of symptoms.

7) **<u>Denial of symptoms including the desire to normalize the situation or keep it under control, sense of blame, shame, guilt etc</u>**.: It is extremely difficult for parents to acknowledge that their child has a potential 'disorder' which is unfortunately a lifelong one. The social stigma attached with a disorder is abhorrent for families. In one of the narrative by a family, the mother of the affected child would often invite children from neighbourhood and also the children of domestic helpers to play with her child in order to resort to various rationalizations to cover up their worries. Urmil mother of Raghav aged two and a half years recalled: " *We all were fooling each other........we could see that things were not fine at all......but we were making deliberate efforts to see to the other*

*side. Our child used to smile looking at us but he was not able to hold my finger, neither he was able to kick me from his small little feet which were always still".*

8) **Needs competing with illness responses**: Families could not seek help due to other commitments and other equally pressings needs which included care of other children, career related responsibilities and limitations like financial constraints, lack of facilities in their region/state which in some cases resulted in push migration.

9) **Normalization of symptoms**: One of the parents in the sample taken asserted that discipline, order and normalcy are revealed only when they are breached and developmental disorder is one such breach. Once it is recognized and acknowledged that the child will remain different and will be dependent throughout his life, one automatically develops strength to counter that challenges of future and look for remedies to help the child grow in the best possible way in the limited things he/she can do.

10) **Availability of treatment (proximity, cost, knowledge etc.)**: The narrative of Rohit's parents discussed above is one of the few families in the sample that migrated to Delhi for better facilities. Families that migrated to a new place faced different hurdles and were subjected to multiple referrals sometimes leading to inaccurate diagnosis and above all 'uncertainty'. It was after many referrals and tests that the exact problem was revealed to the parents. The families faced many other challenges related to monetary cost involved in the consultation of doctors, long leave from work, loss in business and above all managing a child with difficult behaviour in altogether a 'new place'.

Unlike physical deformities and handicap, developmental disorder like Cerebral palsy is a disorder that is also characterized by social and emotional deficits which are not easily recognized as a symptom of a neurological condition. Thus, numbness in child, his/her aloofness,

speechlessness can be attributed to his/her nature or characteristics. But gradually when these symptoms pose a challenge to the functioning of a family and create situations of social embarrassment, the need to 'normalize' overcomes the need to seek help. When the family of the affected child acknowledges that there is something that cannot be explained, then the search for the proper diagnosis acquires salience. The next section deals with the complex process of obtaining a diagnosis.

## 2.3 THE PROCESS OF OBTAINING A DIAGNOSIS

Recognition of the problem is the first step of the process in the understanding of the 'unusual' happening to the child. Parents are usually disheartened to learn that there is no single test to accurately diagnose a child with CP. A series of medical evaluations are initiated in order to form a diagnosis. Parents on the other hand prepare for a long and sometimes a frustrating process that will in time provide answer for the child's condition becomes extremely difficult for parents to acknowledge what is exactly wrong with the child who otherwise looks physically pleasant and attractive but at the same time are apprehensive about the child oddities.

Some of the narratives bring out the ordeal of parents and reveal "moments of truth" that forces them to confront that something is amiss. One of the parents described how his two year old son woke up from sleep one morning...... *The look on his face was completely blank.....which shocked me. I called up my wife who was in the next room. She consoled to me that he will be fine after few minutes but I knew then......it just hit me and made me very uncomfortable".*

Different narratives had different "diagnosis stories" but there was one thing common in all the narratives and it was the oscillation between doubt and hope. The uncertainty of not knowing the reason of what is happening to the child as the doctors and specialists appeared unsure initially.

Later, on revealing the cause of the child's problem, parents were in the state of shock, pain and disbelief when they received the news that the child's problem has 'no cure'.

## 2.4 MULTIPLE DIAGNOSES AND MULTIPLE REFERRALS

The diagnosis of Cerebral Palsy is a time taking process. Parents often get frustrated with the ambiguity associated with CP as there is no singular test that will accurately diagnose a child with CP.Doctors and practitioners have to be cautions. It is required that they draw a fine line between making the families aware about the child's deficits and sensitizing them towards delays in child's development and delivering a definitive diagnosis which may break the spirit of the families. In the narrative of Rohit's parents discussed above it was revealed that thedoctors were not always sensitive. The doctor they visited in Kota, Rajasthan gave the diagnosis which was not less than "a death sentence", for Rohit's parents. They were told by one of the private doctor that, "isskakuchnahi ho sakta….bas ghar par rakhoisse" (Nothing can be done for him. Just keep him at home).

Most of the parents in the sample taken, reported that they had visited a number of doctors before obtaining the right diagnosis. In all the narratives it was revealed that the parents of the affected child visited their family doctor (general physician) who had usually seen the child since day one. The doctors would try to reduce the family's worries and fears by giving them reasons like; all children are not the same, some take time to adapt and learn, or blaming parents for not taking adequate care of the child. The family would usually return home reassured but soon become disturbed by the child's symptoms (new ones or persistence of the earlier ones). Some families returned to the same doctor while others sought another opinion usually a pediatrician, orthopedic surgeon, private practitioners and other specialists.

However, during a personal conversation, a doctor remarked on how difficult it was for medical professionals to give a 'definitive' diagnosis because of cultural and social factors……. "it is extremely difficult for us to say directly that there is no cure of the disorder that the child has and in some cases the child will be dependent throughout his life…in such a case parents shatter completely…... and there are families, rich, educated ones who just put the child away for the rest of its life because he/she is disabled and there is a stigma attached to disability. The scenario is worst if it a girl child." Apart from medical diagnosis some parents also referred to the Internet and other sources like magazines to inform and educate themselves about the disorder.

## 2.5 IMPACT OF THE DIAGNOSIS

Hollinrake in her work 'Young Children with Disabilities' (2005) talks about the good and the bad practices in diagnosis and disclosure. She writes that she is often struck by how parents with children suffering from disability readily discuss their recollections of the later year. She further assets that the freshness of the past memories is an indicator that how alive does the issues remain for them as it was a significant turning point in their lives. Further, in her work she criticizes professional culture which gives much emphasis to the medical model which focuses on cure and treatment and has nothing to offer to parents of children with disabilities. She cites the work of Cunningham et al (1984); Quine and Rutter (1994) and Scope (1994) which demonstrates that the way in which parents are informed about their child's disability negatively impacts their attitudes and ability to adapt to parenting a disabled child in the long run.

The narratives of the parents reveal that the moment of truth about the child's disability is a liminal moment. It is a time when their inner subjectivity does not fit with that of the world around them. The world around them turns hostile as if there is no place for the child and his/her

family in the world. Many parents reported that at this crucial juncture of their lives, they needed the support of people who could understand them instead of giving them strange looks or blaming and ridiculing them.

We will understand that how the respondents construed disability before they experienced it themselves (on knowing that their child is disabled). Most of the parents in the sample taken had seen or known someone in the extended family and in the community with some sort of disability but none has encountered disability in their immediate family (parent, sibling, paternal or maternal aunt, uncle or cousin). Cerebral Palsy was an alien term for many as they were unfamiliar about it. Only few had heard the term before while reading newspapers and magazines. However, none of them had an idea of what CP is all about, how actually it 'looked like', what were its behavioral manifestations and how it was different from other disorders. The term 'disabled' connoted an individual who was dependent, helpless, pitiful, dull, vacant, slow, with sluggish physical movements, physically unpleasant, drooling mouth and low intelligence. One mother informed that she could not digest that her child had a lifelong disorder which is has no cure at all...... "*I was shocked to hear that my daughter had CP, we could never make out till she was 18 months old....she looked like an angel and was so beautiful when she was born.....who could say she had Monoplegia*".

Since the stereotype associated with disability contains strong elements of rejection, fear and revulsion, people with disability are considered 'unfit' to live in a world that values independence, productivity and achievements, especially the non- disabled people. Trent in his work 'Invention of the Feeble Mind' (1994) brings out the mind-body dualism characteristic of Western thought. This thought has now disseminated to the ideological make-up of the Indian middle class, where much emphasis is given to academic achievements which is considered as

the key to social mobility and status. Thus, when the parents were informed about their child's life long disability, it came as a great shock to these middle class and upper class and well qualified families. One of the mothers shared ………..."*When I was pregnant with my first baby, I had no particular choice of a girl or a boy, I always wanted that my child should be beautiful and brilliant*". The realization of the child's disability came to her as a great shock as the disability associated with the child meant the loss of a beautiful and a brilliant child that she and her husband was expecting and coping with reality that the child will be dependent throughout his life and he will have to be nurtured and taught with utmost patience unlike other children in their family and social circle who did everything with such ease.

The reactions to the diagnosis by the families were greatly influenced by the middle-class aspirational structure, the need to earn a living through one's physical and intellectual capacities and attainments, the competitive educational system and the changing family structure which is diminishing the traditional avenues of support. The disclosure of the child's actual problem resulted into tension and worries about the future but their immediate response to their child's disability range from denial, shock, anger, despair and disbelief. One of the hardest things for all the parents was to accept that their child's disability was "incurable", that no medicine, therapy or treatment could make the child "normal" ever. Kashish, the mother of Akshay was told by the paediatrician…….."*yeCPhai... iska koi ilaajnahi ... aapise accept karlijiye…..*" (It is Cerebral Palsy, and it is incurable. You must accept the truth as it is). Kashish was to spend the next few months just holding Akshay and weeping all the day as she blamed herself for his condition. She started to compose herself when she realized that the environment at home was negatively affecting her elder son's performance at school and even socially.

All the parents were told one same thing that "your child can never recover" or its variants which came as the greatest shock of their lives. The shock was followed by a long period of intense grieving, sometimes for years at a stretch.

After coming to the term with the child's disability, parents usually engaged themselves in the task of re-organising and re-grouping. The factors that played important role in accepting the child's disability included their affection and love for the child, the need to protect and nurture other children (if any) from the crisis, by believing that they were given a "special responsibility" to be the parents of a disabled child by the almighty. The following quotes from the narratives represent the last point:

"*My wife and myself consoled ourselves saying that we are on a special duty and Saumya was given to us for a special purpose*". (Devendra and Seema, parents of Saumya (now 21 years old)).

"*I conceived after 10 years of my marriage to Harish. We both were very excited about our first child. But when we came to know about Ansh's brain injury during delivery we were taken aback. Gradually, we came to know that had spastic diplegia cerebral palsy because of which both his legs were unresponsive. This was not easy for us to digest but then we told to ourselves that it is our destiny.....and there is a part of God in our Son*" (Khusboo, mother of Ansh who is 17 years old).


## 2.6 GRIEVING AND COMING TO TERMS

It is not easy for parents to come in terms with their child's disability so easily. The psychological models are derived from the concerning human reactions of loss that is used to understand the impact of a child's disability. These models are based on the notion that the

parents are grieving the loss of not having a normal child that they were expecting to have. Worden (1991) and Bowlby (1979) in their model bring out certain stages and phases of shock and grief along with certain tasks that have to be accomplished in each stage. These broadly cover the following:

- shock and numbness

- sadness and depression

- denial

- anger

- bargaining

- yearning and longing

- acceptance and re-organization

These models impose certain judgments about what is normal and abnormal ignoring the individual difference in grieving process. Payne (1999) brings out that the new models give much emphasis to the individual context of grief, social behavior, spiritual as well as emotional and physical ones.

Wickler (1981) used the concept of "chronic sorrow" which was developed by Olshansky. He applied the concept of chronic sorrow to the parents of disabled children suggesting that the grieving process was ongoing and the day to day events often serve as reminders for the loss they have suffered of not having a normal child which re-awakens the process of grieving. For example: watching kids of other family members and friends grow and develop normally reminded parents of their child's life long disability. Chronic sorrow surfaced sharply during social get together and family occasions when these differences became evident. Parents reported that during social gatherings when the achievements of other children were discussed with pride,

they felt completely helpless and had nothing to share about their child with their friends and relatives. The father of a young boy shared that his son had all virtues a person should possess like simplicity, honesty, affectionate and hardworking but he was compelled to remain on the fringes of society because of his disability.

It was also seen that the grieving process is also gendered. The mother on one hand reported extreme emotions due to the greater proximity with the children and hence took the news of the disability very hard. The mothers usually felt a sense of helplessness, anger, discomfort and blamed God and destiny for the condition of the child but they were simultaneously more protective and showed the feeling of love and care. On the other hand the fathers too were extremely disturbed with the family circumstances but soon had to resume their position of bold and strict yet being doting fathers. Undoubtedly, the disability of the child was extremely disturbing for the fathers. Some of them started devoting extra time to work with the justification that they need to provide for the child's future thus, extending the working hours. One of the respondents resorted to staying out of home for long intervals and took refuge in drinking to get away with the sorrows for a while. But majority of the couples became each other's support system in the tough times. They shared the grief together seeking solace in each other. They compensated for each other's weaknesses so that the care of the child was not compromised. Some felt that the bond between the husband and the wife has deepened and they understood each other better. Blumstein (2001) defined the couple's dependence on each other, speaking for each other, covering of each other's lapses and presenting a united front despite their innate differences as "couple work".

## 2.7 a) CASE STUDY

Ritu and Naveen's Son Anurag was diagnosed with CP when he was one year and one month old. Riyu recalls that those days were not less than a nightmare for her and her family. She could not console herself for months and was in state of depression. She found her rescue in 'puja' and used to go to the temple twice in a day. But she was always surrounded with negativity after doing almost everything. She was still not able to digest that her son had CP. More than understanding what is CP and what should be her next course of action for her son, she always wondered why her son acquired this problem and what went wrong? She kept reminding herself that when she did not do anything wrong with anyone how could such a bad thing happen to her child? But she failed to get the answers to all her questions that disturbed her every minute. Her husband, Naveen used to spend most of his time outside his house. Ritu recalled that Naveen was never so busy before, she felt he was simply running away from the reality although she too could not accept the reality. Naveen had developed drinking habit and used to drink heavily. She was scared to talk to him and never used to open her heart in front of Naveen as it always lead to emotional scenes that left both drained and uncommunicative which further used to exaggerate the tension. She became highly protective of her son and became very sensitive towards her comments. Naveen on the other hand believed that he was repaying a loan of previous birth. They did get support from both the sides of the family but the well-meaning advice which was only given to Ritu about how to handle the child which always used to upset her. She could not sustain the frustration inside her and one day broke down and wept in front of her husband. She confessed her helplessness in front of Naveen. As her knowledge and awareness about CP increased gradually, she realized her son's case was better than others as Anurag had moderate CP which came to her as a major relief. The birth of the second child who was absolutely normal

gave back her confidence as she was engaged in rearing up her baby girl normally. Anurag too was quite affectionate about her baby sister and showed improvement in his social skills.

Ritu tried to create a smooth environment at home by comforting her husband. Naveen who had completely broken from inside kept his feeling to himself. Ritu realized that men are inherently weak and it is the women who have the courage to self-sacrifice and are ultimately responsible for holding their families together. Moreover she believed that Anurag needed the support of both his parents and therefore, was determined to save her marriage to Naveen for her children's sake. With the passage of time Naveen reconciled with the truth of his son's disability and devoted himself spiritually. He saw gradual improvements in his behavior and his affection for his wife and children and the sense of responsibility towards his family increased specially for Anurag .

Today the couple has reached a stage where the truth of their child's disability has penetrated in every aspect of their lives. They desire for 'no miracle' to happen and have accepted the reality as it is. Naveen regrets for his behavior in the past and praises Ritu for the immense courage and patience in holding the family together. In the same family the parents showcased different styles of coping with their child's disability. Now they stand together to help Anurag who is in his early 20's to meet the future challenges.

## 2.7 b)DISCUSSION

The above narrative brings out plethora of emotions experienced by Naveen and Ritu. It brings out that how acceptance and grieving are not just individual experience but are experiences in response to and in synchronicity, with the feelings of other family members as well. Although Naveen and Ritu both were initially experiencing their own burden of pain and sorrow because

of their child's disability yet they gradually accommodated for each other's responses. Before reconciling with the truth of their son's disability Naveen enacted the role of a tragic hero while Ritu was the long suffering heroine. With each of them putting the efforts to keep the family intact is evident. The 'couple work' they perform ensures that the family is not shattered and is not threatened as a unit. The immense grief and pain which was once a part of the couple has now paved way for determination and commitment the couple has towards both their children especially more for Anurag. They put strenuous efforts in upbringing their disabled child to enable him to "pass". Ritu puts an extra effort to dress up Anurag and is very particular about his appearance and behavior in public. Naveen on the other hand makes sure that Anurag interacts with his friends and other people in social gatherings. Both of them are particular about his studies as he is presently enrolled into an undergraduate prgramme. The couple is doing their best to make Anurag 'fit in' so that he is accepted in a society which is ruled by the non-disabled population.

## 2.8 a) MAKING SENSE OF THE DISABILITY: EXPLANATORY MODELS OF CEREBRAL PALSY

A disease or illness is not merely a biological event but it has cultural connotations as well. Susan Sontag in her work "Illness Metaphors" (1989), brings out that how certain myths, ideologies and metaphors (either positive or negative) are associated with any disease or illness which may gradually change with time  and is sometimes based on half or incomplete knowledge about the disease. These myths and ideologies have a powerful impact on both the patient and the care giver. Susan pertains to cancer and AIDS for her analysis of illness metaphors. Sontag in her work brings out that how AIDS is conflated with delinquency, indulgence and perversity and

cancer with warfare. Kleimman (1980) brings out the "disease explanatory models" through which he reveals that how people attribute meanings to various diseases and perceive them in accordance with the meaning they attach to it e.g., leprosy is interpreted as danger and defilement of 'inferior races' due to its preponderance in tropical countries which were the victims of colonization (cited in Bharat, 2000) .

Shalini Bharat in her work 'Perception of AIDS in Mumbai: A Study of Low Income Communities' (2000) studied the perception of the low income communities in Mumbai towards AIDS. She brings out that AIDS was considered as an alien disease which was brought to India by morally degenerate foreigners. It is perceived that AIDS is picked up by engaging in shameful and promiscuous acts often with prostitutes. It is also viewed as God's punishment for sinful acts. It is seen as the disease of 'others' which is polluting and contagious and isolates people from the community. Such beliefs and myths indicate why the sufferers of the disease and their family is ostracized and even sometimes denied the basic human rights.

In case of physically deformity caused by Cerebral Palsy, people usually associate it with helplessness, dependence, vulnerability, inefficiency. He/she is considered as incompetent in performing day to day duties and incapable of playing different roles which a normal person does with ease. The families of affected person or the sufferer is usually blamed for the individual's condition. Since people have less or no knowledge of the reasons and causes of CP and is also not curable it is viewed as the punishment of past deeds or the product of past Karma. In the section below an attempt is made to make a sense of the metaphors that the family (from the sample taken) of the patient associated with cerebral palsy.

   a) **Cerebral palsy as Karma**: Some couples associated the disability of their child as their or their child's 'karma' in the previous birth. Even the highly westernized, English

speaking, cosmopolitan couples attributed the reason of the child's disability as 'fate'. Kavita mother of Prateek recounts that her mother in law blames her for her son's condition as she violated meat eating taboos soon after her delivery and consumed meat and chicken on regular basis. One of the fathers of the affected child blamed himself for getting his child discharged early from the hospital even when the baby was kept under observation. He also blames the doctors and the hospital staff for misguiding the couple. In the early years of grappling with the child's disability many couples searched for the explanation regarding the condition of their child but gradually they gave up thinking 'why' and focused more on 'what next' and 'what should be done to comfort the child?' A Hindu Brahmin family expressed their faith in 'God' and believed that whatever has happened to their daughter is simply 'God's will' but expressed their concern and worries they have regarding the up-bringing of the child. They further believed in the power of their prayers which eventually resulted in the improvement in the condition of their daughter. One of the single mother shared that she had terminated two pregnancies seeing her family condition and her husband's ill health. But later when the couple wanted to have a child, they were blessed with Tejas who had severe CP. She considers it to be her fate that Tejas was born to them and believes that maybe it is a punishment by 'God' for terminating the previous two pregnancies. She also shared her tough times when she lost her husband but could not miss Tejas's treatment (physiotherapy) even for a day.

b) **Cerebral Palsy as a Curse**: Some parents in the sample taken believed that their child was an accursed being because of the difficulties he/she has to face on account of the disorder they are suffering with. One of the parents shared that they feel completely helpless when they are unable to identify the reason and the cause of their child's distress.

Sudarhsn father of Kavita shared that her problem is a curse not only for her but for the entire family. Kavita exhibits very difficult behaviours like screaming, crying and sometimes becomes very rigid……..'*We cannot leave her alone for a second; she becomes uncontrollable if she sees me walking out of the door. My wife is a qualified engineer but had to leave her job because of Kavita. It seems that nothing is left now and our future seems dark to me'*.

The fear of the parents that their affected child will always be dependent on others for mercy negatively impacts the psychology of the parents. The belief that their child will never be able to experience companionship, love, sexuality and parenthood fortified the notion that disability is a 'curse'.

iii) **Cerebral Palsy as an enigma (a person or thing that is mysterious or difficult to understand):** Cerebral Palsy is a complex disorder as a range of unpredictable symptoms and strange characteristics of children make it difficult for parents to deal with it. The mother of Manav aged 10 years shared, '*when we take Manav for a haircut he is very unpredictable every time. Sometimes he does not allow the barber to come close to him and starts shouting which make the situation difficult for us. We also believe that the snipping sound of scissors close to his ears aggravates his sensory issues. The strangeness of barber's chair and cape wrapped around him further aggravate his fear and discomfort. Although, we and his counsellor train him for different situations at home yet we cannot predict his behaviour*'. Undertaking elaborate exercises which appear to be a daily routine and mundane activity for others often frustrates and exhausts the families of children with cerebral palsy. Training and counselling of such children does

not guarantee success always. Also it is difficult for parents to predict that how their child will respond in a particular situation.

Cerebral Palsy undoubtedly impacts the social interaction that makes it an enigma. The absence of any physical deformity and the very 'normal' physical appearance of children in some cases make it harder for parents to comprehend the reasons of uneasiness of their child.

iv) **Cerebral Palsy as a sign of divinity**: The innocence and the sensitivity that parents attribute to their child with cerebral palsy are sometimes conceptualized in mystical terms. The appearance of the child, their self-absorption in the world of their own and the physical beauty some children are endowed with are few features that are associated with 'divinity' and them being 'spiritual' beings.

## 2.8 b) DISCUSSION

The metaphors highlighted in the narratives of parents appear contradictory like curse versus divine, but in their very contradiction they epitomize the complexities that are associated with cerebral palsy. The use of metaphors like innocence, divine, curse, karma etc. bring out the never ending efforts of the affected families to make sense of their child's disability and to come in terms with the circumstances. Despite the severity of the disability the affected children are not viewed as some deficit rather they are loved and cared like any other member of the family. Parents in the present study spoke at length about their love and affection for their children with cerebral palsy. The parents feelings for the affected child had elements of pity, sorrow, fear, responsibility, protectiveness, frustration, resentment etc. This complicated mix of feelings reflected in their understandings of the child's disability. The parents gradually adapted to circumstances where they started viewing Cerebral Palsy as intrinsic to the personality of the

child rather as an impediment which will stay with their child throughout his/her life. Some parents even found it a difficult task to imagine their child as normal and cured of the disorder as then the child will not be him/her but somebody else.

It was hard to accept that parents did not take recourse to some kind of magical, faith-healing and supernatural remedies as it is deeply ingrained into our cultural matrix. There lies a contradiction in the conceptualisation of the disorder by the parents. On the one hand cerebral palsy was conceptualized in mystical terms rather than medical whereas on the other hand parents insisted on medical interventions for the treatment of their child.

The daily encounter with CP as narrated by families is an ongoing process of adjustment and understanding. The ingrained notion of normalcy further complicates the acceptance process. The redefinition of parental roles and grieving for the 'lost' normal child while loving and accepting the one that has been given to them involved a great deal of negotiations and sometimes challenging the conventional norms of childhood and parenting.

# CHAPTER THREE

# CRITICAL-INTERPRETIVE ANTHROPOLOGY OF DISABILITY AND SEXUALITY

## 3.1 HISTORY OF ANTHROPOLOGICAL CONTRIBUTIONS TO DISABILITY STUDIES

Anthropology is the study of humanity as it focuses on the representative members of a society. Anthropology as a discipline has contributed immensely to the knowledge about cultural relevance, cultural relativity and defined meanings of culture (Klotz, 2003). In anthropology, the lens of culture can be applied to disability in a variety of ways, for instance, disability can be considered as a culture, culture can be considered a disability and cultural values influence the conception of disability (Mc Dermott &Herve, 1995). Cultural anthropology is based on the perspective of the 'outsider' with respect to how different cultures perceive 'otherness'. The largest contribution to disability has come from cultural anthropology and medical anthropology. In anthropology, disability is understood as a socio- cultural experience and a mental or physical condition (Mc Dermott, 1995).

Initial studies, in the field of disability in anthropology were conducted by Ruth Benedict. His work on the cross-cultural conceptions of epilepsy is a major anthropological study in the field of disability. Further in 1948, Lucien Hanks published a cross-cultural study that focused on various social factors that influence the status of people with disabilities in different cultures.

During 1950's Margaret Mead, a student of Ruth Benedict and an anthropologists argued that "any member of a group" is representative of that group provided that his position within that group is properly specified (Mead, 1953). The introduction of disability rights movement in 1960's and 1970's brought attention of the people on disability and sparked interest of medical and cultural anthropologists (Edgerton,1993). Robert Edgerton was the first anthropologists to explore mental retardation from an anthropological perspective. Prior to 1970's disability was considered as something unfortunate and was a private problem of people with disabilities and their families. Before 1970's disability was a marginalized field of study but during the mid 1970's Frank brought 'phenomenological perspective to anthropology' of a "congenital amputee". Frank's work attempted to present the subject of research in a close approximation to the perspective of the subject. Anthropological studies previously used to focus on the etic accounts of behaviour which uses culturally neutral description by an outside observer that can be applied across cultures. In contrast Frank used emic approach which is culturally specific and describes human behaviour in terms of its social environment. Frank in her work accomplished this via developing relationship between the subject and the researcher which led to a deeper level of self disclosure by the researcher. Frank in her study gave a detailed description of an American woman, Diane DeVries who was born with no arms and legs. Her intensive ethnographic interview with Diane and a profound presentation of her experience widened the scope in the discipline of anthropology to include people with disabilities in its ambit (Frank, 1986).

During 1980's many anthropologists emerged as major scholars in the field of disability studies in anthropology. Louise Duvall, a medical anthropologist started a newsletter 'The Disability and Culture Newsletter' which became an important sources for anthropological theory on disability.

Yet another interesting work was brought out by Nora Ellen Groce (1985) who through her finding on deaf and hearing individuals on Martha's Vineyard brought a difference in disability studies. Deafness was so common in the Vineyard i.e. hereditary deafness occurred with such frequency that it was not considered as a disability. In the 1990's the story of 'The Elephant Man', Joseph Merrick continued the interest of anthropologists in the field of disability. Many anthropologists described and analysed the experience of Merrick with a condition that caused extreme and progressive facial deformity (Ablon, 1995).

Robert Murphy's work The Body Silent is about his own experience of disability. He was paralysed owing to a tumour in his spine. His work became one of the classic text for both anthropology and disability studies (Murphy, 1990).

During the 1990's, Ingstand and Whyte came up with a book on socio-cultural aspects of disability, titled Disability and Culture. Their work emphasized on personhood and phenomenological approaches rather than traditional medical anthology. In the recent times, Shuttleworth's work on disability and sexuality and on social constructions of disability brought disability to the centre of anthropological discourse (Shuttleworth, 2004).

## 3.2 TYPES OF ANTHROPOLOGICAL RESEARCH ON DISABILITY

The anthropological research on impairment and disability can be divided into three broader categories:

a) Cross-disability research

b) Disability constructed from specific impairments

c) The self-reflection of disabled anthropologists

Cross-disability research is less common research. Cross-disability work primarily focuses on a single society and often highlights the cultural beliefs of a particular society informing their particular categorization of disabilities. Some anthropologists have attempted to theorize about disability in general in the cross-cultural context (Murphy, 1990; Whyte, 1995). But anthropologists and other social scientists have overlooked some of the important understudied variables like level of pain, visibility, social acceptability, availability of accommodation etc (Kasnitz, 1995).

The research conducted so far on a specific type of impairment have usually been constructed around the roles, statuses and the experiences of people having a particular impairment which are often analyzed in small societies. Some of the researches used the emic approach to understand impairment in a particular person. For instance, Cerebral Palsy by Shuttleworth, 1997, 1998; People with mental retardation by Edgerton, 1984; Polio by Kaufert, 1984. The advantage of studying a particular category of disability group provides a close-up view of the members of these groups resulting in a rich ethnographic description.

The last category is the self-reflection and personal experience of disabled anthropologist's. For instance the work of Murphy (1987); Kasnitz (1993) provides a significant literature of biographical, autobiographical description of disability and the experience associated with disability. A close examination of the lives of people with disabilities can enhance the understanding of life course dynamics and social change. Anthropologists who have suffered with some kind of disabilities themselves have written about their experience and the impact of their disability on their research (Steiner, 1994).

## 3.3 THEORY IN ANTHROPOLOGY OF DISABILITY

The anthropological research on disability has been accompanied by a theoretical lacuna. Much of the research in the field of disability in anthropology has been conceptualized on few theoretical notions like liminality and stigma. Goffman (1963) defined stigma as a discrediting attribute, an undesired differentness from social expectations. Stigma as a concept has been utilized in anthropological studies to understand the socio-cultural construction of certain chronic illness and disabilities (Edgerton, 1967). However, Goffman's perspective has been criticized on several grounds especially on the ground that it is not sensitive to issues of politics and empowerment (Hahn, 1985).

Wendell (1996) has further criticized him for reflecting some of the cultural stereotypes and meanings of disability. He also criticizes Goffman for "lumping together all sources of stigma, which causes him to over generalize and prevents him from seeing some crucial aspects of the stigmas of illness and disability" (Wendel, 1996:57).

SusmandeniesGoffman's critics when she argues that Goffman, does view the link between stigma, deviance and disability as inexorable, nor does he claim that disabled people are inevitably passive and victimized. Rather he holds that "the meaning of disability is social and therefore, is a changeable construction". Huges (1999) on the other hand, asserts that the concept of stigma has emerged from non-disabled discourse on disability. He attempts to pathologizenon disabled perception to be a significant development in disability study discourse.

Herskovits and Mitteness (1994) in their work assert that the degree of stigma varies from different chronic illness and disabilities depending on different societies and their cultural values. The base of the proposition lies in the fact that stigma maintains its analytical cogency by being

broadly inclusive hence; its distinguishing feature needs to be specifically filled in for particular groups of people in specific contexts.

Stigma as a concept remains a disembodied notion in the anthropological work discussed so far. It is important to analyse that whether stigma can lead to internalized oppression or can lead to self empowerment, needs further evaluation which is theoretically grounded in inter-subjective processes. How people with different disabilities engage and contest inter subjectively with a particular form of stigmatization to enhance their societal participation at an embodied level of experience.

Frank (1986) in her early work on a woman with missing limbs, Diane DeVries brought a phenomenological perspective into the anthropological study of disability but Frank focused on one person's experience of disability and her perception of her body. She later attempted to show how people with missing limbs since birth became empowered yet, her discussion is not adequately grounded theoretically (Shutteworth,2001). Frank in her case study of people with missing limbs analyzes that people with disabilities use their highly visible impairment to challenge "the negative construction of their lives by non disabled people" (114). Frank asserts that "*self empowerment may be defined as the result of symbolically assessing situations and engaging in strategic behaviours in ways that permit individuals to participate actively in society against a background of stigma, discrimination and functional limitation*"(112). Shuttleworth in his work questions the credibility of the definition given by Frank and questions that how one can become empowered? He further supports his argument by saying that although Frank quotes Scott's important proposition that "Goffman's theory should be critically assessed for its fit to concrete situations"(Frank, 1988:97) yet she fails to extend this argument to encompass the contextual variability of both stigma and normative gaze. Further, Shuttleworth asserts that

Frank's study lacks social context, subjective stances and inter-subjective dynamics in her definition of self empowerment.

The symbolic anthropological study of disability was somehow confined to the ritual notions of liminality (Shuttleworth, 2001). Victor Turner (1967) in his work elaborated on Arnold Van Gennep's understanding of 'rites of passage' especially focusing on the luminal or the transformational phase. Gennep proposed that rituals concerning the transition from one social state/status to another are marked by three phases which are Separation, Liminality and Incorporation. He asserted that every change of place, state, social structure, social position is a 'rite of passage'. He further went on saying that the energy found in any social system needs to be renewed at crucial intervals and this renewal is accomplished in different social settings through rites of passage. These rites protect and free the social system from undue disturbance in order to foster change at both individual as well as collective level. In the first phase i.e. separation, the individual detaches from a prior social state. The term separation connotes that there is something from which the individual is separating either from outside of him or something that defines 'who he is'. The second phase is the state of liminality (betwixt and between; threshold). Liminality stems from the Latin word 'limen' meaning threshold or margin. This phase is ambiguous as liminality is the place of in-betweeness of no longer belonging to the old and not yet to the new. Liminality is thus, the place of uncertainty, of anxiety and of hope in the betwixt and between. In this phase questions may arise about the sense of belonging, identity and social relationships. According to Turner, the individual crossing the threshold comes in contact with divine elements and gains sacred knowledge that is both informative and potentially transformative. Being in this phase often creates a sense of vulnerability but this phase is necessary if more fundamental change is to occur. The last phase i.e. incorporation is about

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consolidation/ amalgamation of the lessons learned and the changes made. An individual applies new developments and this phase is marked by challenges.

Robert Murphy (1990) in his eloquent autobiographical account of his disability experience in the book 'The Body Silent' proposed that the concept of liminality could also be applied to the social responses towards disabled people. He further asserted that the concept of deviance and stigma did not accurately describe the social relationships between the disabled and the non-disabled people. Murphy brings out that disabled people have often been isolated, made invisible, avoided, and sometimes deprived of status. These responses are reminisces of the past which initiates that who will undergo the luminal phase of many rites of passage. He further argues that "'disability is not a thing', it is a juncture within a process, an assortment in the life history that is dramatized in a rite of passage frozen in its luminal stage (241)".

## 3.4 a)ANTHROPOLOGICAL RESEARCH ON CULTURE AND DISABILITY

Science dominated knowledge production regarding disability for nearly a century (Foucault, 1967) and it was defined as a bodily restriction which affects the performance of an activity (Oliver,1990). It is only after 1981 that the World Health Organization understood the importance of understanding disability in local contexts. The reason behind this is well deduced by Mehrotra(Ingstad& Whyte,1995, Mehrotra, 2013, p.115):

*"It is suggested by scholars that through cross-cultural analysis of disability can push any authentic attempt to define disability which will be historically, culturally and contextually informed".*

In other words, different cultures and communities have their own ways of conceptualizing disability which should be taken into consideration and must be given prominence. It should be asserted that if someone defines disability without critically engaging with the kind of life a disabled person is living, he or she is furthering the stigma through distorted knowledge production.

To view disability as a cultural construction is nothing but to explore whether disabled people are able to manage themselves in their own surroundings with the coping mechanisms that each society provides in some form or the other. Mehrotra (2013, p.116) claims on the basis of knowledge about disabled life:

"*The notion of disability has moved away from institutionalized medical definition of locating individual purely in a biological terms which requires rehabilitation to get back to normalcy*"

So it is cultural rationality through which insights about lived experience of disablement is to be attained. In other words, it basically means to closely observe how disability is being understood by natives in different cultures. Here it is crucial to point out that any discussion about disability and its native understandings does not always mean that they are unaware of scientific discourse about disability, but is only to point out that being disabled does not always at all places is considered as a personal tragedy (Oliver, 1996). The significance of cultural construction of disability is also noted by Bendict (1934); Edgerton (1967); Groce (1985); Holzer, Vreede& Weight (1999); Hubert (2000); Mehrotra(2013). All of them supported that it is through an understanding of culture that policymakers can better serve disabled people.

So is the case with notion of the relationship between the concept of personhood and disability. The concept of personhood gives great importance in analyzing the way person is situated in the

community (Ingstad& Whyte, 1995, Mehrotra, 2013). Here it is logical to analyze through the literature review how anthropologists have described local understandings of disability as against the global one that is dominated by medical knowledge.

In defining the meaning of disability, Ida Nicolaisen(1995) brought the attention towards understanding of personhood of Punan Bah of Central Borneo. Nicolaisenfound that the disabled people among Punan Bah were judged through their social standing rather than their bodily deformity. It is interpersonal ties related to marriage or other kin group relationships which holds significance in the community. As Nicolaisennoted:

"*Individuals whose parental kin have not been established for one reason or the other are known as children of Dogs*" *(1995, p.49).*

Similarly, Talle (1995) discovered that among the Masai, who are semi-nomadic, living near borders of Kenya and Tanzania, being social makes disability irrelevant. Talle claimed that the Masai do not really conceptualize the physically impaired as disabled. They give importance to communality. Marriage is the symbol of a full life among the Masai because it provide social acceptance not only to the sexual alliance between two individuals but also to their offspring Tallenoted:

"*Disabled people are neither hidden away nor taken to be so impure or polluting. They live their lives alongside relatives and friends thus allowing them to fully participate in the rewarding sociability of homestead and neighbourhood" (*1995, p.69).

Among Masai, being disabled does not affect their personhood as he or she is viewed as someone who is capable of becoming parents. Contrary to this there are societies in which being

disabled is stigmatised. Bodily deformity is considered discrediting for a person in Huber community. According to the beliefs prevalent in the community, disability does not give a person scope of emancipating from disable/sick identity. Bernhard Helandar (1995) saw among Huber community of South Somaliathat they do not make distinction made between disease and disability, and try to treat disability as a disease. Disabled people are viewed as "sick people" and more commonly disabled people tend to be addressed in terms of the specific disability they suffer from, which tends to shape the notion of personhood of Somali disabled. Devlieger (1995) argued that defining what disability is a very complex task. Belief in cosmology helps community members to categorize the new born disabled. Devlieger (1995) saw among Songye of Zaire a belief that locates human body in relation with cosmology, for example, if twins are born, they would be referred to as superhuman.

Further, among Songye, the type of the body with which a child is born affects the notion of personhood  in the community. As it is pointed out by Patrick Devlieger:

"*Abnormality is defined in three ways, that is, "ceremonial children, bad children and faulty children*" (1995, p.95).

Songyeconceptualise "*ceremonial children*" as superhuman and they are believed to have special healing powers which provide them with a higher status within the community. On the contrary, "*bad children*" consisting of albino, dwarf and hydrocephalic children are considered to have lower status in Songye society owing to the belief that they would not live for long, as they have come to human world for destructive purposes. Songye consider that bad children have anti-world supernatural powers out of direct connections with sorcerers.  Faulty children are those who cannot socialize because of their bodily and cognitive deformities, such as spasticity.

They are neither accepted nor rejected (Barnartt, 2010). Monk and Frankenberg (1995) viewed disability by situating themselves in modern social settings where values of individualism and independence affect the personhood of disabled people. They argue that the self of a disabled person is dynamic in nature as it depends on the idea of time which holds great significance in modern societies. Through the life course perspective, Monk and Frankenberg (1995) have argued that it is the experience of living with disability that shapes the personhood of disabled.

The picture that emerges from the above analysis is enough to suggest that disability is a cultural phenomenon rather than a biological one. So the social status of a disabled person is culturally determined.

## 3.5 b) ANTHROPOLOGICAL RESEARCH ON DISABILITY AND SEXUALITY

In anthropology minimal research is done in the field of disability and sexuality and disability is virtually ignored (Vance, 1991). Marginalization of disability research itself within anthropological studies has further discouraged anthropologists to conduct research on the sub-discipline like focusing on the sexual component of people with disabilities. Many anthropological studies on disability have often brought out that the opportunities for people with disabilities to establish sexually intimate relationships and to marry with non-disabled peoples are greatly reduced (Ablon, 1984; Nicolaisen, 1995). There are few studies in anthropology that examines the way cultural values and belief system, social structure and gender expectations impact the chances of people with disabilities in sexual and marriage relationships.

Wolf and Dukepoo's (1969), study on the high incidence of albino births in the Hopi population shows how interplay of socio-cultural forces conspire to marginalize people with disabilities and restrict their access to establish sexually intimate relations with others. In their study they describe the reasons for the overall positive acceptance of albinos in Hopi society. But this acceptance is restricted to marriage. The Hopi culture does not allow albino men to work in the fields in the order to sustain their families. Their interview with many Hopi's revealed that albino women socially withdrew themselves but in the case of albino men, although they were rejected as marriage partners yet this rejection did not extend to sexual activity. Since albino men were not allowed to work in the fields they remained in the village with the non albino women. This gave albino men ample time and opportunities to develop sexually intimate relations with the non albino women which gave them advantage over non albino men. Wolf and Dukepoo were partially successful in demonstrating that physical difference can sometimes reap benefits in establishing sexual relationships but they grossly failed to examine the experience and meanings of sexual intimacy for people with albinism in Hopi. Further, they could not examine the specific socio-cultural beliefs and gender relations that led to the withdrawal of albino women from sexual and marriage arenas.

In yet another anthropological study undertaken by Ablon (1984) brings out that women with disabilities in the U.S societies have greater disadvantages than men with disabilities in developing sexually intimate relationships. She conducted her research on people suffering from neurofibromatosis. She asserts that women are socialized to be connected in a relationship therefore, the persistence of women with disabilities in finding a partner was much more higher than that of men with disabilities. She further explains the reason for such a practice and says that in the case of men with disabilities connectedness or attachment is overridden by cultural

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expectations of male achievement, thus, the lack of achievement by some of the men suffering from neurofibromatosis to meet the gender expectation negatively impacts their gender identity, effectively blocking their desire for an intimate relationship. But women with neurofibromatosis continued to fantasize and strategize to connect with men.

Sentumbwe (1995) in his work brings out the interplay between cultural knowledge and social relations operating in making sexual or marriage choices of non disabled persons with people with specific-disabilities. He elucidates the reasons as to why non-disabled men of Uganda will have sexual relations with blind Ugandan women but keep them as their mistress without marrying them. The cultural connotation of blindness in Ugandan society considers blindness as physically incapacitating. The people with blindness are considered more vulnerable as compared to persons with other disabilities. It is an assumption especially with blind women that they cannot adequately fulfill their domestic role. This assumption is sanctioned by the society which results in less socially legitimate relationships which are primarily based between men and blind women. Apart from these assumptions, blind women are considered adequate for sexual relationships but are considered as unattractive as marital partners by the sighted men of Uganda. Most sighted men of Uganda refuse to take on any woman's activities; hence they need competent housewives who should be physically able and thus sighted. Contrary to this, blind Ugandan men are more likely to have sighted wives because they are actively involved with income generating activities along with other men dominated activities. Hence, they do not have to depend on their blind husbands for any assistance. Whether men or women with specific disability are seen as legitimate sexual or marriage choice by non disabled people differ from society to society depending on the cultural beliefs.

# CHAPTER FOUR

## OBSTACLES IN ESTABLISHING SEXUAL RELATIONS

The previous chapter employs anthropological theories to understand the relationship between disability and sexuality. Few researches in anthropology were incorporated in the previous chapter that examines the way cultural values and belief system, social structure and gender expectations impact the chances of people with disabilities in sexual and marriage relationships. The non-disabled people usually tend to make broad assumptions about people with disabilities with regard to their sexuality. The individual experience of people with disability is contrary to the broad based assumptions. People with disabilities have the same desire of love, affection and sexual expression like any other 'normal' individual. Therefore, the onus lies on the society to accommodate the development of intrinsic sexual expression which lies within every individual with disability. This chapter will focus on reviewing the existing literature regarding the barriers in establishing sexually intimate relations and sexual development faced by people with disabilities. It will also explore the attitudes of the non-disabled people towards those with developmental disabilities like that of Cerebral palsy and the impediments that people with such disabilities have in regard to their sexuality.

There are many initiatives and programs which are focused to integrate the people with disabilities into community living settings where the emphasis is given to dressing and grooming along with their educational and habilitative needs. Many researches indicate that the hidden motive behind such programs is to focus on sexuality of people with disabilities and their right to sexual expression and sex education. It is only in the past two decades that the topics of sex education and support for sexual expression and desires of people with developmental

disabilities became important to researchers and professionals (Stinson, Christian & Dotson, 2002). Although, there is a gradual increase in the recognition of the basic human rights of people with disabilities yet there exists a high level of anxiety and uncertainty concerning the sexuality of people with disabilities. Unfortunately the parents, care givers, counselors, teachers and other members of the society hold many stereotypes about the sexual behavior of people with developmental disability. They fail to recognize that sexuality plays a significant role in the lives of people with disabilities as it has a direct impact on the mental, physical and social aspect of their lives (Marten, 2006). The fact is not duly acknowledged that the people with developmental disabilities like rest of the non-disabled people have varying degrees of reproductive ability, sexual response and sexual interests and have the same requirements for love, affection, and fulfilling interpersonal relationships as any other member of the society.

## 4.1 SEXUALITY

Sipski and Alexander (1997) describe sexuality in the broadest sense. They asserted that: *'sexuality is not merely an act of copulation or an activity to derive sensual pleasure rather it also includes different ways in which people present themselves to others. It is an act of expression to convey love and companionship. It is a way to exhibit different aspects of personality and emotional existence that expresses the femaleness and the maleness'*.

Sexuality is a broad term that covers a range of issues. It not only includes sexual behaviour but also gender identity, sexual orientations, roles, sexual identity, relationship patters, feeling, attitudes etc. It also comprises of the social ethical, cultural, moral and spiritual concerns of an individual. Hence, sexuality means different things to different people. For some people sexuality could connote the act of sex and sexual practices, for some it could connote sexual

orientation or identity and/or preference and yet for others it could connote desire and eroticism. Therefore, sexuality has many facets and encompasses many ideas.

Since enlightenment, western discourse has employed a reason as a tool over irrationality via pursuit of scientific fact over fiction. Theorist like Michel Foucault argue that with the advent of scientific professions especially the medicalization of the body resulted in the production of discourses on sexual deviance and normality, justifying the need to control sexual body and the criminalization of non conformity by the state (Foucault 1980 in Maksinmowski, 2012). Foucault theorized that the ultimate representation of such power is the self regulating, confirming individual. The use of public and academic discourses as the tool for the construction of sexual bodies, identities and practices historically and politically situates them in a manner that gives more concreteness to these categories by creating people within them as objects for control as well as subjects for community and disunity (Foucault, 1980). Sahlins(2002) writes that the power in this sense comes from above and below as it constructs and embodies a person, individual can utilize this power for other purposes through resistance to counter hegemonic discourse and its reproduction. Carol Vance (2005) extending the discussion further writes that the marginal groups who do not fit in dominant discourse "*create their own subcultures and worlds of meaning*".

Anthropology as a discipline has existed in a social vacuum as noted by many authors. It has ignored the political and social upheavals of the times (Lyons & Lyons, 2004). This is true for the Victorian era where the upper class men used to collect and analyse information about sexual practices sitting in their libraries or setting out on ships to understand sexual practices in exotic climates. The purpose was to explore and to gain a better insight into the path of progress within

European civilization through knowing the other. They believed that to know oneself and to understand the human nature it is important to understand the 'other self'.

These early accounts were merely a starting point in the production of discourse on sexuality. In the early 18th century, the European society felt the need to talk about sex and sexual practices in order to sanction what is normal and morally acceptable and to control sexual practices. Many works on the danger of masturbation and the immorality of contraception served this purpose. Laws against prostitution and homosexuality were established to monitor the deviant persons and were seen as a means to protect the non-deviants from the immorality and disease. The medicalized view on sexuality in the 19th and the 20th century further sanctioned the middle class heterosexual norm problematizing the same sex lust as perversion along with prostitution, masturbation and the use of contraception. (Foucault,1980). The state established norm of heterosexuality served as a tool to control citizens and bring them under authority. Under this discourse the normal marries the heterosexual and was never the subject of scrutiny as they were legitimate. Foucault further asserted that the sexuality has been repressed and has been used as a key tool in constructing identity around a powerful discourse by defining normal and deviant sexual practices (Foucault, 1980)

Although prostitution was seen as a deviant practice yet, it has been tolerated throughout history as an institution to maintain the necessary social order and to prevent anomalous acts such as sodomy from challenging the heterosexual order and patriarchal values (Truong, 1990 in Maksinmowski, 2012). However, prostitutes along with other lustful women were medicalized and labeled as nymphomaniacs, hysterical who suffered from a biologically determined predisposition to lewd and immoral sexual behaviour (Foucault, 1980). All these laid standards of the Victorian era preferred a monogamous family that practiced sex as means of reproduction.

Richard von Krafft- Ebing was a physician who worked primarily with sexually disturbed people. His writings belong to a period when Victorian standards strongly suppressed thinking about human sexuality. His writings indicated that sexual activity is something to fear and supported the idea that men have sexual freedom and the women do not. His writings had a biased view of sexuality which was highly influenced by his apparent discomfort with the sexuality of women. Although, Ebing's writings had false assumptions of sexuality, yet they were able to convince some physicians and researchers.

Maine and Morgan were among a few early anthropologists who viewed primitive societies as less morally evolved as they lacked in European like institution of marriage. The human evolutionary progress resulted in decreased sexual licence and challenged the primitive promiscuity. The evolutionary model of family forms privileged the notions of patriarchy and ignored the possibility for equality between sexes, naturalizing unequal sex and gender relations in the Victorian society. The anthropological discussions on sexuality in the Victorian era privileged the voices and sexual concerns of middle class male Europeans and silenced the female voices on sexual issues. Early anthropologists studied human sexuality from a distance during the Victorian era and preferred studying and analyzing the sexual practices of other faraway peoples and different races in order to better understand human sexuality.

With the advent of the 19th century Victorian morals were being questioned along with the institutional arrangements that they made. Liberalism and social changes resulted in questioning the prevailing discourses on sexuality within the European society (Lyons and Lyons 2011). The institution of marriage and sexual relationships of all kinds became a matter of public scrutiny and the State took over the religious control as the religious control had become more lax (Foucault 1980).Thus, there existed in this time various conflicting discourses of social purity

and liberalization (Lyons and Lyons 2004). Feminism grew in response to the double standards that prevailed for men and women where men were treated superior to women.

During this period the anthropological representations of primitive sexuality were radically altered. In the new discourse the anthropologist viewed primitives as undersexed and not possessing the basic human sexual drive. Margaret Mead's ethnographic work *Coming of Age in Samoa (1928)* during this period highlighted the non- flexibility of Western notions of social morality rather than danger in the primitive sex. Mead viewed sexual behavior as socially conditioned by culture and environmental factors and disagreed with the idea of a universal human nature. Mead's study focused more on the specifics of sex and sexuality in other cultures i.e. to know the 'Other' in order to understand one's own culture. Apparently functionalism took an ahistorical and apolitical approach to study sexuality and thereby failed to question in whose interests these controls were placed, on whose bodies and which particular sexualities (Lyons and Lyons 2011).

Bronislaw Malinowski in his work *The Sexual Life of Savages* in 1929 studied the Trobriand Island culture and brought ethnography into the realm of science. In his work he asserted that sex permeates everything and sexual behaviour can be studied in a scientific way.  He in is work brought out that less organized societies also conceived of sexual morality in a rather loose way, and thus prostitution was absent. The concept of homosexual and heterosexual identity was absent in many groups yet the ethnographer was able to label sexual practices in accordance with the western discourse (Malinowski 1929 in ).

As a functionalist, Malinowski viewed that the role of society is necessary in regulating sex to maintain its functioning as human sexuality was considered as an instinctual force which needed regulation.

Vance (2005) asserts that in the early twentieth century, anthropologists focused more on studying sexual practices in relation to specific cultures and hence explaining that culture naturalizes sex and sexual identities. He further goes on to say that much focus was not given to sexual difference as a product of racial difference and cultural evolution.

Anthropologists during this time made a huge contribution to cross-cultural studies of sexuality and questioned sexuality as universally biologically given. The ethnographic work of Mead led the West to question its laid discourses on sexuality as natural and a must for the functioning of human society. She in her work on Samoan culture brought out that although there existed sexual norms and taboos in Samoa yet there were no conceptualizations of adult sexual perversions and sexual practices outside marriage.

While Mead described the existence of sexual norms and taboos in Samoa, she also demonstrated the absence of Samoan conceptualizations of adult sexual perversions, and an accepted fluidity of gender boundaries and sexual practices outside of institutional confines, such as marriage (Mead 1928 in Lyons and Lyons 2011).

Thus, Mead and Malinowski through their studies showcased sexual practices from other cultures and challenged the laid dominating discourses on sexuality by the West.

## 4.2 SEXUAL DEVELOPMENT

Sexual development involves number of social dimensions and as asserted by Greydanus and Omar (2008), '*sexuality continues to be a core and profound component of humanity in which human beings need other humans'* (p.1315).

LeVay and Valente (2006) describe sexual development as a complex process that includes biological maturation of sexual organs and biological systems. It also affects the psychological constructs like gender, gender identity and sexual orientation. The development of these systems is crucial during childhood and adolescences (McKenzie & Swartz, 2011). People with disabilities experience physiological complications and variations in the sexual development process due to their specific disability. More commonly it is the socio-cultural barriers related to disability that are more difficult to manage by people with disability (Di Giulio, 2003). The societal attitudes towards the sexuality of people with disability can be highly demoralizing and stigmatizing. It can affect the confidence of an individual and negatively impacts the sexual self concept of an individual (Walter &Knupp, 2010). Many researches show that the ideal path to mature adult sexuality begins with love, care and affection received by an individual as an infant during his/her childhood which has a long term effect on the adult ability to give love and affection to others (Haroian, 2000).

Performing activities with others in childhood like playing with others is a medium of self exploration which helps to develop self knowledge and social knowledge. Playing helps in building self confidence as while playing, children try new things, take risk, make mistakes and learn to explore themselves.

Milligan and Neufeldt (2001) divide disability into four broad categories namely i) chronic illness ii) congenital iii) traumatic injury and iv) psychiatric. Further they assert that all these types of disabilities have various influences on the sexual development of an individual. Many a times it is the biological difference caused by the disability and the medical treatment undertaken for a particular disability that impacts the sexual development process of an individual. For example: Cerebral Palsy may cause early pubertal development. Hence, the adolescent having

CP may start at a different point and progress at a different place than the typical teen of his/her age (Woodard, 2004). Marten (2006) in her work brings out that sexuality and disability is too much complex and gets further complicated with impediments associated with disability.

## 4.3 CONCEPTUALIZING SEX WITH CEREBRAL PALSY

Construction of sexuality by the people suffering from Cerebral Palsy is misinformed by a range of public and private factors (Simon &Gagon, 1986, 2003). While the sexual construction are largely influenced by public attitudes and perceptions but it is the private and therefore, the most personal aspect of sexuality which drives the ability to perceive oneself as a sexual being and understanding one's own sexual desires. People with disabilities are no different and possess the same desire for sexual interaction with others but unfortunately, the negative perception towards disability questions the ability and willingness of such people to establish sexually intimate relationships. Hence, the socio-sexual experience of people with disability is not acknowledged (Dune, 2014)

Construction of sexuality is a private mental process which involves inner dialogue with oneself. This mental process which is a private affair is greatly influenced by the way in which individuals internalize their sexuality. Various factors that influence the private construction of sexuality are:

- disability and sexual identity
- sexual agency
- constructions of sexual self:
  - ➢ body image and body esteem
  - ➢ sexual esteem

➢ sexual desirability

## DISABILITY AND SEXUAL IDENTITY

People with disabilities construct their identity based on the experiences they have had with their respective disability and the experience that the non-disabled had with their disability

(Shakespeare, 1996). This understanding was criticized by many scholars as it lacked holistic elements. Gidden (1991) assets, "*self-identity is not a distinctive trait, or even a collection of traits, possessed by the individual. A person's identity is not to be found in behaviour nor-important though this is in the reaction of others, but in the capacity to keep a particular narrative going*" (p. 53).

In this way identity is created through the complex interplay between the perception of the society and the interaction with oneself to create a homogeneous self. For instance through the concept of Disabled community (Deaf and Dumb association) Weeks (1977) suggested that the concept of identity is similar to finding a map to explore a new country. Thus, these understanding of disability as an identity may not be intrinsically negative for people with disabilities but the experience of disability as a negative identity arises out of a process of socialization.

Shakespeare in his work used a quote by Morris (1991) to explain that the identity of the person with a disability in relation to those around them influences how they will interact with others:
*"One of the most important features of our experience of prejudice is that we generally experience it as isolated individuals. Many of us spend most of our lives in the company of non-disabled people, whether in our families, with friends, in the workplace, at school and so on.*

*Most of the people we have dealings with, including our most intimate relationships, are not like us. It is therefore very difficult for us to recognize and challenge the values and judgments that are applied to us and our lives. Our ideas about disability and about ourselves are generally formed by those who are not disabled"* (p. 37).

Thus, the negative construction of the 'disabled identity' results in stigmatization of people with disabilities. Further, some people with disabilities separate the effect of their impairment from the construction of their sexual identity.

This split was analyzed by Overstreet in Splitting sexuality and disability: A content analysis and case study of internet pornography featuring a female wheelchair user (2008) where Texas Rose a female pornstar with a physical disability and whose primary form of movement was her wheelchair was investigated based on her website photographs. In the first set the photos which were analysed , the wheelchair was fully or partially pictured and Rose was not sitting on it. His actions consisted of activities like applying lotion on her body, blowing kisses etc. In the second set of pictures where the wheel chair was absent the actions were more sexual. When the results were analysed based on the response of the viewers it was concluded that sexual activity when paired with disability (here in the presence of a wheelchair) was viewed as unsexy. On the other hand conditional portrayal of sexual activity in the absence of wheelchair resulted in a normalized construction of sexuality and hence the photos were perceived as sexier. Hence, the dichotomy that exists in terms of restrictions on individual construction of sexuality may impair one's ability to exercise choice and control over sexual experience.

# SEXUAL AGENCY

World Health Organization (2011) defines sexual agency as a basic sexual right and includes, "*the right to have one's bodily integrity respected and the right to chooseto choose whether or not to be sexually active, to choose one's sexual partners, to choose to enter into consensual sexual relationships, and to decide whether or not, and when, to  have children*"(Parker, 2007, p. 973). Froyum (2009) asserts that sexual agency is not only about the right to choose but also to seek knowledge and assert sexual desires. Taking the argument further Wilkerson (2002) argues that sexual agency is not merely the capacity to engage in, or refuse sex acts, but is more profound and involves a larger social dimension. Wilkerson's conceptualization of sexual agency includes the interdependence of public and private experiences of sexual expression and behavior where the sexual agency is demonstrated as a key component of the liberation struggles particularly important in rehabilitative contexts for people with physical disabilities. Wilkerson in her work reports three instances in which medical discourse, often in the very literal form of a doctor's words, denied the sexuality of people with disabilities. In the first instance she talks about a lady who had broken her back and was aparaplegic. She quotes the lady:"*about fourdays after I broke my back I asked my surgeon, I don't have my birth controlpills with me. Is there something I can do about that? He said ,Well, you don't needthose anymore,' and walked out of my room"(*p.34).

In another instance she narrates an ordeal of a couple who had spent years livingin an institution for people with epilepsy who wanted to get married to each other. The couple requested for the permission of the doctor of that institution to move ahead with their decision although they were allowed to get married but were strictly advised to not have sex (p. 48). In yet another instance she brings the abuse of a young boy with a developmental disability: the young boy who was

living in an institution masturbated in the presence of others —by rubbing his thighs together. So the staff at the institution attached sandpaper to the insides of his thighs (p. 34).

In the instances described above the relationship between disability, sexual identity and agency, are determined and controlled by doctors and healthcare providers who stand as the custodians of the medical discourse. The intersection of the attitude of the society towards the sexuality of people with disability and the self analysis of a disabled individual of one's sexuality may lead to sense of powerlessness. The interferences in the sexual agency of people with disabilities due to unfair restrictions, coercisions, penalties restricts them to access information about their sexual rights and is a hindrance in the exploration of their sexuality.

## CONSTRUCTION OF SEXUAL SELF

Construction of sexual self is guided by three important factors namely: body image and body esteem,sexual esteem and sexual desirability. Due to the existence of hegemonic sexual schemas people with disabilities may experience impediments when attempting to establish their experiences of sexuality in relation to others. The difference that people with disabilities may experience in the people's construction of their sexuality and their own construction of sexuality may have a detrimental effect on the ability to make a sense of positive sexual self.

## BODY IMAGE AND BODY ESTEEM

One's body is perhaps the most apparent basis upon which the construction of sexuality is based. Body image is an integral part in the conception of sexual self (Grogan, 2008).Taleporos and McCabe (2002) defined body image "*as the combination of an individual's psychological experiences, feelings and attitudes that relate to the form, function, appearance and desirability*

*of one's own body which is influenced by individual and environmental factors*" (p. 971). Further the body esteem can be defined as an individual perception of his or her own body. These perceptions are largely influenced by body image and personal experience to establish sexually intimate relations by the people with disabilities. Social environment plays a crucial role and is a powerful mediator of body esteem among people with disability (Palombi&Mundt, 2006). Physical impairment or a deformed body can have a negative impact on the psychological experiences and attitudes of people with disabilities towards their own body. Taleporos and McCabe (2002) through their study demonstrated that sexual esteem, body esteem and sexual satisfaction are strong predictors of self esteem and depression.

## SEXUAL ESTEEM

Sexual esteem is yet another fator in determining one's sexual self. Perceiving oneself as a sexual being indicates that one is deserving of sexual attention which contributes greatly on how one feels about his/her sexual worth. Guldin (2000) asserts that as "*so much of our sexual value is based on what we can do for our partner(s) and how well we can satisfy them, sexual esteem increases when we can show our partner(s) a "good time*". Guldin's research is important to the discussion on sexual esteem as it explored how people with mobility impairments"self-interpret and self-claim their sexuality in light of cultural assumptions which largely desexualize them" (p. 233). Further with the her research, Guldin asserts that sexual satisfaction can be experienced in many and different ways. Her research reinforces that there are plenty of activities that people can engage in that are sexually arousing and satisfying without necessarily including penetrative sex.

## SEXUAL DESIRABILITY

The popular constructions of disability and sexuality which represent people with disabilities as sexually desirable partners are quite few. Glass and Padrone acknowledged that positive experiences of sexuality and perceptions of sexual self were undermined by attitudes and assumptions which resulted from a lack of information experienced by people with disabilities as well as the various disciplines that serve them (i.e. medical, psychological and palliative).Rintala (1997) found that women with physical disabilities had self-defeating attitudes about their disabilities and ultimately themselves.As some people with physical disabilities feel that their disability is what restricts them from being thought of as a potential sexual partner some begin to socially invert. Due (1995) explains that "many people with disabilities fear they'll be screened out before they can even say hello."*Some figure they'll not even try -and not trying can become a lifestyle*" (p. 5D). The mixture of how people with disabilities perceive themselves and how they are perceived by others has a definitive effect on their ability to negotiate and access satisfying sexual relationships.

## 4.4 RELATIONSHIP AND MARRIAGE

People with disabilities are often socialized in a way which increases their dependence on others and therefore, they may lack the ability of independent thinking. Usually, the well-intentioned family members, friends and care providers treat people with disabilities like children even when they are adults and capable of decision making. This attitude towards people with disabilities results in their low self-esteem and a lack of confidence in initiating any relationship beyond the scope of care or support. With the negative attitude associated with disability often people with disabilities grow up believing that theydo not deserve to be in a relationship as they are not

attractive or worthy enough. In a research conducted by Tarshiit was revealed that young men with disabilities often felt that the overriding factor behind them being liked by someone is driven more by the feeling of pity than love. Although, these young men also believe that the other person might not always be driven by pity, but it was their lack of confidence in themselves that developed a feeling of inferiority complex especially if the other person involved is not disabled. Also, if the relationship fails for any reason, they believe that they were rejected because of their disability. There is always an overriding fear of being used or misled either emotionally or physically. It was further asserted that the main issue as far as sexual needs and desires of a person with disabilities is concerned stems from loneliness and isolation. The lack of opportunities for interaction, the lack of confidence in oneself and the stigma of being a burden often is a hurdle for people to even explore relationships. Further, in order to develop relationship it is required that people should meet whether in real or virtual spaces. But the lack of opportunities in terms of inaccessibility of physical spaces like parks, museums, movie halls, bars, restaurants and other leisure spaces, and even work spaces restricts the movement of people with disability which also narrows down the scope of establishing relationship with others.

The negative stereotyping of the society towards disability and the perception towards people with disability adds to the complexity of the issue. They are often assumed to be either 'asexual' or 'oversexed'. Society largely considers them unattractive and therefore incapable of being in sexual or in intimate relationships. There is also a negative perception about people with disabilities that they can never have 'real' sex. 'Real' sex itself is viewed as penetrative intercourse culminating in an orgasm. The other accompanying assumptions are that sex has to be 'spontaneous' and must involve vigorous physical activity. There is a possibility that some impairment may be a hindrance in vigorous and spontaneous activities but they do not preclude

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the possibility of sex. Many researchers have found that sexual activities that do not involve penetration or stimulation of the genitals can also be sexually gratifying and pleasurable, but these are often not regarded as 'real sex'. Unfortunately, many people with disabilities also buy into this myth and start believing that sex is not meant for them.

The challenges faced by people with disabilities gets aggravated when their sexual or gender identity does not conform to mainstream society's notions of 'normal'; they then face stigma, discrimination and marginalization at multiple levels. It is no wonder that those people with disabilities who identify as lesbian, gay, bisexual or transgender (LGBT) are invisible in society. In addition, sexuality is almost always associated with heterosexual marital relationships, negating other relationships like a heterosexual dating relationship or same sex relationships. Consequently, access to information and services is also unavailable to those who fall outside the so-called social norms (Tarshi, 2010)

Marriage is considered as a life changing experience. It is often the only legitimate space within which sexuality canbe played out. Marriage is also often seen as an answer to problems.In India, where marriage is traditionally arranged by families, peoplewith disabilities are not considered 'marriage material' particularly ifthey are women. Beliefs about the cause of disability enter the picturewhen a person's 'marriageability' is considered and when marriagenegotiations are undertaken. The fate model of disability is quite popularin India. Needless to say, there are different standards for women andmen with disabilities when it comes to their 'eligibility' for marriage. For example, families of men with disabilities may look for non-disabled brides who can then take on the care providing role from the family. It is often seen that the non-disabled women from lower socio-economic strata areoften married to men with disabilities who belong to a higher socioeconomic class.This is often seen as a win-win situation as the poorerfamily of

the woman does not need to worry about dowry for her and the man's family is satisfied that they have found someone to care for their son with disabilities. But the situation is not same in case of women with disabilities. The parents of a girl with mild disability can compromise for a man who has mental disability or any other disability but the chances are rare that she will get a non-disabled man (Addlakha, 2007).

Addlakha (2007) brings out that situation gets worst with women and girls with disabilities. The families of young girls with disabilities often conceal their daughter's disability at the time of marriage. This is more prevalent in case of invisible disability like mental illness. Women are also vulnerable to domestic violence and some may be ill-treated, abused and eventhrown out of their homes for any number of reasons ranging from aninability to satisfactorily perform household duties to bearing a childwith disabilities.

It is thus, important for the society to understand that people with disabilities experience sexuality and have similar desiresas their non-disabled counterparts. They also havethe right to explore their sexuality and be comfortable with their body. They need information to enable them to experience a selfaffirming sexuality and have equal rights to access and receive thisinformation. This will empower them to make decisions about theirsexual lives from the perspective of both pleasure and safety.

## 4.5 CASE STUDY

Manoj is a 34 years old good looking man. He hold a B.tech degree in computer science. He is a happily married man with one daughter who is absolutely normal. Manoj was diagnosed with Cerebral Palsy when he was eight months old. He is suffering from moderate CP and both his legs and his one arm is paralyzed. He recalls, *"my childhood was not easy and neither was my*

*late teens. I always questioned that why do exist in this world when I actually can't do anything myself"*.

He further shares:

I have received all my education in a conventional way. I was sent to a normal school. I had a personal attendant who was also my driver. He helped me to reach my classroom in the morning and picked me up from the classroom in the afternoon. During school hours I was helped by my friends to move from one place to another. I always felt restricted in my attendant's presence as I had no freedom to talk to my friends after school. I always liked engaging in 'guys talk'. My friends always talked about their crushes and girlfriends but nobody asked me that whether I liked any girl or had a crush on someone? I remember that strange episode when one day during the recess time one of my friend discussed about masturbation and he sympathetically told me that it will be difficult for me. That time I felt incomplete in a peculiar way. I just wished to go home and explore myself and my body. With days of extensive research and net browsing and discussions with my friends, I explored that I was like any other boy of my age which gave me internal satisfaction.

But my biggest concern was whether I would ever get to experience sex. In my mind, this was a totally legitimate question and one that I had no clear answer to at the time. I only had hope. Relationships in general were such a big obstacle for me growing up because the people I met when I was younger weren't interested in being with someone with cerebral palsy. All this led to a lack in my own self confidence as I could not understand why someone would want me? But as I grew older, and entered college my confidence in myself changed for the better. During my

school days my interaction with girls restricted to academic discussions only but it was in college when I became a little free with girls.

But things were not easy for me when I started feeling for the girl I liked a lot in college. I had utililized all my strength to propose her and to my strange she accepted my proposal there and then. Gradually things started moving ahead and we were comfortable talking to each other about everything even sex. As things progressed we decided to get married. But I was no better. Even after my marriage and my conversations with her regarding sex I was entangled by many thoughts and another mental obstacle for me to overcome was to let her near my body in an intimate way. As a kid, I was used to getting help with various tasks, some more private than others. So I wasn't unaccustomed to having less privacy in some areas, but that was in a totally different setting. When it came to intimate and sexual settings, I felt way more uncomfortable, in part because I was uncomfortable with my own body.

Silly things started bothering me a lot like scars on my body became a source of worry when they hadn't been before. My stiffness and clumsy movement became a source of embarrassment as well. It took many hours of thinking and experience before I finally became comfortable with letting someone so close.

I remember the first time I had sex, I was unsure and insecure. However, unlike most other people, I was also unsure because of my CP. Would I be able to do everything? What if I started to get spasms or cramps in the middle of it? How embarrassing! Will she think I'm clumsy? Should I tell her I'm nervous about this? Will she think I am not a man enough if I confess my apprehensions to her? These questions and concerns were going through my head prior to my first time. I remember deciding not to say a word because I was too insecure about it. And, quite

frankly, I didn't even know what to expect from myself. For the first time in my life, I didn't know how my body would react.

Initially it was difficult for us to establish physical comforts with each other. But with time we could adjust to each other's needs and it ended up giving me some additional benefits .Because of my insecurities with myself, I ended up focusing on her a lot, simply because it was easier and I had less chance of messing up. I don't think she realized that was the reason, but I don't think she minded either way. But even if you find a partner who is quite co-oeartive and adjusting to your needs, they may not treat you as you would expect them to treat everyone else in that situation. I've experienced being "handled with kid gloves" even as an adult at school by teachers, my parents and friends in everyday situations, because they were unsure of what I could do on my own. That didn't exactly make me feel very independent.

The same can unfortunately occur when it comes to sex. Your partner may go out of their way to be careful or not act as free and uninhibited as they normally would for fear of hurting you, which is quite ironic because people with CP can experience pain and discomfort to some degree every single day. But to your partner, you may be "fragile" due to your disability. I think it is more good that I want for my partner that makes me feel incomplete in some sense but needless to say my wife has changed my life and has given me a reason to be happy about myself. I know I am incomplete yet I feel complete with her.

## DISCUSSIONS

The above narrative brings out a cluster of emotions experienced by Manoj. It brings out some negative perceptions that Manoj had of his body image, but this did not necessarily had a

significant impact on the construction of his sexuality. Although he was sure that he can initiate a relationship but he was never sure of establishing sexual relationship as he was largely defined by what his body cannot do. His ability to be sexually agential was impeded by many apprehensions. Through exploring his possibilities by reading and by talking to friends he could foster positive body esteem yet he was apprehensive about his performance in front of his partner. Further it can be said that his sexual agency was constrained as the feeling of incompleteness in him restricted him from asking what he required from his sexual partner. The concern of his wife to be protective towards him during the sexual course led to the decrease in the sense of sexual empowerment.

## 4.6 IMPEDIMENTS

There exists a myth that people with disabilities are asexual beings which has its root in the western culture. Although these myths are less pervasive in the present times yet the myths surrounding sexuality of people with disabilities is very much present even today as asserted by Milligan and Neufeldt (2001). Further they assert that the sex acts performed by people with disabilities are not accepted and are viewed negatively in comparison to same sexual behavior performed by the non disabled people. Di Giulio in her work 'Sexuality and people living with physical or developmental disabilities' quotes Anderson and Kitchin who put the myths associated with people with disabilities and their sexuality as:

*"Cultural representations of disabled people as "sick and sexless" are supported and sustained by a set of myths. Myths in relation to disability and sexuality include disabled people being asexual, that is lacking a biological sex drive, being unable to partake in sexual activity, and that*

*disabled people (particularly those with a developmental/intellectual disability) lack the requisite social judgement to behave sexually in a socially responsible manner".*

1) **<u>Asexuality Myth</u>**: Many researchers have stated that society largely views people with disabilities as asexual. The myths of asexuality associated with disability makes the disability experience more difficult. Attitudinal barriers, difficulty in finding a suitable partner and problems in establishing sexually intimate relationship further contributes to the myth associated with disability. DeLoach (1994) argues that the cultural representation of people with disability as sick and helpless and stereotyping them as sexless negatively impacts them and leads to the internalization of negative attitudes by the disabled themselves. Such attitudes isolate people with disability to such an extent that the presumption of asexuality can become self- fulfilling prophecy which restricts them to form any intimate sexual relation with others (the non-disabled).

Masters and Johnson's 'Sexual Response Model' is one of the widely accepted models to understand the sexual dysfuctioning in an individual. The Sexual Response Model categorizes the sexual functioning in four different stages namely: i) excitement, ii) plateau, iii) orgasm, and iv) resolution. This model is used to ascertain the dysfuctionality in the sexual process as categorized in the Diagnostic and Statistical Manual of Mental Disorders- IV- TR (DSM) (American Psychiatric Association, 2000). Therefore, the absence of any one or more stages leads to the diagnosis of sexual dysfuctioning which is usually based on DSM classification as asserted by Winze and Cary (2001). Di Giulio in her work 'Sexuality and people living with physical or developmental disabilities' (2003) applies Masters and Johnson's 'Sexual Response Model' to the people with disabilities. She asserts that the traditional models of sexual response usually have a chronology of

psychological functioning. She further brings out that this model can be extremely problematic for addressing the sexual health issues of people with disabilities. She brings out that a disabled person can have an equally healthy sexual desire as the non disabled. But the sexual response of people with disability may vary depending on the condition of an individual i.e. severity of the disability. They may be more adaptive to his/her particular needs and condition which means that there is a possibility that they may not pass the standards of sexual functioning laid down by DSM. However, this may not by default make the sexual response of people with disability less satisfactory. In such cases the current diagnostic scheme can be deceptive as it may label the sexual response of a disabled individual as dysfunctional but in reality it might be highly functional for that individual. Therefore, the 'Sexual Response Model' will consider many people with disability as sexually dysfunctional simply by the virtue of their disability. Tepper further supports the argument made by Di Giulio inher work 'Sexuality and people living with physical or developmental disabilities' (2003) .He asserts that DSM-IV-TR differentiates between the orgasmic disorder in men and women in general and sexual dysfunction due to a medical condition like spinal cord injury. This distinction recognizes that some disabilities have sexual consequences and reinforces the assumption that people with disabilities will have negative sexual repercussions which has no remedy because of the medical condition. He brings out that the traditional model of sexual response gives a genially focused and performance oriented connotation of sexuality that challenges the sexual potential of people with disabilities. Tiefer (1991) in his work extends this argument further and criticizes Masters and Johnson's 'Sexual Response Model'. He brings out the traditional model brackets human sexuality into specific body parts that

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must function "normally" in a proper sequence of performance. He also suggests that the sexual response model is male centric. He further with the support of other researches on the same issue asserts that women with disability usually consider emotional and affection communication more important in a sexual relationship which is highly satisfying for them and is indeed fulfilling than in achieving an orgasm. Hence disability is a lived experience of a person which determines what is 'normal' and 'satisfying' sexual experience for him/her. Di Giulio's quotes an example of a disabled man who do not have genital sensation but is able to feel the pleasure by pleasuring his partner. This man will be considered sexually dysfunctional according to the sexual response model given by Master and Johnson but he may be fully satisfied and functional as he has adapted his sexual response depending on his circumstances.

Crow in his work 'Including All of Our Lives: Renewing the social model of disability' (2007) advocates that the impact of stigma associated with disability and the connotation construction of disability by the society make the disability experience of an individual more difficult than the disability itself.

2) **Privacy**: As discussed above, people with disabilities have the same need for love, affection and their sexual desires too are just like any other the non-disabled individual. The only difference between the people with disabilities and the no-disabled is the ways in which they express their feelings and desires depending on their specific circumstances. But people with disabilities have to face a lot of barriers to express their sexual desires. According to DiGiulio (2003), people with disabilities often lack access to knowledge pertaining to sexuality especially knowledge and information specific to an individual's condition. They are never made to understand about 'how to appropriately

express their sexuality?' and they lack effective sexual communication skills. On one hand people with disabilities do not have access to authentic information about sexuality and on the other hand they are often given misleading information about sexuality in order to curb their interest and discourage them to engage in any sexually intimate relationship.

3) **Lack of Private Space**: People with developmental disability like cerebral palsy are majorly dependent on the parents, care givers and counselors to perform their day to day activities. Also in severe cases it becomes essential that someone should always be there with the affected person to monitor his/her activities. In such a assisted living setting these people lack privacy for sexual expression and to have private sexual relations. Those living in rehabilitation centers and group homes lack privacy to have even basic warm comforting touch because of unlocked door policies, presence of roommates and continuous room check by the staff. Such individuals are then pushed by conditions in which they live to engage in inappropriate sexual behavior which results in negative stereotyping (Frankowski and Clark, 2009).

4) **Self Esteem, Sexual Identity and Self Image**: People with disabilities often struggle with low economic and social value forced upon them by the society because of their deformed body (Sait, Lorenzo, Steyn&VanZyl, 2009). Some researches bring out that 'sex' is endorsed as a domain of white, heterosexual, physically attractive non-disabled people (Tepper, 2000). The analysis of many women and men magazines suggests that these magazines promote sexual and gender stereotypes, often enforce a deceptive picture of sexuality by using picture perfect models which gives a conlicting message to the readers that 'sex' is made for people who are physically attractive and for the non-

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disabled (Hahn, 1981). A lot of research has gone into the process of understanding the sexual selection and mating since Darwin's 'the origin of species'. Many studies assert that sexual strategies are innate biologically driven biases that encourage human towards certain specific characteristics in sexual partners which might vary depending on gendered traits. These biases are developed by individuals to solve the evolutionary problems such that heterosexual men may be attracted towards the physical beauty in women as certain traits correlate with fertility. Similarly, heterosexual women may be more attracted to cues that suggest that a man is monogamous and is a good provider. Disability is a lived experience of an individual and may vary from person to person depending on different circumstances. A person suffering from Cerebral Palsy which is a disease from birth will have a different disability experience in comparison to a person who has suffered a spinal cord injury at the age of 35. For the person who has suffered disability at later years of his/her life may have suffered burdensome and intrusive thoughts regarding their sexual performance during sexual activity due to the loss of their ability (Tepper, 2000). Similarly, a person suffering with mental disability may have difficulty in making judgement about sexual situation in comparison to a person with disability.

According to a study conducted by Bellin and Brei (2007), young women with physical disability reported limited dating experience which resulted in lack of confidence and they experienced lower levels of sexual esteem and sexual satisfaction. Some women also reported signs of sexual depression which were more prevalent in women with severe physical disability than women with moderate or minor physical disability (McCabe and Taleporos, 2003). Women with spinal cord injury reported concerns regarding their

physical and sexual attractiveness, their ability to please their partners sexually and their concerns regarding urinary and bowel control (Nosek, 1996). Body esteem is about how one views his/her body. In a study conducted by Seal, Bradford and Meston (2009) it is reported that the body esteems of the non disabled women is found to be a strong predictor of a woman's experience of sexual desire and sexual satisfaction. Many women with disability try to prove normalcy by engaging in sexual activity to overcome the threats posed by disability on the sexuality of people with disabilities but end up with results like STD's and unwanted pregnancy (Greydanus and Oman,2008). Some researchers also highlighted that many women were apprehensive about the sexual consequences after the first intercourse due to the stereotypes that are attached with disability.

McCabe and Taleporos (2003) asserted that men with physical disabilities are more likely to be single than women which indicates lower levels of sexual esteem and sexual satisfaction. Treatments for men who have acquired disability in later years of their life focused on assisting the damaged male to regain his potency (Fiduccia, 2000, p.168). Many researchers have found that the men with disabilities are genetically focused to derive sexual pleasure rating oral sex and nude cuddling to be important whereas women on the other hand focused more on the emotional bonding.

Similarly, people suffering from mental disability may have difficulty in making judgement about sexual satisfaction in comparison to a person with physical disability. The social impediments regarding sexuality of people with disabilities leads to an increased feeling of negativity and the stigmas associated with disability make them feel that they are less sexually desirable than the non disabled.

5) **Physiological barriers**: Sipski and Alexander (1997) assert that different disabilities can have varying impact on an individual's sexual expression depending upon the effects from medical treatment and intake of drugs. Disabilities such as CP that cause motor impairment affects the sexual expression of a person as he/she lacks motor strength to achieve orgasm and is not able to pleasure his/her partner (McCabe and Taleporos, 2003). Disabilities that affecst the spinal cord of a person results in the impairment of vaginal lubrication in women and erectile difficulties in men (Sipski, 1991). Strong medical intervention in severe cases of CP like creation of stoma (a pathway connecting the bowels to a pouch for excrement outside the body) increases the life expectancy of an individual but causes problems like ballooning, constipation/diarrhea, granulomas, pancaking parastomal hernia, prolapsed, rectal discharge and rectal pain that can affect the body image result in increased level of anxiety (Ayaz, 2009).

6) **Regulation, violation and sexual abuse**: The need for sexual pleasure by the people with disabilities is a rarely researched topic and that to the research is limited to men with disabilities. The cultural bias toward women focuses on regulating the fertility of 'dangerous female'. In the context of women with disabilities, researchers have limited their studies to fertility, menstruation, pregnancy, STD's and has largely ignored to explore about the sexual needs, desires and satisfaction of such women (Nosek, 1996, p.107). There exists an irony as on one hand women with disabilities are considered as asexual beings with closely monitored sexual choices whereas, and on the other hand these women are at a higher risk of sexual abuse and are likely to have unwanted pregnancy and are more prone to sexually transmitted diseases. Young girls and women with disabilities in both developed and underdeveloped countries are more vulnerable to

experiences such as forced sterilization, early use of birth control pills and sexual abuse (Sait, Lorenzo, Steyn and VanZyl, 2009). RajeshwariSundarRajan, through the analysis of the widely reported cases of hysterectomies performed on mentally retarded women in Pune in February 1994, brings out the issues confronting institutionalized women against the worries produced by the unregulated sexuality. The experts in favor of the procedure dwelt upon the rise of unwanted pregnancy and the dirtiness of the menstrual cycle. The experts further argued that "the institution offer protection to women from the outside world just like a familial home because women are vulnerable; and they offer protection to the society from women because of the threat and danger they represent" (Rajan,2005: 142).

The cruel procedure of hysterectomies, therefore, 'disciplined' the uncontrolled sexuality of these women in its more visible manifestations viz, the danger of unwanted pregnancy and the 'pollution' of menstrual bleeding.

As indicated in the report of Centre for Justice Statistics, 1994 in Roeher Institute (1995), Canada, men with disabilities are twice as likely as men without disabilities to be sexually abused in their lifetime. Men are usually the victims of sexual abuse during their childhood and the perpetrators are their care givers who take advantage of their dependency. Efforts are made to curtail "inappropriate masturbation" in men. Some of the most extreme remedies undertaken to curb masturbation in men have involved chemical sterilization or surgical procedures such as orchidectomy to avoid inappropriate sexual behavior (Carlson, Taylor, & Wilson, 2000).Further interpersonal violence like physical, sexual and psychological abuse in a romantic relationship was common in both young boys and girls (Mitra, Mouradian and McKenna, 2013).

7) **<u>Health Care</u>**: Care givers and health providers have a strong influence on the sexuality of people with disabilities and that effect can be positive or negative depending on the approach of the provider (Dune, 2012). Many agencies that do that have a defined set of policy on the sexuality of people with disabilities; leave the decision making to the untrained staff. The health care providers are left on their own to rely on their views of sexuality and disability, their views in regard to the expression of sexuality and their own personal experience when providing support to such individuals. Care givers who could not handle the inappropriate sexual behavior of these individuals termed people with disabilities as sexual deviants. Lack of proper training, comprehensive policy and lack of knowledge of the care givers further contributes in creating negativity towards disability and sexuality.

The barriers faced by people with developmental disabilities cluster around social factors related to negative stereotyping about disability and perceptions about disability in general rather than physiological effects of disability. People with disabilities may feel excluded from the rest of the society in many areas of sexuality. The stigmas attached with disability contribute majorly in the exclusion of these people. Myths such as people with disabilities are asexual beings negatively impacts them. Their sexual identities are framed with feelings of sexual inadequacy related to physical attractiveness and performance.

# <u>CONCLUSION</u>

The research indicates that there is growing awareness about the Western bio-medical conceptions of child rearing and child development, the notions of 'normalcy' and the developmental deviances. There exists a contrast between the parenting styles of contemporary times and the parenting styles of earlier generations which were more relaxed and were dependent on 'folk wisdom' like boys are late talkers etc. There exist fear and anxiety among young parents about 'child rearing' and 'normal development' along with skewed non-egalitarian educational system and cut throat competition for scarce resources like admission in a 'good' school, job prospects etc. Under these circumstances the markers of 'normal personhood' comprises of mind-body dualism, characteristics of western culture and emphasis on intellectual capabilities. Other prized qualities include the ability to interact with people outside the family, internalize social norms and display behavior in accordance with the norms laid down by the society. The difficult conditions and the rule defying aspects of cerebral palsy alienates the affected person from the society and also puts the family of the affected person under immense stress and confusion. Through the personal narratives of the parents with children with CP the study culled out the metaphors that represent their understanding of disability and the process undergone to come in terms with disability of their child. These include conceptualization of CP as a product of Karma, CP as a curse and as an enigma which is hard to explain. These metaphors indicate that it was very difficult for families to deal with the symptoms that were unusual to them. Further the innocence of the child provides a positive image with which these children were viewed. They were frequently referred to as simple and innocent and their impulsiveness, stubbornness and lack of self control is couched in these terms. At the same time the parents are fearful and anxious that permanent childhood implies failed adulthood and

lifelong dependency of their children which will freeze these individuals in the luminal zone as described by Murphy (1990).

Chapter two was based on fieldwork strategy whichrelied upon unstructured interviews and participant observation and elicited data on everyday routines pertaining to feeding, grooming, recreation, schooling, commuting, attending social gatherings in other words, the activities and practices that form the bedrock of domestic life, in and through which families constructed the disability of the child and negotiated with it. It was observed that families built up and modified their routines around those of the disabled child and, over time, the special efforts and adjustments they made became absorbed into the family routine.The child's disability compelled the families to come out of their secure worlds and motivated them to take brave decisions like migrating from one place to another for their child's future and compromising other interests and commitments. At the same time making such difficult choices caused much psychological distress to the parents. The conceptualization of CP as a curse indicates the difficulties faced both by the child and the family. The complications that stems from motor and sensory difficulties of the child and the handicapping responses of the society like rejection, ridicule, stigma etc. fortified the notion that disability is a 'curse'. The constant fear about the future of the child was common in all narratives. Another major concern that was common in almost all narratives pertained to identification of symptoms and diagnosis of the child's problem by the parents. The apparent inability to pick up social cues, tendency towards aloofness, inability to react to situation, inability to understand simple commands and to respond to the stimuli was a breach in the 'taken for granted' development process of a child.

My own association with disability gave me the opportunity to interact with several families whose children were affected with Cerebral palsy and helped me to establish contacts which

proved to be of great use in the study. Although the type of disability I have is completely different in terms of its severity and outcome yet being a part of the disabled community gave me an edge to establish rapport with the affected people along with their families.

The endeavor to transform the nature and scope of my experiences from a patient to those of a researcher in Sociology was a problematic one. Many families from the sample undertaken shared with me that they had been interviewed or surveyed before by researchers from the field of psychology or special education, and they did cooperate with them with the intention of creating awareness and knowledge. At the same time, they expressed their apprehensions that the researchers were only interested in statistics with facts and figures. They merely treated them as data providers and not as persons with an emotional baggage. In one of my initial conversations with a mother of the affected child, she angrily told me, "what do young girls like you understand about what I'm going through? Many came before you, asked their questions, filled their forms and went ... But do you know how it is ……. do you understand ………. ".  This kind of acceptance and rapport with respondents in the field situation highlights the need for "insider" studies of disability and sexuality.  Before I approached any affected person and their families, I made sure to acquaint them with my purpose by explaining to them the aims and objectives of the project. I assured them about the confidentiality of the project and hence, all the families I approached to participate in, agreed to do so. Many families were very co-operative and understanding as they did not appear to have serious reservations about these issues and told me that I could ask them anything I wanted and even use their real names.

Only one couple who were parents of a girl child had concerns about what they termed "privacy issues" and expressed the desire to see what I had written about themand how I had represented their narratives. However, all names and personal details have been anonymised.

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During the time of my field work all the people who were affected by Cerebral Palsy were between the ages of *5 to* 12 years and between 16 to 35years. It was thought that families of children within the age group of *5* -12 years were in a position to understand and articulate more clearly the concerns of raising such a child, as compared to parents of very young children who probably had recently received a diagnosis, and were thus grappling with shock and emotional distress.

Further, it was observed that people within the age group of 1*6* -35 years appeared "different" from their regularly developing peers as the socio-emotional developments that take place at this stage are very complex. The issues pertaining to puberty, sexual maturation etc. that confront older children like menstruation in girls and development of secondary sex characteristic (pubic hair, spurt in height, deepening voice etc.) in boys further complexes the scenario.

In a nutshell, families of persons with Cerebral Palsy within the age group of *5* -12  had the time to get over what Wolfensberger (1983) terms "novelty shock". At the same time they were grappling with the issues of raising young children (the child with cerebral palsy and his/her regularly developing siblings), ageing parents, workplace expectations and other pressures.

The study also found that not all families could bear the expenses of a trained and a professional care giver therefore, the casual hired help or care givers were kept for miscellaneous assistance. The parents heavily depended on their support to carry out the day to day functioning. Hired help and care-givers thus, played an important role in urban households, particularly those under difficult circumstances or where women work outside the house. Few families reported that since the affected person spent their maximum time with the care givers they felt more connected to them. One of the mother shared,…… *"Our maid Shobhna who must be in her late 30's and  has been kept specially for our son Prateek is deeply attached to him. He follows all her commands.*

*Prateek always throws tantrums when with me and his father in terms of clothes, food and even watching television for that matter. But when with Shobhna, he is a disciplined child. He follows all her commands, does his exercises and eats whatever she serves him. Shobhna is no less than 'God' for me. I wonder what we would have done if I had left my job. It is difficult to survive on one person's salary with so many medical expenses. She knows when to be strict with him and when to show love. Although Shobhna is illiterate and is not so well versed with Prateek's problem yet she handles him like a professional and disciplines him by scolding him whenever required. "*

In yet another family, the unmarried *massi*(mother's younger sister) plays a supportive role and helps to keep the child entertained. Childhood is construed as an enterprise, a work-in-progress and successful attainment of mile-stones is viewed as a measure of successful parenting. In a competitive urban milieu, conformity to norms is the key to success. The arrival of a developmentally disabled child alters the life-plan. However, the efforts to find treatment, cure, therapy, rehabilitation, medication, and the willingness to undergo hardship "for the sake of the child" are as strenuous, if not more so, than the efforts to "make" the future of the regularly developing ones.

The present study involves review of literature on the sexuality of people with developmental disability like cerebral palsy. The study has two main findings: i) The study suggests that the society largely disapproves of people with disabilities establishing sexually intimate relationships with others ii) people with disabilities face number of barriers in regard to their sexuality.

In chapter three I discuss the need for anthropologists to contribute to the discourse of disability and sexuality by tracing the key factors responsible for the negative representation and

subjugation of people with disabilities such as sexual orientation, hegemonic notions of sociality and desirability etc.

The limitation of the present study is that there have been only few studies in the field of medical anthropology and sociology that examine the disability and sexuality of people with disability. The lack of comparative material was a hindrance in the study as not much work is done on the issue of interpersonal negotiation of sexual intimacy. Lunsky and Konstantareas in their work 'The attitudes of individuals with autism and mental retardation towards sexuality' (1998) give different factors which are responsible for limited research in this area. They assert that the misconception regarding disability and sexuality may have resulted in placing little value on the sexual attitudes of people with disabilities. Previous research shows that people with disability are perceived as sexually deviant, asexual and sexually immature, hence their attitudes are not considered worthy of study. Another factor that adds to one of the many reason for limited research is the difficulty in collecting valid data from the individuals with developmental disability.

Chapter four gives an understanding of the barriers that people with disability face while establishing sexually intimate relations with others. One of the reasons that can be attributed to this is their lack of knowledge and awareness about sexuality due to the socio and socio-sexual isolation during the adolescent years of the affected person. Other reasons include over protective attitude of parents, poor body image, cultural ideals of attractiveness etc.

Researchers argue that people with severe disabilities may not be able to understand the questions asked to them. In past research it has been observed that it is the family, caregivers, friends and counselors who usually answer on behalf of people with disabilities which is meaningless and does not give an accurate picture. Unfortunately, the first-hand accounts of

individuals with developmental disabilities are largely absent from the literature. Much research work in the past has focused on people with mild disability as they are easiest to access and therefore, much less is known about the attitudes of individuals with moderate and severe disability.

As a researcher my idea was to give an unbiased and holistic picture of the current subject undertaken for study. But unfortunately, out of the seven respondents whom I interviewed between the age group of 16-35 only two were women respondents and had severe disability. The parents of the girls one aged 21 and the other 27 were apprehensive to talk about any unusual behavior that they demonstrated with respect to their sexuality. One of the mothers told me "*Geeta is not at all comfortable during her monthly cycle. She cribs every time I change her sanitary pad. After so many years she has still not accustomed to the monthly cycle*".

Dotson, Stinson, and Christian (2003) assert that women with severe disabilities are usually absent from research studies based on sexuality. They further believe that due to inappropriate research designs and tools, the attitudes of women whose needs and experience requires more attention are least understood and are not considered in the research. They assert that in order to understand the views of people with severe disability the researcher might need to use photos, sign language, role-plays, or interactive computer programs to communicate with these people which is not always readily available.

I too faced discomfort while interviewing my respondents as I did not know how to put forward my questions regarding sexuality in a situation when few of them were uninformed about sexuality. Also talking to the parents of affected people gave me a vague picture due to the taboo associated with sex and sexuality.

Although many barriers continue to exist for the people with disabilities to establish sexually intimate relations yet it encouraging that these issues are now being increasingly recognized and discussed. McCarthy in her work 'Whose body is it anyway?' (1998) interviewed women with development disability asking their perception about themselves and their body, their sexual desires and feelings, health and reproductive problems they face and their control over the choices concerning their bodies.

Her findings bring out that these women had a lot to say about their experience of disability when given an opportunity. She further asserts that there is a need to set aside age long perceptions and assumptions about these people and view their ideas afresh. Di Giulio (2003) asserts that it has been observed by the professionals that people with disabilities often suffer from a low sexual esteem. Therefore, the onus lies on the care givers and the counselors to help people with developmental disabilities to affirm their status as fully sexual human being. It is important to develop confidence in their ability to express their sexual desires as they may feel dehumanized by the negative attitude of the society in regard to disability and sexuality of people with disabilities. It is important for the care givers to not to assume that the difficulty in the sexual expression of individuals with disabilities is related to their disability. It is found that people with disabilities internalize negative societal attitudes regarding their sexuality. With focused efforts to recognize and understand the needs of people with disabilities, it is believed by researchers that the impediments will gradually erode and these people will have increased opportunity for sexual growth and fulfillment. There is also an urgent need to challenge the harmful beliefs and power imbalances that exists between people with disabilities and the non-disabled people. Undoubtedly there is a growing awareness about developmental disabilities like cerebral palsy and greater visibility of such individuals in the public realm. The time has come to

acknowledge the sexual desires and needs of people with disabilities which are suppressed due to stereotyping and negative attitude of the society towards them.

Strategies to change community attitudes seem to be most effective when they include policies at all three levels (personal, organizational and structural), include people with disability in the design and implementation of the policies, are sufficiently prolonged and resourced to reinforce positive attitudes and replace negative attitudes, and address the diversity of disability experience.

Now, the question is will the society continue to misinterpret and misunderstand the basic sexual needs of people with disabilities?Or will an 'ethical community' supported by the welfare State reinterpret and revitalize the sexual needs and desire of people with disabilities and consider it to be a crucial part of their life like any other non-disabled being ?

Only time will tell.

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