IS 'SUFFERING' INEVITABLE?
STATE, SOCIETY AND DISABILITY.

Dissertation submitted to the Jawaharlal Nehru University
in partial fulfilment of the requirements for
the award of the Degree of
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CERTIFICATE

This is to certify that the Dissertation entitled "IS 'SUFFERING' INEVITABLE? STATE, SOCIETY AND DISABILITY" submitted by Ms. UPALI CHAKRAVARTI in partial fulfilment of the requirements for the award of the Degree of MASTER OF PHILOSOPHY of this University, has not been submitted for any other degree of this university or any other university and is my own work.

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

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CONTENTS

ABBREVIATIONS

AIIMS	All India Institute of Medical Sciences
CAPART	Council for Advancement of People's Action And Rural Technology
CBR	Community Based Rehabilitation
CP	Cerebral Palsy
DPEP	District Primary Education Programme
DRG	Disability Rights Group
ICDS	Integrated Child Development Services
NCPEDP	National Centre for the Promotion of Employment of Disabled Persons
NGO	Non Government Organization
NIMHANS	National Institute of Mental Health And Neuro Sciences
NSS	National Sample Survey
NHS	National Health Services
PHC	Primary Health Centre
PWD Act	Persons With Disabilities Act
RCI	Rehabilitation Council of India
SSNI	Spastics Society of Northern India
WHO	World Health Organization
UNDP	United Nations Development Programme

The disabled body exposes the illusion of autonomy and self determination that underpins the fantasy of absolute able-bodiedness and perfection.

THE CONTEXT OF SUFFERING

> *"Development means social change which weakens forces disabling people, households, classes. If gender and environment can become intellectual paradigms, why not also disability which raises fundamental questions about human welfare"*
>
> *- Barbara Harriss-White.*

The Problem

Discussions of both suffering and ethical choices have conventionally tended to be decontextualised in social science research. Suffering has been regarded mainly as an individual experience, determined by individual circumstances except in certain situations involving groups of people such as war, genocide and famine. In discussions around health, suffering is also individualized in terms of the solutions offered. Similarly ethical choices are individualized because the choices are presented as determined by an individual, even though such choices are shaped by the larger society. It is also significant that when a context is sought to be provided both suffering and ethics have been linked to culture more often than to the political economy and we therefore have only a partial understanding of both phenomena. There is thus a need to provide a political economy context to both ethical choices and suffering. Such concerns are beginning to be reflected in social science and medical research in recent years.[1] These developments have opened up the possibility of examining disability, and the suffering and the ethical choices associated with it, in the light of this new research.

There are very few studies dealing with the low priority given to disability in conceptualising the public health needs in a society.[2] Despite the claim that the goal of alleviating suffering is integral to public health it has failed to include disability within its purview. Although the data[3] indicates that a small proportion of the population is disabled, they constitute a large minority and disability can afflict anyone at any time. Public health is defined as the organised effort of the community to deal with disease prevention, cure and rehabilitation; hence public health does not deal with just the individual but also with the community within which the person is located. In this context public health has an important role for the disabled and their families by recognising their suffering which is impacted by the socio-economic relations of society and the ethical choices that it makes. The purpose of this study is to explore the relationship between political economy, suffering, and 'choices' or decisions people make in the context of disability, as well as to try to develop an expanded understanding of public health so as to include disability in its purview.

This study focuses broadly on two types of material: first it examines the literature on public health, suffering and social polices with respect to disability. A second aspect of the study is ethnographical in that it is centred on indepth interviews with parents/ primary caretakers /family members of disabled persons-i.e. it generates primary data and attempts to provide an analysis of this data. Within the framework outlined above. Among the issues that this study seeks to highlight is the need to view disability as important not just in terms of a problem to be tackled by Public Health clinically but to understand the social component, i.e. the social construction of disability, and to explore the scope for public health intervention in the field of disability.

The study provides an overview of the available data which covers a range of characteristics with regard to the number of people with disabilities, different types of disabilities and categories of people most affected by disability. The study explores the level of state intervention vis-à-vis policies and legislations for the disabled, the extent of their implementation and the success and failure in achieving their aims. The study also briefly traces the entry and role of the NGOs in the disability sector in terms of reasons for their entry into the sector, the type of services provided, sections of the disabled they are catering to, the extent to which the needs of the disabled are being met and their role in advocacy for the disabled. The data, the level of state intervention through legislation and the resource allocation, as well as the provision of services for the disabled by the state and the NGOs provides the political economy framework for locating the experiences of the disabled and their families in coping with their existential realities; these may appear to be individual but are deeply shaped by the policies of the state and the availability or non-availability of facilities for those who experience disability.

An important component of this study then is to explore the issue of suffering and to understand the nature of suffering across classes. If alleviating suffering is recognised as one of the issues under the purview of public health how can a public health perspective help in dealing with the issue of disability? Could it be through an understanding of the framework of the 'suffering' undergone by the families of the disabled and the disabled themselves?

However the data in this study and interviews with disability activists indicates that if measured by resources committed and by rhetoric, alleviating the condition of being disabled is unquestionably the lowest priority on state welfare agendas in practically all underdeveloped countries, just as it is in the developed world. It is also without doubt the least researched aspect of social development.

The low priority for disability is evident even in the way development is measured. The 1993 Human Development Report of UNDP for example contains compendious data on all aspects of the human condition, with the exception of disability on which there is nothing. This low priority can be disposed off simply in public choice theoretic terms: by the political weakness of disabled persons on the one hand and by the high perceived political and economic costs and low perceived political and economic benefits of state response to the problems of the disabled people on the other. At a general level, Harriss-White points towards the inadequacy of the cost-benefit calculus as a basis for justifying expenditure incurred on the alleviation of disability.[4] Costs and benefits are often hard to identify and even harder to measure. The methodology restricts attention to initiatives of a 'rehabilitative' nature. Isolating the benefits attributable to such rehabilitative response is always difficult; and the employment solely of the money metric as a measuring rod misses out on much of value.

More recent developments suggest that while the state is abdicating its responsibility for public health, it never displayed any significant accountability for providing relief in the event of disability in any case. And yet the need for intervention in terms of providing services, resources, and integration into society--in short ensuring that the rights of the disabled citizens of India are not violated since the figures of those whose rights are being violated are enormous. In 1991, the number of the disabled persons in India was estimated at 32 million - roughly equal to the population of Colombia and about half that of Tamil Nadu and of the UK. Unfortunately the disasters visited on large numbers of people in India are frequently absorbed in their 'small proportions'. At around 3.7% of the total population (even though four to five times that many will have a disabled family member), the disabled account for a segment which a less than conspicuously caring state can afford to overlook. In 1991, at least 32 million of the total population of 844 million was likely to have been disabled. Their families and those working in caring institutions, people affected indirectly by disability, would have amounted to perhaps four to five times as many. This taken together with the fact that the disabled do not constitute a vocal, empowered section of the population has meant that their neglect by state and society alike has been 'painlessly' achieved. The National Sample Survey of 1981, which shows that that there is nothing random in the distribution of disability among the population classified by educational standing and the close relationship between education and economic status is thus well established.[5] It can be inferred that a substantial proportion of the disabled population is defined by the intersection of the poor, the illiterate and the backward castes. Furthermore, 'old age' occurring on an unprecedentedly mass scale in rural India tended to be identified by the onset of incapacitating disability more often than by calendar age. The survey data with regard to the disabled people reveals widespread need for simple equipment such as spectacles, hearing aids and crutches which were unavailable, or if available, out of the financial reach of the bulk of the disabled people for whom such conditions mark a downward mobility.

The low priority accorded to the disabled by the state and society is reflected in academic research too. There are no systematic studies to show how disabled people gain access to livelihood, how households cope and respond, or the nature and type of social and economic costs involved. There are also no studies regarding the position of public health vis-à-vis disability. The scope of public health is to include all organised activities in the field of health: promotion, prevention, care and rehabilitation. Health promotion, specific protection, early diagnosis, prompt treatment, disability limitation and rehabilitation - are all considered to be preventive activities according to Hugh Leavell.[6] The understanding is that health is a collective product, which requires joining of social forces in a collective effort thereby differentiating public health practice from classical clinical medicine approach. It is a holistic approach to all health problems of a community. Consideration of causative factors opens up issues, which fall within the wider social, economic, and political spheres which may influence the cultural perception and cultural meanings of different health problems and health behaviour.

Given this wide scope of public health along with one of its aims being to alleviate suffering, the neglect of the disability issue is surprising if not outright callous; this study is a small attempt at redressing the low priority of disability in social science research and a way of understanding why that bias exists in the first place in our society.

Chapterization

This study begins with a review of the existing literature on the following themes that run through the thesis: the politics of disablement, the ideologies of caring, theoretical perspectives on caring in the context of social justice, the relationship between the political economy and disability policies, and locating the roots of social suffering. These issues are the subject of Chapter One titled Theorizing Disability.

The next chapter, Chapter Two titled The Welfare State and After, examines the history and development of the welfare state in selected countries but which are representative of different types of social and political systems and the policies of rehabilitation they have framed for the disabled. This survey is an attempt to explore the relationship between disability and the larger context of state and society in several other regions so that the Indian situation can be better understood.

The next two chapters examine disability in India; the first --Chapter Three titled Recording Disability is based on the statistical data comprising the NSS and Census; the second --Chapter Four titled State, Society & Disability in India, begins with an analysis of the concept of the welfare state in India and tries to outline the contemporary situation with respect to disability; it is primarily based on a series of interviews with professionals and activists in the field of disability. It also draws upon secondary literature dealing with planning, health and disability, and the welfare state in India.

The final chapters are based on a series of interviews with parents of the disabled and the disabled themselves wherever possible. It comprises a series of narratives of the disabled, the experiences of their families, their coping strategies and their anxieties about the future. This is the subject matter of Chapter Five titled Narrativising Disability. The next chapter--Chapter Six titled Embedding Individual Biography-- draws out the implications of the two previous chapters comprising the ethnographical data and attempts to provide a framework for understanding the narratives of the lives of the disabled.

Methodology

Since the main focus of the study was the household level, interviews were conducted with parents of persons of Cerebral Palsy (CP). The reason for choosing CP as the condition was because first, it is among the third highest cause of locomotor disability according to the NSS data. Further it is a physical disability: hence the amount of physical care that is required is much greater than any other physical disability, and the level of care varies with the degree of severity. Second, apart from speech disability CP can also occur along with hearing disability and/or mental retardation, complicating the situation in terms of long term care. In order to understand disability from a public health perspective and to view rehabilitation and long term care of persons with disabilities, the selected persons whose parents were interviewed were all in the age group of 14 -25 years. The condition varied in terms of degree of severity from mild to severe CP. Care was taken that those interviewed represented different economic statuses. All the cases belonged to the urban area, 9 in Delhi and 1 in Bangalore. Hence it was a stratified random sample. Interviews were conducted around 10 open-ended questions covering the areas of case history, initial reaction, services accessed, family support, social interaction, economic adjustments, role of the government in the field of disability, coping strategies, and the future envisaged for the disabled person as well as any other issue the interviewees considered important.

Interviews were also conducted with professionals and disabled activists. There were 10 open-ended questions. The areas covered were disability awareness, the disability movement, services available, role of the NGOs, role of the state, model/s of rehabilitation, role of the family, coping strategies used by the families, their view of suffering as an aspect of the family in dealing with the situation and any other issue they considered important.

Limitations of the study

There are a number of limitations of this study: in terms of the data - the sample was only confined to the urban areas in metropolitan cities. In most of the cases the interview was conducted only with the mother: in 2 cases the mother was a widow, in 5 cases only the mother was present because the father was away at work and in 3 cases both parents were present. No persons from the medical or public health field were contacted. Programmes and policies operative in different Indian states for the disabled have not been studied indepth. The whole area of genetics, euthanasia and ethics, though important, have not been explored in this study.

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[1] D. Turnbull, 'Genetic Counselling: Ethical Mediation of Eugenic Futures?' *Futures* 32, 2000, pp.853-865; M. Russell, 'The Political Economy Affects Us All', *Kaleidoscope*, 38, 1999, pp. 6-13; P. Farmer, 'On Suffering and Structural Violence: A View from Below', in A. Kleinman et. al. ed.,*Social Suffering*, Oxford University Press, New Delhi, 1997.

[2] D. Allen et al., 'Creating a Public Health Focus on Disability', paper presented at National Conference on Disability and Health: Building Bridges for Science and Consumers, Texas, 1998; G. Jones, 'Health Care Access and Utilization Patterns of Persons with Severe Activity Limitations', paper presented at National Conference on Disability and Health: Building Bridges for Science and Consumers, Texas, 1998; P. Pardo, 'Portraits Of Pity Or Possibility? Images of People with Disability From Around the World', *Disability Information Network*, 2000.

[3] *Census of India* (1981), Government of India; *National Sample Survey Organisation*, 36th Round (July-December), 1981, Governement of India, *National Sample Survey Organisation*, 47th Round (July-December), 1991, Government of India; A. Baquer, *Disability: Challenges and Responses*, Concerned Action Now, New Delhi, 1994.

[4] B. Harriss-White & S. Subramanian ed., 'Introduction', in *Illfare in India: Essays on India's Social Sector in Honour of S. Guhan*, Sage, New Delhi, 1999, p. 25.

[5] Ibid., p. 24.

[6] H. Leavell, cited in D. Banerji, 'Trends in Public Health Practice in India: A Plea for a New Public Health', 32nd Annual Conference of Indian Public Health Association, Hyderabad, 1988.

THEORIZING DISABILITY: A REVIEW OF SOCIAL SCIENCE LITERATURE

> *The pain in our shoulder comes*
> *You say, from the damp; and this is also the reason*
> *For the stain on the wall of our flat.*
> *So tell us:*
> *Where does the damp come from?*
>
> *- Bertholt Brecht*

This chapter is focused on a selected review of literature for the purpose of the arguments and issues being raised in this study. The first theme to be addressed is the social construction of disability. One of the pioneers of formulating the social theory of disability is Michael Oliver who has drawn on the works of many scholars to develop a social understanding of disability. This study draws upon mainly his work to understand disability in a social context.

The second theme that has been explored in this study is the political economy framework within which the issue of disability can be understood. For this purpose the work of Marta Russell, who was disabled herself from birth, has been extensively used.

The third theme to be addressed in the study pertains to the issue of caring and caregiving. This aspect has relied on the works of Gillian Dalley and Martha Nussbaum.

The fourth theme that has been explored is the context of social suffering. Arthur Kleinman's and others have done extensive work on this subject; hence their work has been used to understand the issue of social suffering in the context of disability.

Literature related to other themes and issues raised in the study are discussed in the relevant sections and chapters.

DISABILITY: DEFINITIONS AND MEANINGS

World Health Organisation (1980) defined the key terms in disability as:

- Impairment - 'Any loss or abnormality of psychological, physiological or anatomical structure or function'.
- Disability - 'Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'.
- Handicap - 'A disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex, social and cultural factors) for that individual'.

Hence 'impairment' includes those parts or systems of the body which do not work 'properly', and 'disability' centres on those things that people cannot do, primarily basic skills of everyday living. Most of the novelty of the WHO schema lies in the interpretation of 'handicap'. This extends the notion of 'consequences' to difficulties in carrying out social roles, while acknowledging that these vary across social groups and cultural contexts.[1]

The WHO definitions have generated considerable critical debate primarily because the approach relies on medical definitions and uses a bio-physiological definition of 'normality'. Secondly 'impairment' is identified as the cause of both 'disability' and 'handicap', thereby implying that the way to overcome 'disability' and social disadvantage is through appropriate medical and allied rehabilitative interventions. The criticism of the WHO's International Classification of Impairments, Disabilities and Handicaps (ICIDH) has led to bringing out a revised version after undergoing field testing which adopts a so-called 'biopsychosocial' model that endeavours to synthesize the medical and social approaches to disability.

Rejecting the close connection between impairment, disability and handicap the Union of the Physically Impaired Against Segregation (UPIAS), while broadly accepting the medical definition of impairment, turned around the meaning of disability as:

- Impairment - Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body.
- Disability - The disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from Participation in the Mainstream of social activities. [2]

However, according to Barbara Harris-White, no matter what the official definitions of disability it is a relative term because cultures define their norms of being and doing differently.[3] In South Asia for example, social deviancy is classified by many local people as a disability, as is being outcast from the caste system. Economically oppressive, socially tyrannical and politically disenfranchising forms of work such as child labour and bonded labour are sometimes considered to be disabling. Physical and mental disability, as recognised clinically and legally, may be considered as 'fitting' retribution for particular sins (in a past life), responsibility for which lies entirely with the individual.

Further according to Harris-White, as a form of deprivation, disability is intractably complex.[4] Yet the concept of 'disability' is a crude political label akin to that of being 'black'. Impairment forms a continuum from 'ability' to a range of kinds, combinations and intensities of incapacity. Medically, and sometimes for the purposes of legal claim, they are distinguished according to type and severity. The condition may be static or it may change progressively. That disability causes poverty is incontrovertible but disability also affects the non-poor as well as the poor and the social and economic costs of a given disability will differ according to social location, social or ethnic group, gender, age and economic status. Impairment may be ascribed a social stigma and may affect status as a citizen. Mortality may be heightened for social and economic rather than medical reasons. According to Harris-White the reasons for disability (disease, congenital causes, accident, war) can and do affect legal entitlement.[5]

PERSPECTIVES/APPROACHES TO DISABILITY

Disabled people have existed in all societies. However the experiences and treatment of the disabled, both individually and collectively, have varied from society to society and from period to period. Hanks and Hanks, two anthropologists, noted difficulties in collecting data on physical disability because no uniform classifications exist cross-culturally and also because the social disabilities of individuals and groups are peculiar to the social conditions of the particular societies concerned. From their review it is clear that the individualised tragic view of disability in modern industrialised society is not universal by any means. Such variations that occur are not random but are determined by a range of factors two of which Hanks and Hanks focus upon: the social obligations to, and the rights of, disabled people in a given society. They also recognise the existence of other determinants - "the type of economy, the need for manpower, mode of distribution, the social structure whether egalitarian or hierarchical, and how it defines achievement, and values age and sex".[6]

Unfortunately, according to Oliver, none of these writers provide a conceptual framework, which explains or integrates these differences. Within the anthropological literature there are three theoretical perspectives attempting to explain what happens to the disabled people:

Implicit Theories of Disability - One of the first implicit theories stems from the influential work of Evans-Pritchard. This work suggests that in societies dominated by religious or magical ways of thinking, disability is likely to be perceived as punishment by god or individual disabled people to be seen as victims of witchcraft. The example Pritchard gives is of epilepsy, which is seen as a phenomenon that fits within the belief system of possession by evil spirits. Such an explanation sees religious or magical beliefs as autonomous and as the sole determining factor in both defining disability and in accounting for the way disabled people are treated in a given society.[7]

The second theoretical approach is based on the work of Turner and develops the concept of 'liminality'.[8] This theory has been used to explain the social position of the disabled in all societies. The gist of the theory is "the disabled spend a lifetime in a suspended state. They are neither fish nor fowl; they exist in partial isolation from society as undefined, ambiguous people".[9] There are problems with such an explanation: one is that not in all societies are the disabled people, either individually or collectively, placed at the margins. Secondly the explanation of the social position of disabled people is reduced to the idea of a binary distinction of human thought or the search for symbolic order. This reductionism sees societies as the embodiment not of social and economic relationships but of thought systems. Further, it perpetuates the idea of a metaphysical 'otherness', whilst directing attention away from the real physical and social differences which disadvantage disabled people.

The third theoretical position is termed the 'surplus population thesis' which argues that in societies where economic survival is a constant struggle, any weak or dependent members who threaten this survival will be dealt with severely. Thus disabled children are killed at birth and disabled adults may be forced out of the community, and the disabled old simply left to die. However according to Hanks and Hanks one should not be misled by the simplicity of economic factors in such cases.[10] And certainly, in relation to mental handicap, both Farber and Soder attempt to go beyond economic determinism and point to the role of values and ideology in shaping social practices, in capitalist societies at least.[11] In sum, in attempting to develop a social theory of disability the intent should be that disability can only be understood within a framework, which suggests that it is culturally produced and socially structured.

Thus to develop a theory of the social construction of disability it is important to understand, in a historical context, the view of disability as an individual, medical problem and a personal tragedy that has become the dominant view especially in modern capitalist societies. According to Michael Oliver the work of Marx, Weber and Comte can provide a framework to facilitate our understanding of the social construction of disability.

Deriving from historical materialism, Finkelstein developed an evolutionary model of disability along the lines of the three stages of the historical materialist model. His model is in terms of three phases of historical development.[12] Phase One corresponds to Britain before the industrial revolution. The economic base was agriculture or small-scale industry and did not exclude the majority of disabled people from participating in the production process. Phase Two corresponds to the process of industrialisation when the focus of work shifted from the house to the factory. In this phase many more disabled people were excluded from the production process. This situation arose, as Ryan & Thomas put it, because "the speed of factory work, the enforced discipline, the timekeeping and production norms -- all these were a highly unfavourable change from the slower more self-determined and flexible methods of work into which many handicapped people had been integrated."[13] The changes in the organisation of work from a rural based co-operative system to an urban factory based system with the individual waged labourer had profound consequences especially for the disabled.

Such changes resulted in the disabled people being regarded as a social and educational problem. They were segregated into institutions such as workhouses, asylums and special schools. Phase Three is to mark the beginning of a transition to socialism as predicted by historical materialism. According to Finkelstein Phase Three will see the liberation of disabled people from the segregative practices of society largely as a consequence of the utilisation of new technologies and the working together of professionals and disabled people towards common goals.

Thus Finkelstein considers disability a paradox involving what he describes as "the state of the individual (his or her impairment) and the state of society (the social restrictions imposed on an individual)".[14] In his model he sees the paradox emerging in Phase 2. Explaining this further he states that in Phase One the disabled persons formed part of the larger underclass. However in Phase Two they were separated from their class origins and became a special, segregated group resulting in the emergence of the paradox and disability came to be regarded as both an individual impairment and social restriction. In Phase Three that is just beginning he sees the end of the paradox and disability will come to be perceived only as a social restriction.[15]

Evaluating this model, Oliver states that the model has explanatory power to enable an understanding about what happened in Phase Two. However the happenings of Phase One are oversimplified and present an idealised community where the disabled were treated more benignly. Oliver concedes that the emergence of capitalism had profound effects on social relations and directly affected disabled persons. But whether these changes affected the quality of the experience of disability negatively or positively is difficult to assess "largely because history is silent on the experience of disability".[16]

A similar model has been developed by Sokolowska et al. to explain variations in social responses to and personal experiences of disability in the modern world.[17] According to this model there are three kinds of society in the modern world - developing, intermediary-developed and highly-developed or Types I, II, III. Type I societies are characterised by the spontaneous participation of the disabled people; Type II societies are characterised by the separation of the disabled people from the rest of society; and Type III societies are characterised by the integration of disabled people, made possible by the supply of 'necessary appliances'. The major criticisms of such implicit theories are that they are over-simplistic and too optimistic in that both models assume that technological developments will liberate disabled people and integrate them back into society.[18]

August Comte's evolutionary model to understand the development of human history has been used to understand changing historical perceptions of 'deviance' including drug addiction, homosexuality, alcoholism and mental illness, each being regarded first as moral, then legal and finally as medical problems. As a result of these perceptions particular deviants were subjected to moral, then legal, and finally medical mechanisms of social control.[19]

Conrad & Schneider have reviewed the medicalization of deviance and suggest "that three major paradigms that have held reign over deviance designations in various historical periods may be identified thus: deviance as sin; deviance as crime and deviance as sickness."[20]

Soder has analysed the ideology of care underlying the development of services for the mentally handicapped persons. Soder suggests that initially the care provided was based on a philosophy of compassion linked to religious and philanthropic perspectives. After that services were provided based on the philosophy of protection, both for the disabled individual and the society; and finally care was provided on the basis of optimism, linked to the development of new scientific and pedagogic approaches to the problem of mental handicap.[21]

Pasternak has used Comte's model to illustrate changing patterns of prejudice vis-à-vis people with epilepsy: Increasing rationalisation did not ameliorate social prejudice against epileptics - it merely caused one form of prejudice to be substituted for another. The person was no longer isolated as a ritually untouchable person, but instead was isolated as insane and placed in institutions where the person was subjected to extremely substandard conditions of life. However later evidence suggests that further rationalisation and increasing knowledge of the causation of epilepsy, separating it from insanity, may lead to improvements in social conditions for epileptics - as the culture catches up with findings of the scientific community."[22]

There are two major criticisms of such evolutionary models and their application. One criticism is that the 'phenomena' are not 'mutually exclusive' as implied by Comte. While one perception may dominate at a particular point in history, it does not do so at the expense of the others. According to Oliver in modern industrial societies people with epilepsy may still be perceived by some as possessed by demons, still subject to legal regulation and yet be the recipients of sophisticated medical treatment. Similarly, the explanation for the birth of a disabled child may be a medical or scientific one, but that does not mean that some parents may not feel that it is a punishment for some previous sin. Thus such models may help understand changing perceptions of deviance and disability but they do not explain them in causal terms.[23]

The other criticism concerns the issue of causality and the Marx/Weber debate and states that the changing perceptions cannot be accounted for only in terms of the mode of thought.

Jones & Tillotson describe how "the drift to the town and the growing complexity of industrial machinery at the time meant the development of a class of industrial rejects for whom it was clear that special provision would have to be made.... The problem of severe epileptics in a city such as Bradford, where the wool trade meant fast moving machinery and crowded workshops must have been particularly acute."[24] Thus according to Oliver the nature of disability can only be understood by using a model that takes account of both changes in the mode of production and the mode of thought and the relationship between them.[25]

The rise of capitalism brought profound changes in the organisation of work, in social relations and attitudes with implications for the family. There were new problems for the social order and a breakdown of traditional social relations resulting in what Oliver states as new problems of classification and control.

According to Rothman the main solution to this problem was the institution. While institutions existed in feudal times, it was with the rise of capitalism that the 'institution' became the major mechanism of social control thus resulting in a proliferation of prisons, asylums, workhouses, hospitals and industrial schools.[26] The institution according to Elias was a remarkably successful vehicle in dealing with the problem of imposing order and it was in accord with changing social values consequent upon the 'civilising process'.[27]

According to Althusser the institution was successful because it embodied both repressive and ideological mechanisms of control. It was repressive because it offered the possibility of forced removal from the community of anyone who refused to conform to the new order. And it was also ideological because 'it acted as a visible monument, replacing the public spectacle of the stocks, the pillory and the gallows, to the fate of those who would not or could not conform'.[28]

It was not just the prisons and asylums which operated as mechanisms of social control; the workhouses also were crucial and its ideological function was always more important than its repressive one. In the institution the state had found a successful method of dealing with the problem of order and in the workhouse, a successful method of imposing discipline on the potential workforce.

However there was often the problem of separating those who *would not* from those who *could not* conform to the order. Hence throughout the 18th and 19th centuries institutions became more specific in their purposes and selective in their personnel. These developments facilitated the segregation of disabled people, initially in workhouses and asylums and gradually in more specialist establishments. The Poor Law Amendment Act (1834) played an important role in this process of increasing specialisation and the disability category was crucial in separating out those *unwilling* from those *unable* to work. According to Stone the Poor Law had 5 categories that defined the internal universe of paupers; children, the sick, the insane, 'defectives' and the 'aged and infirm'. The 5 groups were the means of defining who was able bodied; if a person did not fall into one of them, he was able-bodied by default.[29]

In the feudal period the family and community were the places where the disabled people lived. With the coming of capitalism the family still remained the setting where the majority of the disabled people lived. But to an extent, as a consequence of the ideological climate created by institutions, setting people apart from the rest of society was necessitated and disability became a matter of shame. The process of stigmatisation caught the deserving as well as the undeserving. However not all families could cope with the difficulties of having a disabled member, particularly working class families which were already under pressure in the new capitalist social order. Hence disabled people became segregated from their communities and wider society, and only when families were unwilling or unable to cope did they become possible candidates for the institution. According to Parker 'nobody wanted to go into an institution but not every relative found it possible to keep their dependent kin, especially so it seems, the mentally disordered and the aged'.[30]

As a consequence of the increasing separation between work and home, the boundaries of family obligations towards disabled people were re-drawn. According to Ignateiff the new asylums and workhouses met a need among families struggling to cope with the 'burdens which for the first time may have been felt to be unbearable'.[31]

Thus both the family and the institution became places of segregation and remained so into the 20th century. What changed in the 20th century was the balance between institutional and family care. With the de-institutionalisation movement in the latter part of the 20th century many people previously in institutions were returned to the community. Commenting about the return to the community, Oliver highlights two important points: first that the proportions within each group such as the poor, old, sick, disabled, insane were different and so too were the rates of discharge back into the community. Second the ideological shift from institutional to community care has been more significant.[32]

In order to understand why these changes took place and what happened to disabled people with the coming of capitalist society, Oliver takes the help of explanations based on the theoretical frameworks of Comte and Marx.

The Comtean framework suggests that what happened to disabled people and others can be seen as the progressive evolution of reason and humanity and the move from community to institution reflects changing ideas about social progress. Abrams calls this view 'the enlightenment theory of social welfare' and it incorporates the establishment of segregated institutions in Benthamite terms as improvements on earlier forms of provision.[33] It also incorporates the variants of the anti-institution movement of the late 20th century sparked off by the work of Goffman on asylums and a number of damning public enquiries about the conditions in longstay hospitals. Such a move back to community care reflects changing ideas about the appropriateness of institutional provision in modern society.

However according to Scull what such a view fails to explain is that many of those confined in institutions experienced this as punishment rather than treatment but studies have also shown that a return to the community can also be an extremely punitive experience.[34]

According to Abrams changing ideas about the nature of the institution and of community incorporated in the enlightenment theory are 'too one-dimensional to be altogether satisfactory'.[35] The success or failure of these ideas is dependent upon a whole range of other factors such as the economic and social conditions under which they develop and the support or resistance they encounter from people in powerful political positions and institutions.

Drawing from the Marxian model as the second explanation which suggests that changes in policy and provision for disabled people were determined by changes in the mode of production Ryan & Thomas state that 'the asylums of the 19th century were... as much the result of far-reaching changes in work and family life and corresponding methods of containing the poor, as they were the inspiration of philanthropists and scientists. With other similar institutions of the period, they have remained the main alternative to the family ever since.'[36] The change back to community care was not just the product of anti-institution ideas, but also because according to Scull 'segregative modes of social control became... far more costly and difficult to justify.'[37] This explanation according to Abrams is known as 'the necessity theory of welfare'.[38] However the 'action theory of welfare' is also important and Parker, reviewing the historical context of residential care, suggests two factors of significance: first that the willingness or otherwise of families to care for their dependants was important. He explains this point with the help of the work of Ignateiff, which shows that the working class families have played an active part in the history of institutional development. He suggests that 'the level of demand for institutional care seems to have been a function of (a) the acceptability of that care as perceived by relatives; (b) the costs which they consider they and their families bear in continuing to look after the dependent or 'disruptive' member and (c) the number of dependent people without close relatives'.[39]

The second factor suggests that institutions have been important historically because of the role they have played in campaigns of rescue, notably of children in the latter half of the 19th century. This rescue mission was also an important factor in the development of residential care for disabled people after the Second World War.

Thus while the 'action theory of welfare' may not explain the forms that provision may take when extracted from the historical context, it is useful in developing an understanding of the nature and form of provision, and consequences of influence on individuals, families and groups at a particular time. However the action theory does not explain that some groups prove persistently more influential than others, necessitating the development of a 'power theory of welfare'. Undoubtedly the group that has been most persistently influential in the context of disability has been the medical profession.[40]

Thus in conclusion it can be said that the rise of the institution as a mechanism of both social provision and social control has played a key role in structuring both perceptions and experiences of disability. They have also facilitated the exclusion of disabled people from the mainstream of life. It is believed that no attempt to develop a social theory of disability can ignore the issue of ideology, for as Abbot & Sapsford state 'there is a clear relationship between prevailing social structures, dominant ideology and the way society handles its deviants'.[41]

As already mentioned earlier that the rise of capitalism excluded disabled people from the process of work and had consequences on social relations. It also changed the way disabled people were viewed for, as Burton puts it, 'capitalism, whether free market or welfare, encourages us to view people... as a commodity for sale in the labour market'.[42] The requirements of the capitalist economy were for individuals to sell their labour in a free market necessitating a break from collectivist notions of work as the product of family and group involvement. Thus as Dalley states ' individualism is seen as being the ideological foundation upon which the transition to capitalism was based.' Relating this to disability it is the construction of 'able-bodied' and 'able minded' individuals which is significant.'[43]

The idea of disability as individual pathology only becomes possible when there is the idea of individual able-bodiedness, which is related to the rise of capitalism and the development of wage labour. Prior to this when differences in the individual's contributions were noted they did not have to suffer exclusion. Under capitalism disabled people could not meet the demands of individual wage labour and so became controlled through exclusion.

Further, by focussing on the physical body of individuals and populations this process of exclusions was facilitated. The main group that focussed on the body was the medical profession. What is called the medicalizing of disability was related to the rise of the medical profession and the development of the 'germ theory of illness and disease'. With the increasing medicalization of society, medicine acquired the right to define and treat a whole range of conditions and problems, which previously may have been regarded as moral or social in origin. While it is acknowledged that there have been substantial gains from the medicalization of disability in terms of increased survival rates, prolonged life expectancies and eradicating some disabling conditions, there are issues that still remain. As Brisenden puts it 'in order to understand disability as an experience, as a lived thing we need much more than the medical facts... the problem comes when they determine not only the form of treatment but also the form of life for the person who is disabled.'[44]

POLITICAL ECONOMY OF DISABILITY POLICIES

According to Marta Russell, whose work is focused on the U.S., disability benefits in the U.S. lagged far behind the European social democratic countries, which set high inclusionary standards for public health programmes in the early 1900s. It was not until 1956 that a grossly limited public disability insurance became available to Americans; Medicare was not available till 1972; and till 1973 the disabled poor had no employment history and could not obtain public assistance.[45] Edward Berkowitz describes how during the 1920s-40s, insurance companies experimented with disability benefits with the private insurers trying to squeeze profits from disability insurance.[46]

Businessmen formed the largest single group on the Social Security Board set up in 1938 and the advisory council in 1948. The prevailing scenario was one in which the private insurance industry, vehemently opposed to public disability insurance, wielded great clout. The American Medical Association (AMA) was also against public disability assurance because it feared socialised medicine (perceived to work against physicians' financial interests) would creep into America as it had in Sweden, France, Germany, Canada and Spain. According to Berkowitz, after the passage of the first disability insurance act, 'one AMA member whined in dismay, "This is the end of the medical profession."[47] Berkowitz explains AMA's position vis-à-vis the disability insurance debate:

> The AMA, increasingly worried about the passage of national health insurance, took the lead in opposing disability insurance, arguing that it would perpetuate the condition of sickness and would work against rehabilitation. Further, the AMA said the law would allow the federal government to supervise the doctors who examined the disability applicants. Who knew where that practice might lead? The solution to the problem of disability, the AMA claimed, was to eliminate it, not to encourage it.[48]

Thus the AMA introduced the insidious argument that the motive for rehabilitation would be destroyed if disabled people were provided with income. The impossible promise of an end to disability has been equally damaging, creating in the public mind the false notion that funds spent on the disabled would be better spent on medical research to end disability.

Although Roosevelt tried to pass disability insurance, the Republicans (representing capitalist interests) fought and delayed its passage for about twenty years. The Democrats prevailed when a reluctant Eisenhower signed a much compromised benefit system into a law in 1956.

The first disability insurance programme, Social Security Disability Insurance (SSDI) applied only to injured workers over the age of 55, a limitation insisted upon by oppositional forces since the 1940s. In the 1960s eligibility was incrementally expanded to include younger workers and their children, but the public health care component, Medicare, often the only form of health care disabled people could get was not created until 1972.

The group of disabled who were not injured workers had no social security until 1973 when Supplemental Security Income (SSI), a needs-based programme was set up for them. SSI, the disability welfare system is the humiliating lowest rung on the socio-economic ladder of disability benefits. The SSI is means-tested, so the person must remain destitute to stay qualified. In the U.S. disability social pyramid, the military disabled are at the top and the least valued members i.e. those with no work history are at the bottom. The resulting inequity is that individuals with the same level of disablement receive different levels of public assistance and have different standards of living. Hence according to Russell, the goal of the SSI to lift the disabled out of poverty by providing a national income floor has never been reached.

Marta Russell examines the Money Model of disability, "under which the disabled human is a commodity around which social policies are created or rejected, based on their market value'.[49] The corporate "solution" to disablement - institutionalisation in a nursing home - evolved from the cold realisation that disabled people could be commodified; we could be made to serve profit because federal financing (Medicaid and Medicare) guarantees an endless source of revenue. Disabled people are "worth" more to the Gross Domestic Product when we occupy a "bed" instead of a home".[50]

Wolf Wolfensberger traces the original societal goals of institutions for mentally disabled people "first the professional's goal was to make the "deviant" un-deviant through behaviour modification; that gave way to sheltering the deviant from society by isolation; and next, the goal was to protect society from the deviant through inexpensive warehousing, segregation, and sterilisation. But eventually experience and research led professionals to a loss of rationale for all the above practices. Today they are likely to be the victims rather than the perpetrators of social injustice. The experts realised that "deviance" was largely a social construct".[51]

Disability historian, Paul Longmore explains that the first widely held view of physical disability is the "moral model"; that is, society believed that disablement was a "deviance" caused by a lack of moral character or intervening supernatural forces, dangerous to society. The next historical view is the medical model - that disability is biological by nature but must be controlled by curing the "defects" - and resulted in medical and paternalistic social intervention such as sterilisation, segregation and institutionalisation.[52]

When the state in the 1970s began to unload disabled people from its warehouses they were shifted into nursing homes. Wade Blank, sensitive to the displacement of disabled youths, first attempted to "reform" the nursing homes. Going past reform, he proposed to emancipate disabled people entirely from the nursing home by moving them into the community. Blank saw that the disability movement must go beyond the independent living concept in an institution or nursing home.[53]

According to Russell, it is revolutionary to alter the American landscape with architectural changes brought to bear under universally accessible design. However she states that it would be more revolutionary to force corporate America to hire disabled people and to prevent firing employees upon disablement. But it is the economic arena - the arena "beyond ramps that is central to breaking out of the underclass that has kept us on the bottom of the socio-economic rungs of the capitalist pyramid" as she puts it.[54]

The social contract came out of people's movements during the New Deal of the 1930s and the Great Society of the 1960s. Social security is a part of the social contract, the Keynesian welfare state that benefits the entire population. Today there seems to have arisen a situation where there is a demand that Social Security retirement benefits and disability benefits be separated from the body of "welfare", but all such benefits had come out of a universal attempt to redistribute wealth to promote the public good - to mitigate hardships like high unemployment, disability, poverty and ageing. The fact that both identity groups believe that their programmes will be politically contaminated if included in the same boat with welfare is indicative of just how far the right has come since the original welfare disability legislation of Supplemental Security Income was signed by Nixon, says Russell.

What the right in America led by the monied class would like is an end to all social security programmes but as Noam Chomsky explains due to strong popular support for social programmes, the monied class had initially been restrained politically to do more than contain the expansion of existing programmes. Reagan, a long time opponent of Social Security, feared to directly attack the safety net in the 1980s, but the right has found an opening in the 1990s. According to Chomsky - "... changes in the international economy in the past 25 years, accelerated by the end of the Cold War, have enabled the decision-making classes to move from containment of the threat of democracy and human rights to a rollback of the despised social contract that had been won by long and often bitter popular struggle." [55]

Thus ending the Social Contract according to Marta Russell is a threat to democracy itself. She argues eloquently:

> Thwarted democracy is the largest single problem now facing the country - indeed the world - because without citizen control of government there is no means to address the rights of the citizenry nor "to promote general welfare" of the people. Without democratic control of our institutions, the self-serving elites will preserve their corporate welfare and the monied interests will see that the elected "representatives" do not step on corporate toes.
>
> When the few accumulate the political power to perpetuate massive unemployment, level wages to the lowest global common denominator, devolve the welfare state, undermine social

services, further redistribute the wealth upwards, engage in capital flight, practice destructive currency speculation and disinvestment, unload the costs of doing private business on the public and destroy the environment upon which we all depend for life, then our "democratic" government has proven a failure for the majority.

Yet government is necessary for social order. A government which acts on the public interest is necessary to solve social problems, to determine the common good, to act as the protector of the people against the ravages of free market excesses.

It is simply subterfuge on the part of those who would undo government to claim that government does not "work" because social policy has been thwarted by monied interest. It is cowardly capitulation to those interests to label the welfare state obsolete when social welfare has never been fully implemented. One can argue whether Keynesian liberalism in the long run perpetuated economic evils that might have been overcome by a more humane system or whether liberalism postponed a bloody reification of capitalism's misery-producing components. One can argue whether the decline of the socialist threat, and consequent lack of a countervailing force to curb capitalist excesses have made the Democrats and Republicans so cosily subservient to "free" market doctrine, but of immediate concern is that the globalisation of capital has generated a crisis in which even the meagre underpinnings of the Keynesian welfare state are threatened by the enormous growth of power of the multinationals. The welfare state with all its imperfections remains the moral apex of social consciousness in America. As long as capitalism is here to stay, the welfare state is imperative to cushion against its inherent inequities.

There is no justice without democracy but there can be no democracy without economic justice. We need economic as well

> as political democracy. The questions raised by the "left" are as legitimate as ever maybe even more so now that "democracy" in America has been exposed to be blatantly auctioneered to the highest bidder. Can equality, democracy, social justice ever be met under capitalism?[56]

CARING AND CAREGIVING: COMMUNITY, FAMILY AND GENDER

The organisation of caring in a given society is closely linked to the way in which the society organises different aspects of social relations. According to Gillian Dalley, within the context of the family under normal circumstances, responsibility for fulfilling the caring, nurturing function in relation to the rearing of children and the servicing of adult family members falls upon women.[57] Women are also expected in 'extra-normal' circumstances to care for the chronically dependent (the disabled and elderly) persons. In traditional societies because there is relatively little specialised division of labour, caring becomes absorbed into a collectivity if none of the functions is demarcated by a public-private dichotomy. According to Dalley, what has been termed as the social construction of dependency is of a different order in such societies as compared to its capitalist construction. In the latter those who cannot work (for wages) due to physical or mental impairment, or those who have passed beyond the age limit imposed by society on the end of working life, automatically become dependent either on the state or on the family. Elaborating the point she argues that their dependency is not intrinsic to their physical or chronological condition; instead they have been 'socially constructed' as dependent because they are arbitrarily ruled out from being party to the bargain or contract which non-dependent individuals are able, or obliged to enter into with society. Hence systems of support and care may vary according to the degree to which the confinements of the disabled are compounded by the social constraints of marginalization and stigmatization, or mitigated by the social supports of integration. In societies, which do not have formal segregated care systems, the principle structure of kinship provides the basis for caring. She further states that in situations where the society takes on responsibility for providing care, the form of care adopted has tended to be modelled closely on the familial model. The post-war period has seen a consolidation of guiding objectives underlying formal care policies, promoting dependence on the familial model of care.

In her book dealing with the ideologies of caring Dalley has focused on dependent people and women who usually care for them. Dalley highlights the ideology - the pattern of beliefs and attitudes, which underlie action. In particular, the competing ideologies upon which alternative social policies for the provision of care for dependent people are based, namely familism and collectivism.

Analysing the meaning of caring, and taking the example at the affective level, Dalley states that a distinction can be made between 'caring for' and 'caring about'. The first is to do with the tasks of tending another person; the second is to do with the feelings for another person.[58] Caring for and caring about are deemed to form a unitary, integral part of a woman's nature (which cannot be offloaded in the 'normal' state of affairs). In the 'extra-normal' situation of a child being chronically dependent beyond the constraints of dependency dictated by its age - through sickness and handicap - the mother automatically extends and is expected to extend her 'caring for' function. Just as the affective links which form at birth are tied into the mechanical links of servicing and maintenance in the case of healthy children, similarly the same affective links in the case of disabled and chronically dependent family members gets tied to the servicing and maintenance functions.

In the public sphere, the same forces are at work; women go into the caring occupations because their natures and their intertwined capacities for caring for and caring about are thought to suit them well for those types of jobs.

The mixing of the caring functions (for and about) has implications for both parties in the caring relationship. Love, in this context, often becomes fractured or distorted by feelings of obligation, burden, and frustration. But the prevailing ethos of family-based care suggests that 'normal' tasks are being performed, that roles enacted are straightforward, expected and unproblematic. According to Dalley, evidence suggests that the boundaries of obligation and willingness are indeed carefully delimited and the willingness to care is highly relationship and context specific. As long as a handicapped daughter or son is a child, caring falls within the normal parameters (even though it may be arduous). Once the child becomes an adult, tensions in the caring relationship may develop - love, obligation, guilt, dislike - may all be intermingled.

The ambivalence frequently felt by those involved in the process of caring is made more problematic because public discourse insists that there can be no separation between caring for and caring about. Official and lay commentaries on community care policies all assert the conjunction of the two.

For men the entanglement of caring for and caring about does not broadly speaking, exist (and where it does, these men are usually regarded as atypical - in contrast to the case of women, where to disentangle the processes is to be unnatural). Men, it is recognised, can care about, without being expected to care for. The man is expected to provide the setting, within which the provision of care may take place and the finances for it, if he has no wife.

Thus in a society where standards of success are measured in terms of the public sphere of male achievement and where female work, both at home and outside, tends to be dominated by routine, often physically onerous and often unrewarding activity, the cost women pay is high. Why do women accept this cost? The common view is that it is located in women's special relationship to the function of caring, their capacities for self-sacrifice and sense of altruism. Both men and women hold this view. This raises the issue of ideology and internalising the values. A view that holds women to be caring to the point of self-sacrifice is propagated at all levels of thought and action; it figures in art and literature, it is present in the social welfare policies and it is the currency in which the social exchanges within the domestic sphere are transacted. Once this central tenet - of women's natural propensity to care (in contradistinction to men's nature) is accepted, the locus for that caring then becomes determined.

With woman as carer, man becomes provider; the foundation of the nuclear family is laid. It becomes the ideal model to which all should approximate.

For most women, especially the working-class women, the model results in the triple burden - child rearing, housework and wage labour. The nuclear family and the roles associated with it may not always exist in concrete form; but as an ideological construct it is of crucial significance. Land and Rose have discussed how fundamental to the ways of seeing women in modern society is the notion of altruism.[59] They call the personal servicing that women do caring for and caring about as compulsory altruism - which encapsulates both the self-sacrifice and selflessness involved and the prescriptive expectations of society that women shall perform that role. Land and Rose show how social policies have been built on the same assumptions - to such an extent that the altruism which women come to see as naturally part of their character becomes compulsory. The policies could not be implemented and the structure would not function, if women declined to be altruistic. They cite both the Beveridge proposals and current community care policies as examples, suggesting that they reinforce the traditional pattern of enforced dependency and compulsory altruism. This is not to be against the:

> Expression of free altruism which potentially lies within community care and self help strategies... the feminist hostility to community care turns partly on the needs and interests of women which are to be masked once more in altruistic services to others and partly on the needs and interests of the cared for. In considering the needs and interests of both, feminists accept a central insight from The Gift Relationship. Titmuss demonstrated that for the gift to be safe, that is non-injurious to the recipient, it had to be freely given.[60]

This according to Dalley is the nub of the problem. To be critical of community care policies is not to be critical of the importance of caring for and caring about, or of the necessity of enabling disabled and chronically dependent people to live 'normalised' and 'ordinary' lives. Nor is it to deny that people want to be cared for in familiar surroundings, and to be cared about by people about whom they themselves also care. But because there is consensus at the level of public discourse (both official and lay) that community care is the right policy both on ethical and pragmatic grounds, feminists run the risk of being severely criticised as self-interested and uncaring. It is important that they contest these judgements: to fight for women's rights is to fight for justice just as it is to fight for the rights of any disenfranchised, subordinated or devalued group; to question the nature of community care is to seek solutions which are equitable, comfortable and acceptable for chronically dependent people as well as for women as (potential) carers.

For the moment there is widespread acceptance of the way things are. Women have internalised the altruistic ideal; society has capitalised on it. Scathingly Dalley argues that with women being prepared to remain or return to the home to care, society is provided with a readymade 'reserve army' of nurses - an army which does not need hospitals to be built for it to work in and does not need wages to be paid it, because, it is assumed, its members are already provided for by being dependent on and supported by, wage-earning men. It is this 'reserve army' which is increasingly being activated to provide the community care that policies and politicians have been calling for over recent years - a form of care that is largely uncosted and unmeasured, which can be invoked by planners and politicians without its costs being borne by official resources. Women are offered little option as to whether they participate as carers or not. Indeed choice is not available to those in need of care.

In a review article published in the New York Times Martha Nussbaum[61] develops further the arguments on disability and society on the basis of three books on the issue of caring for dependent persons.[62]

According to Nussbaum in 'Love's Labour', which is an account of the disabled child Sesha, Kittay argues that Sesha's need for care suggests both major criticisms of the dominant theories of social justice and major changes that should be made in the political arrangements. To begin with she poses the question who does all the work that extreme dependency requires? In most cases, according to Eva Kittay and Joan Williams, this work is done by women, since women are far more likely than men to accept part-time work and the career detours it requires. Fathers who agree to help care for a child, who will soon go off to school, moreover are much less likely to shoulder the taxing long-term burden of care for an extremely disabled child or parent. Citing the example of the U.S., most women who do such work cannot count on much by way of support from an extended family or community network.

Much of the work of caring for a dependent is unpaid; nor is it recognised by the market as work. And yet it has a large effect on the rest of such a worker's life. For persons who can afford hired help - most of it is from women who are themselves even though paid, neither paid highly nor as generally respected by society as they should be for performing a vital social service.

Debating on what is a just society Kittay and Williams posit that a just society may be one that would also look at the other side of the problem, the burdens on people who provide care for dependants. These people may need many things: recognition that what they are doing is work, assistance, both human and financial; a chance at a rewarding career for themselves and participation in social and political life. Joan Williams shows that it used to be assumed that women, who were not full citizens anyway and did not need to work outside the home, would do all this work. Women weren't asked whether they would do this work: it was just theirs to do.

One now thinks of women as equal citizens who are entitled to pursue the full range of occupations. Also we now generally think that they are entitled to a real choice about whether they will assume the burden of caring for the extremely dependent. But the realities of life in a society that still assumes that this work will be done for free, 'out of love', still put enormous burdens on women across the entire economic spectrum, diminishing their productivity and their contribution to civic and political life.

Answering the question what have theories of justice said about these problems? According to Nussbaum, Kittay insists virtually nothing. Kittay believes that these theories have done real harm, shaping one's practical political ideas through their subtle effect on the ways one speaks and thinks. For example, she suggests plausibly that attacks on providing welfare for non-working mothers are influenced by images of the citizen as an independent worker that come to us from centuries of social-contract thinking. Thus Kittay holds that more perceptive philosophical theorising is important to address these issues in practical political life. Even if not immediately, theoretical conceptions shape public arguments, giving people the concepts they use and shaping the alternatives they consider.

According to Nussbaum, Kittay also suggests that political discourse is pervasively shaped by the idea of society based on a contract for mutual advantage, an idea that has dominated political theory in the Western tradition. All social contract theories adopt a fictional hypothesis that appears innocent: the fiction of competent adulthood. The parties to the social contract are assumed, as John Locke wrote, to be "free, equal and independent".[63] Contemporary advocates of social contract theory explicitly adopt such a hypothesis, for instance the American philosopher David Gauthier, stated that people of unusual need are "not party to the moral relationships grounded by a contractarian theory".[64] Similarly the citizens in John Rawls' Well Ordered Society are "fully co-operating members of society over a complete life."[65] Since the partnership envisaged is for the mutual advantage of the contracting parties, provision for people who aren't part of the bargain will be an afterthought - not part of the basic institutional structure to which they agree. As Kittay shows, Rawls explicitly omits from the situation of basic political choice the more extreme forms of need and dependency that human beings may experience. Although caring for people who are not independent is a "pressing practical question" Rawls argues that it may reasonably be postponed to a later legislative stage, after basic political institutions are designed.

Care for children, the elderly and the handicapped is a major part of the work that needs to be done in any society, and in most societies it is a source of unfairness. Any theory of justice needs to think about the problem from the beginning, in the design of the basic institutions. Rawls' list of primary goods includes liberties and opportunities; income and wealth; and the social bases of self-respect - by which Rawls means the institutional structure ensuring all citizens are treated as having worth and dignity. But care during lengthy periods (or a life) of extreme dependency is never mentioned. According to Nussbaum, Rawls measures relative social position with reference to income and wealth alone, ignoring the possibility that a group is denied dignity may not, as a class, be most deprived economically. Some handicapped people are economically disadvantaged and others not. All encounter special problems in achieving self-respect that a just society ought to address.

Amartya Sen has made a related criticism of Rawls theory of primary goods: that it ignores the fact that people have varying capacities to convert income and wealth into the ability to function effectively.[66]

Kittay doubts that a liberal theory of justice can adequately address these problems. She feels that Western political theory must be radically reconfigured to put the fact of dependency at its heart. The facts, according to her is that we are all "some mother's child" and that we exist in intertwined relations of dependency and this should be the guiding image for political thought. Such a care-based theory, she thinks, will be likely to be very different from any liberal theory, since the liberal tradition is deeply committed to goals of independence and liberty. According to Nussbaum, Kittay seems to believe that a care-based theory would support a type of politics that provides comprehensive support for needs throughout all citizens' lives, as in some familiar ideals of the welfare state - but this would be a welfare state in which liberty is far less important than security and well-being. However Nussbaum points out the inconsistency in Kittay's argument with the example of Kittay's controversial proposal, that of a direct non-means tested payment to those who care for family dependants at home, clearly has, or could have, a liberal rationale: that of ensuring that these people are seen as active, dignified workers rather than as passive noncontributors. Further, to be sure, nobody is ever self-sufficient; the independence we enjoy is always both temporary and partial. As Kittay rightly points out independence should not be seen as a necessary condition of dignity for all mentally handicapped people and Nussbaum states that it is good to be reminded of that fact by a theory that also stresses the importance of care of dependent people. But, argues Nussbaum, is being "some mother's child" a sufficient image for the citizen in a just society? She thinks we need a lot more: liberty and opportunity, the chance to learn and imagine on one's own. These goals are as important for the handicapped as they are for others, though they are much more difficult to achieve.

Michael Berube discussing the different images of the handicapped talks of the "social construction" of various human categories. He writes that both the limitations and the value of that idea became clearer to him as a result of his life with son Jamie. Part of Jamie's condition is clearly not socially created, and Berube gives a detailed genetic and medical account of Down Syndrome. But much of Jamie's condition is social: will he be called a "Mongoloid idiot"? A "retarded child"? Or will he get a chance to meet other children as simply "Jamie", a kid who is a little different, but then children are all different anyway - he's just a little more so? According to Berube such changes in labelling make a difference. Beyond good attitudes we need good laws. But both Berube and Kittay are worried about this aspect for the laws protecting the handicapped are fragile. They can be easily undone, particularly in a society determined to decrease the public sector. Berube's anxiety is about the current view that people, who are not "productive", in a narrow economic sense, are a drag on the whole society.

This takes one to the issue of the caregivers. Both Williams and Kittay see the work of caring for dependants at home as a crucial issue affecting the social equality of women. Holding that women are often subtly coerced by social norms into shouldering the burden of caring for a dependent Williams argues that any solution to the problem has different parts - one is the reallocation of domestic responsibilities between men and women in the home. The second is the role of the state. The state may lighten the burden of people who care for the dependants through a wide range of policies.

Ending the review, Nussbaum, considers Berube right in suggesting that the key to social justice for both the disabled and those who care for them lies in enlarging the imagination. If fellow citizens are not seen as parties to a mutually advantageous bargain, then one will never see value in the permanently handicapped. Value in the disabled elderly is seen only in terms of them as formerly productive people who deserve some recompense for that earlier productivity; this is surely not all that their dignity requires. Another point is that if little value or dignity is seen in dependent people, we will be unlikely to see dignity in the work done dressing or washing them, and we will be unlikely to accord this work the social recognition it should have.

According to Nussbaum, although in both theory and practice American society has moved beyond earlier versions of the social contract tradition, by insisting on human dignity as a central social value, it is far from having shaken off a dark implication inherent in the very idea of a social bargain for mutual advantage, namely that those who remain dependent are not full participants. Thus Gauthier says that while the elderly have paid for the care they receive by earlier periods of productivity, the handicapped have not. Quoting Berube's phrase that "a more capacious and supple sense of what it is to be human" Nussbaum states is crucial if we are to think more clearly about problems of justice.

SOCIAL SUFFERING

It is said that humankind's most fundamental beliefs are those that concern life, suffering and death. This leads to efforts to prolong life, alleviate suffering and prevent death, bringing into focus specifically the roles of the medical sciences and health care strategies and in general the social, economic and political contexts of their development.

Social suffering brings into a single space an assemblage of human problems that have their origins and consequences in the devastating injuries that social forces can inflict on human experience.[67] Social suffering results from what political, economic and institutional power does to people and, reciprocally from how these forms of power themselves influence responses to social problems. Included under the category of social suffering are conditions that are usually divided among separate fields, conditions that simultaneously involve health, welfare, legal, moral and religious issues. They destabilise established categories. For example the trauma, pain and disorder to which atrocity gives rise are health conditions; yet they are also political and cultural matters. Similarly, poverty is the major risk factor for all ill health and death; yet this is only another way of saying that health is a social indicator, and indeed a social process. The clustering of various problems or disorders such as substance abuse, street violence, domestic violence, AIDS or tuberculosis among people runs against the professional medical idea that sufferers experience one or at most two major problems at a time. That grouping of human problems also defeats categorisation of such issues principally psychological or medical and therefore individual. Instead it points to the often-close linkage of personal problems with societal problems. It reveals too the interpersonal grounds of suffering, in other words that suffering is a social experience. Social suffering is shared across high income and low-income societies, primarily affecting in such settings those who are desperately poor and powerless. Though the subject of suffering cannot be examined as a single theme or a uniform experience yet is profoundly social, and the instances giving rise to it are not merely a correlation but a causal web in the global political economy.[68]

W. H. Auden observes in his poem ‘Musee des Beaux Arts’ that suffering is inextricably embedded in a social world. According to David Morris, Auden’s view of suffering contains in its heart an absolute and insurmountable otherness – and mandates our position as the witness, separate and detached from the victim.[69]

Paul Farmer has identified three kinds of suffering:[70] first, the exoticization of suffering as lurid. The suffering of individuals whose lives and struggles recall our own tends to move us; the suffering of those who are distanced is sometimes less affecting. Second there is the sheer weight of suffering, which makes it all the more difficult to render: "Knowledge of suffering cannot be conveyed in pure facts and figures, reportings that objectify the suffering of countless persons. The horror of suffering is not only its immensity but the faces of the anonymous victims who have little voice, let alone rights, in history."[71] Third the dynamics and distribution of suffering are still poorly understood. Physicians, when fortunate, can alleviate the suffering of the sick. But explaining its distribution requires more minds, more resources and most of all a political understanding. The larger historical system has to be understood to explain the local understanding of suffering.

Similar insights are central to liberation theology, which takes the suffering of the poor as its central problematic. Rebecca Chopp notes that liberation theology has attempted to use social analysis to both explain and deplore human suffering.[72] According to theologian Leonardo Boff, liberation theology goes into the structural analysis of these forces and denounces systems, structures and mechanisms that 'create a situation where the rich get richer at the expense of the poor, who get even poorer.'[73] Thus suffering should not be valorised and regarded as morally ennobling.

An understanding of the wider context of suffering is evident from the broad contours of a few selected case studies, drawn from a number of regions. For example in an essay on the sale of kidney organs Lawrence Cohen has examined the context for the selling of kidneys and highlighted the poverty and debt, which condition the lives of the sellers.[74] While this is not an unusual phenomenon, the author's findings reveal that among the "donors" a significant number are women. The author also delves into the debate on sale of kidneys, which has two points of view – one point of view is summed up as Life for Life and the other is about the uncertainty of the solution to deal with their poverty by selling their kidneys. In the case cited by Cohen the wife of a poor labourer sold her kidney to pay off accumulated debts. The decision for her to sell her kidney was justified as, "My husband needs his strength for work, and could not work if he had the operation."

When asked whether she worked the woman said,"Yes I work too," so the decision about which of the two partners should sell their kidney was obviously based on other factors. She also went on to talk about her scar which "still hurts." During the course of the interview she went on to point to the scar and also say, "That's where he hits me. There. When I don't have any more money." The money received in exchange for the sale of the kidney, had not really got the family out of the debt trap and the physical violence experienced by the wife had a relationship in the wife's perception to their continued poverty, which the sale of the kidney had not ended.

Analysing this account Lawrence Cohen sees the situation as having two moments for the woman: a recent past when it marked their successful efforts to get out of extreme debt and support their households, and an indebted present when it has come to mark the limits of that success. The scar is a sign of the embodiment of loans sought to supplement wages and at the same time the scar covers the wound but not the conditions of indebtedness, which persist. However if analysed further the situation described by Cohen highlights three aspects of why women are the inevitable sufferers among the poor: first 'choices' are made as part of the cultural beliefs about the manliness and the notion of the man as the breadwinner wherein their strength is regarded as needing to be preserved. Second the onus of fertility control, both targeted by policy and by choice of the individual family, is borne by women in India. In the particular case in question the woman's body was regarded as predisposed to surgical invasion because of its prior operability through the tubectomy that she had undergone, and so it was she who became the "donor" of the kidney. Third the combined effect of the poverty, the attempt at lifting the family out of the cycle of debt and the failure to do so was also manifested in the interpersonal relationship within the household on two counts: the recurrent pattern of domestic violence and the story of sporadic work, continued indebtedness and resulting frustration is played out such that the woman's body becomes the site of another kind of suffering. The woman's statement "That's where he hits me. There. When I don't have any more money," may be a consequence of the guilt experienced by the husband because it was his wife rather than him who sold the kidney; equally it could be an outcome of his frustration that despite her physical suffering the scar is a reminder of the failure of the family's attempt to come out of the debt trap.

A second case pertains to Haiti where AJ was a resident of a Haitian village which was flooded as consequence of the building of a dam, much like the impending fate of the Narmada Valley residents. The 'water refugees' became exceedingly poor as families lost their lands and tried to eke out a living on harsh mountainside terrain. Hunger was a near daily occurrence for the ousted family. As AJ grew up she drifted into a relationship with a soldier - among the few salaried men in the region. The relationship was brief and a few months later the soldier was dead. AJ became a domestic maid but soon began to fall ill. She was shortly thereafter diagnosed with AIDS. Eventually she died. Shortly after AJ's death her anguished father hanged himself.[75]

This is not merely the story of a tragic and premature death. AJ's story is similar to many other stories and is a grim account of the social and economic forces that have helped to shape the specifics of the AIDS epidemic. From the outset AJ was the victim of structural violence. To make sense of extreme suffering the life experiences of someone like AJ must be linked to the larger social conditions if its representativeness is to be understood. Such social and economic conditions dictate life choices made by millions of individuals and provide the proper context for their interpretation.

A third example is detailed in an article by Gay Becker et al. about Cambodian refugees in the U.S.A. which describes how massive disruptions to a way of life brought on by widespread violence and terror can disorder the body as well as the social order.[76] The authors explore how refugees who live with chronic illnesses and are dependent on the U.S. government's support were affected by the threat of welfare reform and placed further constraints on their lives. According to the authors the story of threatened welfare reform in the U.S. and its possible consequences for refugees is a story of quixotic U.S. politics, policies and antidotes for refugeeism gone awry. The authors describe the living situation of Mr. and Mrs. K. in a crowded two bedroom apartment with their disabled son and nine other refugees, a testament to the extent of the poverty in which they live. This kind of overcrowding poses its own kind of suffering. The perennial uncertainties of Mr. K.'s life include: the threat of further incapacity from his illness, worries about his and his wife's ability to care for their son, and worries about economic security for his family. Welfare cuts threaten Mr. K.'s efforts to create stability and the sense of responsibility he carries heightens the burden he experiences. Mr. K.'s overriding concern is for his son and the grant of a citizenship status, which alone will protect his future. But the hurdles appear insurmountable since the son cannot even sign the papers. Thus in the larger context in allowing the Cambodian refugees to enter the U.S. and resettle there, the U.S. took on a commitment that has been inadequately honoured. The bodily distress expressed by the refugees in this study is a combination of violence experienced during the civil war and from those who presented themselves as saviours of the refugees.

A last example is provided by Novartis, the maker of cyclosporine, which is ubiquitous in the global transplant world and in India. It funds many conferences, not only on organs but also on medical ethics more generally, and its representatives attend public gatherings of welfare associations. At one such meeting, one kidney recipient's father literally begged the drug representative for a free month's supply of the drug, as he had no credit left. The drug was provided, and apparently this exchange was a repeatedly publicized scene. Novartis becomes the great benefactor for this organisation of recipients, but no actions to lower the price were proposed.[77] Other recipients of transplants who may have similar needs will thus have to continue to buy at the prices determined by such drug companies perhaps leading to the erstwhile buyers of an organ to becoming debtors themselves: ironically then both 'seller' and recipient of the organ may finally share a common fate of indebtedness determined by a global political and economic order.

All of the examples cited above provide an insight into the larger context of suffering which are shaped by the structural features of the society in which the individual experiences are played out. Arthur Kleinman and others have studied the experience of epilepsy and treatment among patients and family members in two provinces of China to further contextualize the experiences of individual families coping with chronic illness.[78] Their study reveals that medical anthropological accounts of chronic illness and disability, in their case epilepsy, have to go beyond the stigma model to develop a social theory of the contextual processes within which it is experienced. Although they have taken the case of epilepsy, their analysis can be furthered to cases or instances of chronic illness and disability too.

Susan Reynolds Whyte, based on extensive research in Tanzania, shows that patients and families do not actively avoid biomedical treatment.[79] They are all too often unaware of the availability of effective medicine or treatment. Whyte observes that many respondents have no idea what causes epilepsy. Families and patients struggle in these complex local contexts to make sense of a serious chronic disorder and to provide security for yet another emergency for which inadequate resources are seriously strained. Whyte concludes that stigma which is present is not a straightforward determinant of the social experience of epilepsy patients. Stigma theory, she contends, is not the only or even the most relevant social theory.

Byron Good and Mary Jo DelVecchio Good based upon findings of a study of illness narratives of epilepsy among patients and family members in Turkey, critique the stigma theory for the passivity it ascribes to patients who become oversocialized victims of too determinative labels and inflexible societal discrimination. Patients and families are given the single option of disavowal.[80]

The major finding of Kleinman and others is the social experience of suffering and the social course of illness. According to these authors patients and families grapple with many difficulties. The resources that they require to be successful in coping with a chronic condition especially in times of exigency are usually limited. The local settings include formal and informal sectors of health care and networks of connections that can mobilise needed resources to lighten the financial and emotional burden and to minimise the effects of bias so that disability is avoided. In another case the local world of social experience may deepen the suffering of patient and family.

According to Kleinman suffering as a social experience, in the western tradition, lays emphasis on the subjective feelings of the afflicted individual, often viewed as isolated and forlorn, is the dominant analytic paradigm for understanding suffering that results from serious chronic illness and disability. Framed this way, suffering becomes the pain, hurt, loss and search for meaning of a unique person who alone must bear the deep burden of his or her troubles. Thus the paradigmatic locus of suffering is the private space of the person with the problem. However from the study of the Chinese society in particular, Kleinman has argued that the locus of suffering should be in the intersubjective space of interactions, especially families. Viewed this way suffering is a mode of social experience. The point is not to minimise the seriousness of problems faced by the individual patients but rather to appreciate the importance that they and their families attribute to the interpersonal, relational locus of hardship among the family members. This intersubjective sensibility frequently leads family members to emphasise their own adversity as equivalent to or even greater than the patients' experience.

The focus of concern is on the family and its members. What is most at stake in suffering is the abridgement of the family's aspiration, the threat to the family's life chances, the loss and hurt of the others. The family's success is as much the means of fulfilment of its individual members. The self is its roles and relations with others in the family (and in turn with their collective and individual network). Therefore suffering is as much the intersubjective experience of parents, spouses, siblings and children as that of the sick person.

Appreciating the implications of the intersubjective experience of suffering may begin with understanding its epistemological and moral basis, but eventually requires that we understand suffering as a different way of living illness in the social world. Even within the family the social experience of suffering is not homogeneous and it may even be divided. Some may even attempt to escape from it. Often mothers and wives cannot refuse, but must endure. Epilepsy or any other chronic illness or disability may create a family 'tragedy' whose burden is different for different family members.

According to M.R. Philips the serious consequences of epilepsy are intensified by Chinese society prioritising social control as the chief concern in the societal response to epilepsy and to other chronic conditions such as schizophrenia, mental retardation, substance abuse.[81] The emphasis on social control, rather than patient rights, means that students with epilepsy may be removed from the classroom, workers with epilepsy may not be permitted to carry on with their jobs, work-units may discriminate against patients and families who are requesting more resources for treatment. Social control also works through stigma. Because of the fear that the entire family will be disgraced, family members conceal the diagnosis, may drop out of treatment and often sequester their epileptic members at home even as they try to resist the negative effects of social control.

Concluding their study Kleinman et al. state that the biomedical idea naturalises the illness experience as based solely on pathology. The social course of epilepsy indicates that epilepsy develops in a local context where economic, moral and social institutional factors powerfully affect the lived experience of seizures, treatment and their social consequences. The social course of epilepsy is therefore plural, heterogeneous and changing.

Kleinman further states that the central issues for public health policy have been to provide access to health services that can deliver effective treatment and to focus on preventive causes. Framing epilepsy in terms of its social course suggests that to improve the quality of life and reduce disability, it is essential that health and social policy address the local context of social experience. Stigma, institutional discrimination, the relatively high cost of care in a setting of chronic deprivation and the social resistance put up by sufferers are as important for health and health policy as is basic medical services. They are as salient for the content of medical care as are diagnosis and pharmacology.

Thus Arthur Kleinman argues that the social course of illness constitutes much of what is meant by prognosis.

To sum up Kleinman et al. argue, "epilepsy in China as elsewhere indicates that health policy is inseparable from social policy and that social policy is inseparable form social theory. Especially salient is the powerful constraint of circumstances of deep deprivation, which affect so many globally. In order to join social and health policy, narratives as well as numbers, social services along with health services and social theory together with health science perspectives, must have a place in policy formulation".[82]

Conclusion

An attempt has been made in this review of the literature on disability to argue that suffering is not really a matter of just individual experience and choices but is determined by the larger social, political and economic contexts within which individuals lead their lives. The various case studies cited here have dealt with different regions, categories of people and settings and all reveal facets of a similar reality especially for the marginalized. As Paul Farmer writes "the capacity to suffer is clearly part of being human. But not all suffering is equal" inspite of suggestions to the contrary. It is possible to speak of extreme human suffering and recognise at the same time that those living in poverty currently endure an inordinate share of this sort of pain. It is the marginalized of today's world: women, the poor, and other discriminated categories who are the chief victims of structural violence – a violence that has escaped the analysis of many seeking to understand the nature and distribution of extreme suffering. We need to recognize that "it is the poor who are not only more likely to suffer but also that they are more likely to have their suffering silenced" says Paul Farmer. Some of the features of suffering discussed here will help us to understand the experiences of the disabled and their families in Chapter Five on the Narratives of the Disabled.

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WELFARE STATE AND AFTER: INTERNATIONAL PERSPECTIVES IN HEALTH SERVICES AND REHABILITATION POLICIES

> *The true symbol of the welfare state was much more the National Health Service than social insurance...The Health Service has nothing to do with class relations, Poverty, subsistence or the defects of the capitalist system. It typifies humanity fighting against natural ills as medicine always has done, it suppresses the economic market and replaces it by a calculus of needs...*
> *This is what I believe what it stands for in people's minds.*
>
> *T. H. Marshall*

Concern about disability has a long history, which has reflected the economy, the level of technology, class interests and ideology of the times. Hence, in this context, it is important to understand the development of the welfare state and the various social welfare policies regarding disability and rehabilitation the world over.

The term welfare is popularly associated with some form of economic or non-economic benefits to persons who need support, which they are not able to otherwise secure for themselves. The provider of such support can be a governmental body, religious body, occupational guild, and non-governmental or voluntary organization. However in the context of a welfare policy it is the role of the government that comes into prominence. There have been many theorists and social analysts who have attempted to formulate the kind of welfare policy that should be adopted. Hill noted that it is not possible to separate social policy from economic policy because both involve the redistribution of income.[1] Marshall called welfare policy "the policy of governments with regard to action having a direct impact on the welfare of citizens by providing them with services or income".[2] Titmuss defined welfare policy as "provisions by collectivities" to deal with various "states of dependency".[3] Various reasons have been given for the contexts of the emergence of the welfare state; for example Goodin suggested that the welfare state is set in the context of the market economy and is an attempt to modify the market forces in various limited respects.[4] Its function, however, is not to supplant the market altogether. Esping-Andersen stated that the development of the welfare state can be understood from three dimensions: (1) the roles of the state and the market in making allocations, (2) the impact of the welfare state on society's hierarchies and (3) the process by which certain allocations become entitlements.[5] Thus variations in social welfare policies are seen as guided by variations in the values and ideologies of given societies, variations in the techno-economic bases and market fluctuations within and around given societies, and also that social welfare policies are a camouflage for inherent class and interest group conflicts in society. Thus there are different social and economic models of welfare; Titmuss has identified Welfare as a Residual Burden; Welfare as Complementarity; Welfare as an Instrument of Equality.

The development of the 'Welfare State' is seen in a historical perspective as a part of a broad, ascending path of social betterment provided for the working classes since the 19th century. However state participation in the regulation or policies for the provision of welfare to the people has a long history. Leichter has identified three historical periods in the origins and evolution of state activity in welfare.[6] The first begins with the emergence of the modern nation-state in the 16th century upto the latter part of the 18th century in Europe and parts of Asia. During this period the centralized, positive state first appeared. The political-economic system it fostered was known as mercantilism. The policies of the government during this period were directed toward achieving international power and internal peace in order that centralized national economies could thrive. Thus the range and effectiveness of the state activity was in providing defense and maintaining internal order; public finance; social and economic regulatory policy; and social welfare. Paternalism was the concept that led to the development of state-supported welfare or poor-relief program. By the 17th century, virtually every European

State had some sort of centrally established public welfare program. One of the first was the Grand Bureau des Pauvres established in France in 1550; the Elizabethan Poor Law, passed in 1601; a Russian system of state-operated welfare established during the reign of Peter the Great (1682-1725); and the Prussian system of poor relief that evolved various edicts between 1596 and 1703. Although there was considerable variation in control and operation among the programs, nevertheless there were certain common elements in the features then and some have links with the modern concept and operation of welfare systems. One feature was that the motivation behind early welfare systems was not exclusively paternalistic or religious. In many instances, poor relief was an exercise of the state's police power. Throughout the 16th to 18th centuries, in Europe and elsewhere, landless peasants, persons uprooted by war, and returning and unemployed soldiers, resorted to vagrancy, begging, stealing and extortion to support themselves. Hence the 'welfare' policies were another way of dealing with the problems of maintaining law and order.

Early health welfare policies were related to the doctrine of mercantilism, the reasoning being that the power and wealth of the state depended on a healthy and vigorous, large population. In Germany state intervention in the area of health took the form of 'medical police' ordinances dealing with medical education, disposition of medicines, hospital regulations and epidemic prevention.

Another common feature was the legal distinction between categories or types of needy people. The primary distinction was between those who were legitimately poor (e.g. the aged, insane, blind or otherwise physically handicapped) and the able-bodied 'scoundrels', 'rogues' and professional beggars. Each category of persons was treated differently: for example institutional relief (almshouses) were for the 'deserving' poor; workhouses for the able-bodied poor who were willing to work; and punishment for the able-bodied unwilling to work. From the very beginning poor relief was deemed as justified only in case of severe disability.

A third common feature was the assumption that each locality should be held responsible for its own poor and needy. Although the laws were centrally promulgated, they were to be financed and administered by local authorities.

A final common feature of these welfare programs was that acceptance of public relief carried with it considerable social stigma, marking the recipient as socially inferior. There were at times not only social but also legal sanctions imposed on those who had to turn to public welfare assistance.

The second period, beginning in some nations early in the 19th century was that of the Industrial Revolution in much of Western Europe. This period was characterized in some nations by a more limited concept of the role the state should perform. In the 19th century the concepts of mercantilism and state activism came under attack and in many cases were superseded by a new philosophy. The set of ideas that supported the view of the limited state was summarized by the phrase laissez faire. These ideas were first advocated by the English and French philosophers and economists during the late 18th and early 19th centuries. Laissez faire emphasized natural laws and individual rights of the propertied, rejected government paternalism and intervention and therefore appeared better suited to the new economic order. Although never adopted as the only guide for formulating public policy it did have a profound impact in Europe, the USA and the colonies of Asia and Africa. But as industrialization proceeded in the more advanced nations, it brought with it a changing social, economic and political environment. And the laissez faire began to appear inadequate in the face of the social and political consequences of industrialization.

The third period beginning roughly in the latter part of the 19th century was marked by the adverse consequences of the shift from a primarily agrarian to a primarily industrial economic base; these changes produced, and continues to produce, extraordinary societal dislocations and profound social and economic changes. During the course of the 19th century it became clear to many that the social and economic dislocations and human misery spawned by industrialization required remedial action beyond that which was provided by private charities and that state intervention was needed. A more receptive environment of state involvement existed in Germany, Austria and Russia where paternalism persisted over laissez faire. However in England, France and United States of America, where laissez faire had its strongest advocates, the doctrine was losing support in favour of a more activist and positive concept of state to provide protection against the evils and insecurities of industrialization. The documentation of extreme levels of exploitation by humanist reformers helped to disseminate awareness about the consequences of industrialization and created the climate for reconceptualizing the role of the state and its responsibilities towards its people.

Public health was one of the first areas in which the state began playing an active and decisive role. As early as 1832, France adopted a public health law, and in 1848 a public health act was passed in England. There were a number of reformers advocating state involvement in health such as Neumann in Prussia, Virchow in Germany, Meynne in Belgium, Chadwick in England, Griscom in America. The provisions of free state supported and state administered medical assistance to the needy was advocated. France was one of the first nations to provide free medical treatment and hospitalization for the needy in 1893, followed by Sweden, Norway, Switzerland, Poland and Russia. Industrial legislation was another important area of state intervention. Early factory and labour legislation was concerned with length of working hours, factory safety, sanitation conditions, and the health and safety of women and children. Publicly supported, universal primary education was another important area of intervention.

One of the most significant shifts that occurred was from the concept of poor law relief to the idea of social insurance. As industrialization and socio-economic insecurity advanced, the increasingly large, vocal and educated urban working class began organizing, demanding and receiving greater political power. With the end of the extended family system, the needs of the urban worker for protection from the insecurities associated with loss of wages owing to industrial injuries, disability, illness, unemployment and old age increased resulting in the demand for social security.

The first modern and comprehensive social security program was developed during the 1880s. Chancellor Otto von Bismarck introduced laws for sickness insurance (1883), accident insurance (1884) and invalidity and old-age insurance (1889).[7] One of the factors in Bismarck's radical social program was the Prussian tradition of the paternalistic state and its concern for the needy. The other was the need for social legislation which presented itself in the form of a rapidly growing, radical, socialist-oriented party that threatened the government and monarchy and conservative rule in Germany. By introducing the social insurance measures, Bismarck's dominant concerns were to woo the workers away from socialism and to preserve the country's authoritarian monarchy. Shortly after the introduction of social insurance programs in Germany several nations followed such as Austria, Czechoslovakia (injury insurance, 1887; sickness insurance1888; old age disability insurance, 1906), Denmark (between 1897 and 1896), Italy (between 1898 and 1919) and Great Britain (between 1897 and 1911). By the second decade of the 20th century most advanced nations in the world had a relatively comprehensive social insurance program. The major exception was the United States of America, which did not have a job-related illness or injury insurance program until 1908, and an old age, disability and survivor's insurance program was set up only in 1935 as part of the New Deal in response to the social distress following the collapse of the economy in 1929.

According to Vicente Navarro the most important causes of the evolution of the funding and organization of the welfare state are political. Although the basis for establishing the welfare state preceded World War II, its full development took place after the war, in the golden age of capitalism. This development varied with the political tradition that became dominant in each country. Of these political traditions, four were particularly important: the Social Democratic, the Christian Democratic, the Fascist and the Liberal.[8]

Social democratic public policies were for the most part developed in the northern European countries of Sweden, Norway, Denmark, and Finland and also in Austria. In these countries the labour movement had two instruments to defend its interests: the unions and the social democratic parties. The very strong and powerful trade union movements were able to establish the framework for collective bargaining agreements. On the other hand the social democratic parties had a privileged relationship with the unions. They saw themselves as the parties of the working class. The objective was to expand political and social rights of the entire population through solidarity and universalization of such rights. In order to achieve universality, the aim was to achieve full employment and to establish a welfare state that protected citizens through out their life cycle and through redistributive policies to reduce social inequalities created by the market. The achievement of full employment required the active participation of both men and women in the labour force. Hence the state had to provide a series of services to the families and particularly to women to enable women to enter paid employment. The extensive welfare services included health care, education, and social services to the vulnerable populations such as the children, the elderly and the disabled.

The Christian Democratic countries include Belgium, Germany and the Netherlands. In these countries the family and the life cycle have defined the welfare state. The male was the head of the family, the breadwinner responsible for the family's economic stability, which depended on his wages and pension. The wife took care of elders and children. Hence the key economic element, the standard of living and welfare of the family was based on the salary and pension of the male member working in the labour force. The public policies regarding pensions and other benefits for workers depended on their status within the hierarchy in the production process and in society. The intent was to divide the working classes and disarticulate them. Thus levels of wages and pensions were the focus of major social debates. The women in these countries worked at home--even in the 1980s only 46% of women worked in the labour market (compared with 65% in the social democratic countries).

Since the women worked at home looking after the dependents the scenario resulted in the poor development or absence of child care services or domicillary home care services for the elderly and the disabled. The underdevelopment of the social services created a burden for the families especially for women. According to Navarro characteristic of the Christian democratic public policies is that the responsibilities of care are assigned to different agents of civil society. Hence voluntarism is the key means of calling on people's altruism and compassion. Navarro considers it important to clarify that it is profoundly wrong to try to replace the welfare state by voluntarism and a call for family responsibility. The welfare state and welfare society should be complementary rather than mutually exclusive.

The welfare states in southern European countries such as Spain, Greece and Portugal have been heavily influenced by long periods of dictatorship. These countries had poorly developed social services. A characteristic that these countries share with the Christian Democratic countries is their emphasis on the family and on women as responsible for the care of children and the elderly.

The public policies of the liberal countries including those that have never been governed by social democratic parties e.g. Canada and the USA and those governed by such parties for a long period e.g. Great Britain, are residual and assistential. Such welfare state policies provide services and benefits based on proven financial need (means-tested) rather than as a matter of citizen or worker's rights. There are exceptions such as the universal health services in Canada and Britain. The liberal model assigns welfare responsibilities to the private sector, once the minimums are guaranteed by the state.

Esping-Andersen has also proposed three types of welfare states, which he called the three "worlds of welfare capitalism": the liberal regimes (Australia, Canada, Great Britain and the USA), the social democratic regimes (the Scandinavian countries, and the conservative-corporate regimes (Austria, France, Germany, Italy and Holland). In the liberal regimes the trend is toward "intervention" with groups facing market failure, whereas in the other two regimes, the trend is towards "prevention", so that the vulnerable groups are spared the impact of the market failure.[9]

Given the variations in the histories and the main features of the emergence and operation of social security and of limited notions of welfare in different regions of the developed world some authors argue that the concept of the welfare state has been constructed as a capitalist–democratic project. They are commonly referred to as “welfare capitalist states” or “welfare capitalism” and those societies without a capitalist economy and a western parliamentary democracy are excluded from the definition of the welfare state.

However it is argued that with regard to state intervention, the extensive role of the state in the economy within socialist societies like China may differ from the idealized Swedish model only in degree and not in kind – except that the two countries have vastly different political institutions and authority structures. This leads to the question of what constitutes the definition of the welfare state. The main problem is that a particular definition of the welfare state depends on the purposes of the authority using the concept. For example according to the minimalist definition of the traditional social administration approach, a welfare state consists of a society that secures some basic or minimal welfare for its citizens. However other welfare state theorists do not consider such minimalism to constitute a welfare state. For example Titmuss insisted on using quotation marks in describing Britain as a “welfare state”.[10] To theorists like Titmuss the immediate post war British welfare state had not achieved the prescribed aim of redistributing social resources from the rich to the poor reflecting that the ideal view of welfare state is one where state intervention is for the purpose of promoting social equality. Thus the welfare state definitions are rather elastic – extending from the state’s welfare programmes as accessories to the capitalist economy to defining welfare states according to the aims or effects of social policy ranging from the minimalist goal of alleviating social distress to the maximalist goal of achieving social equality.

It is in the above context that the welfare and health care provision in the socialist countries can be observed. For instance the health care system of eastern Europe was modelled after the Soviet example – a centrally planned system for the provision of health care as a public good with a hierarchical system of organization and excluded private interests. The goal was to provide free and general accessible medical care for all. The health policy was considered an integral part of the social policy and was forced to take over services not directly related to illness such as children's crèches and children's homes. The social policy was clearly interwoven with the economic policy. The classical functions of bourgeois social policy such as insurance against illness, old age, disability and unemployment were replaced through the realization of the unity of economic and social policies.

China is another example where the underlying principle is the state ownership of the means of production and this is prevalent to a large extent even under post reform China. The institutional arrangements and the individual's status in a work unit give access to different welfare packages. The state is not directly involved in welfare delivery and relies upon its productive enterprises to do the job. The welfare system of these work units has been described as "small and comprehensive" indicating the wide spread of the welfare coverage.[11] According to Walker and Wong this is something akin to the almost mythical "cradle to grave" benefits of the idealised welfare state of the west.[12] The distinct set of institutional arrangements between the state and the economy represents a version of the state's welfare system quite different from that commonly defined as a "welfare state". **Thus welfare is not an adjunct to the economy but a part of the economy**. However after the economic reforms, the work units or enterprises require to balance their own accounts. Thus welfare benefits have become a cost-efficiency consideration.

REHABILITATION POLICIES

Rehabilitation is a component of the health care system, which develops after full attention has been given to acute care and reduction of mortality, general health policies and systems typically precede rehabilitation. The diseases and health conditions which adversely affect health status also produce the disability that requires rehabilitation. In order to plan a national rehabilitation policy, it is important to define disability. The manner in which the state defines its relationship to 'welfare' crucially determines the rehabilitation policies it will adopt towards its vulnerable sections, particularly the 'disabled'. Before a more generalized notion of welfare came to be significant, frequently national and local communities had acted to protect those citizens judged to be most valuable for the survival of a particular institution. The US began providing disability benefits for merchant seamen in 1798 at a time when control of the sea-lanes and maintenance of a strong fleet was critical to the security and commerce of the country. Similarly benefits for soldiers were provided during war times, compensation and aid was provided to railroad workers during the 19th century to maintain a skilled labour force necessary for the industrial revolution. Individual social positions were principally dependent upon occupational attainment, based on the value of labour expressed in earnings and prestige. Disability benefits, in turn, generally were determined by an individual's relative position in the labour force and the likelihood of his return to work after rehabilitation. According to Albrecht and Levy these actions reflect the political economy and ruling class interests as well as values of those in power.[13]

Anne Crichton has examined policy development of rehabilitation policies in Britain, Canada and Australia for they share the same language and culture.[14] Their approach to solving social problems is similar in terms of their thought processes; ideologies and social structures have common historical origins. Yet differences in social policies have emerged because of the different resources at their disposal and different environmental and social pressures.

Hence the words 'policy' and 'rehabilitation' tend to be defined differently by all who choose to use them.

Taking a historical approach to the development of rehabilitation policy for the disabled, Crichton has analyzed what the three countries deemed to be 'deserving' groups for state mediated schemes for injured/diseased workmen and war veterans, the blind, the crippled, the totally disabled and the elderly.

In Britain with the break up of the Poor Law and the attempt at post war reconstruction there was a review of the condition of the British people and their needs for social services. The 'welfare state' was chosen as the solution to deal with problems of improving social organization. The 'welfare state' was to provide not only cash when necessary but services in kind to ensure 'equality of opportunity' and 'equality of condition' for all citizens from 'the cradle to the grave'.

Beveridge's classification of groups to be considered for social security coverage revealed that 'employability' was basic to his thinking. And for those who were unable to be employed there would be social assistance. According to Crichton, it was necessary, however to make an exception of the disabled and to develop special provision for them in addition to the general welfare state services because of their problems in getting work. In addition to having open access to the general welfare state provisions, Disablement Resettlement Officers were made responsible for assessing and placing registered handicapped persons in open or sheltered employment. Employers were obliged to take a fixed percentage of handicapped workers and some jobs were to be kept for disabled persons.

In Canada during the postwar reconstruction Beveridge's research assistant Marsh prepared a report.[15] The two main outcomes of the report were that the federal government should (1) provide pensions to identified groups of individuals in need of income maintenance and (2) to provide matching grants to provincial governments of specified social programs.

The Canadian Pension Plan of 1965 subsumed the specific income maintenance programs developed in the early 1950s for the blind, the totally disabled and crippled children into a general minimum income program for designated groups. In 1966 the Canada Assistance Plan was introduced. This provided matching grants for institutional programs for groups in special need. This enabled many handicapped people to be given more care than they had had in the province's old established asylums. Gradually with such shift in the care structure attitudes to stigmatization started changing towards the retarded, the elderly and others who had been put in residential care earlier. The public health service was closely linked with educational provision for the handicapped children who need support, whether in special schools or classes, or who had to be provided with special help in ordinary classrooms or at home. For the support of the handicapped who had passed beyond the schools system an act to facilitate the Vocational Rehabilitation of Disabled persons was passed in 1961.

The Australian commitment to the 'welfare state' was much more cautious than that of the other two countries. The federal government had an income maintenance scheme in the Invalid and Old Age Pensions Act 1941.

According to Crichton, while the British 'welfare state' attempted to reconcile universalistic approaches to support through income maintenance for all citizens with particularistic approaches to support through the NHS and personal social services, other governments devised different schemes. Canada accepted the British principles at the federal level. The Australians seemed to have been less convinced that the whole range of policies were necessary. This belief in selective rather than universal policies resulted in the development of special policies to support the disabled. The government became aware of the need for an improved disablement rehabilitation service for vocational retraining because at the end of the Second World War more than half the men and women discharged from the armed services were medically unfit and were eligible for veteran's benefits.

While the Australians were less willing than the British or Canadians to become committed to a national health service or health insurance scheme, they had, early on, developed universal public health services within states which provided maternity and child welfare, assessment of handicaps and support for children with disabilities.

In order to move towards a more comprehensive rehabilitation policy the disabled groups became active in demanding their human rights since the 1970s in western democratic countries. They raised major issues about the meaning of equal citizenship, the meaning of work in society, how individual worth is assessed and how those who deviate from the norm should be identified and classified.

In the 1960s in Britain, the severely disabled began to form visible and effective pressure groups whose activity resulted in the Chronically Sick and Disabled Persons Act, 1970. Two principles were given recognition: first the importance of providing community care for those who did not wish to be housed in institutions; and second, the need for providing higher allowances for those who were living at the subsistence level not temporarily but for long periods of time. However there was beginning to be a consciousness about the 'welfare state' in its concern for general social wellbeing that had failed many who fell through the gaps between departments of the social service delivery system. There was an awareness within the hospital system that rehabilitation was inadequate and that there were discrepancies between the needs of the elderly and the handicapped for health care. For instance New Zealand had been the forerunner of a separate and different kind of criticism of the welfare state services to the handicapped. The report of a Royal Commission on compensation and rehabilitation, 1967, stirred the English speaking countries to reconsider fundamental principles underlying their policies.

In Canada in the 1960s groups of the disabled embarked on a crusade to improve their image and status and to make a case for better treatment, for destigmatization of the handicapped and redistribution of resources. However they had considerable difficulty in deciding courses of action because the existing structures set up to assist the handicapped were so complex and the principles underlying policies to support the handicapped were unclear. In a review of programmes and policies for the disabled by the Canadian

Department of National Health and Welfare (1971) it was shown that despite improvements in general provision of services introduced in the 1960s, particularistic services were not well developed.

In Australia there was a Community Health and Hospitals programme, which was a plan to begin the redistribution of resources away from high technology medicine to community care. This helped the chronically sick and disabled in the community.

According to Crichton, an analysis of the policies in the three countries and their differing response to pressures indicates that while Britain was more concerned about equalization policies because it is well aware that privilege is still entrenched, Canada and Australia are perceived to be countries where there is greater equality of citizenship. The dominant ideology of the three countries is a western liberal democratic faith was modified to a different extent in each of the countries. Marchak a Canadian sociologist concerned about the way in which policy decisions are made in a liberal democratic society, states that one of the basic principles of liberalism is that government should interfere as little as possible.[16] Resource development has been a matter of entrepreneuralism and, as Benn and Peters pointed out, liberal governments have operated on the belief that with resource development there would be more left over for the weak.[17] The challenge to resource development as the best solution to improvement of the citizenship rights came from the socialists, who were concerned because unrestricted liberalism seemed to be a denial of equality and fraternity and because it created so many casualties on the way. Thus the balancing of utilitarian and humanitarian policies became the challenge to liberal democratic societies. According to Crichton, Beveridge thought he had found a solution in the 'welfare state' concept, but critics of this concept such as Wilding & George, stated that rather than correcting, it compounds injustice because of its failures in dealing with the issue of fairer redistribution of resources.[18]

All the three 'welfare state' approaches were utilitarian in the liberal democratic tradition as their services for the disabled make clear. These were all directed to low-level income maintenance for invalids and vocational rehabilitation. Australia did not retreat far from the concept of 'residual welfare' (individual responsibility) while Britain, and to a lesser extent Canada, showed some concern for those who were trapped in an unfair economic system. Britain in the early days of the welfare state campaigned strongly for destigmatization of the disabled, though the attempts at removal of discrimination were not successful. However attitude changes in Canada and Australia were more difficult and the disabled continued to be stigmatized along with deviant groups.

Walker and Townsend have summarized the themes that had been emerging in public discussion during the 1960s and early 1970s: 'there was the growing desire on the part of the disabled for self-determination and access to jobs and ordinary roles in society.[19] There was the demand of women for parity in treatment with men, for example in calling attention to the rights of disabled women. Most of all there was reaction from many sources of opinion against the fragmentation and inequality of treatment of disabled people implied by dividing them according to type or cause of disability.

Hall et al. have discussed how issues make their way into the system and become policies.[20] One important feature of success is to get attached to other social policies, which are popular and well supported. For example the blind made great progress when they associated themselves with ex-servicemen. Crichton feels that now that the disabled have become visible as a group entitled to their human rights, others may hang on to them, but it will be necessary for them to recognize that, essentially they are a deviant group, tolerated and made the objects of sympathy. Humanitarianism has its limits in utilitarian liberal democratic societies and even with improved recognition of the needs of the disabled there will be hesitations in meeting these needs. It is for this reason that preventive policies are most urgently desired.

Norwegian legislation on social disability

The Norwegian disability law of 1960 stated that everybody between 18 and 69 years of age, with at least a two-third reduction of occupational capacity caused by illness, injury, or defect, has a right to disability pension, after futile rehabilitation efforts.[21] The income maintenance system was not means tested. Thus, entrance was based on certain causes, i.e., medical, and on certain consequences, namely occupational. Several changes in the law of disability have been observed since it was enacted. First, in 1973 the age of retirement was lowered from 70 t o 67 years. Second the level of impairment necessary for access to the benefits of the law was reduced from at least two-thirds to one-half. Third, the rehabilitation condition was no longer practiced for people over 60 years of age. Also, the permanent and objective character of illness and disease as acceptable causes of admission were toned down. According to Jon Kolberg the changes in formal regulations have been without exception in a liberal direction.[22]

In discussing the socio-political context of rehabilitation Kjonstad pointed out that the first public plans in Norway on the national level were characterized by strikingly wide, liberal definitions of social disability; they proposed that disability pension should be accorded to persons having lost their working capacity, owing to illness, age or another weakening.[23] Income maintenance for old age was not suggested the main reason for this being that loss of working capacity in disability does not set in at a specific age. Thus, the disability pension proposed was conceived in terms of a flexible retirement pension. Medical considerations were de-emphasized. In the Norwegian case, the income maintenance scheme for disabled persons, enacted in 1960, after 75 years of deliberation, represented an extension of a temporary law of 1936, covering blind and crippled persons, and of disability pension schemes implemented in about one-third of the communes of the country providing an impetus for action at the national level.

Other aspects of the socio-political context influenced disability programs as a device of legitimization manifested for example in the liberal character of early proposals and subsequent plans. Social problems were conceived in an economic frame of reference and not primarily as medical problems. According to Hanisch, in the 1930s the new labour government based its policies on the

Keynesian paradigm, advocating high levels of public spending to reduce the social problems.[24] In the 1960s during another period of welfare social problems were differently conceived as individual medical problems. Kolberg, using the medicalization-demedicalization dimensions, analyses the liberal legislative changes in different Nordic countries.[25] For instance in Oslo, the Social Committee of the National Assembly at the close of the 1960s advocated that the situation of the client and not the cause of that situation should be the relevant basis of public welfare benefit allocation. People of old age composed a majority of the 'disability population'. This resulted in proposals to cut the age limit or to individualize it. In a Danish proposal, people could leave the labour market at the age of 55 years. In Sweden the powerful Federation of Trade Unions put an explicit proposal for demedicalization at the end of the 1960s. Structural, technological and organizational changes were recognized by the labour movement to have brought about problems of employment and work-related adaptation, especially for old workers. According to the petition people affected by such changes should, get income protection, regardless of the medical condition of the person in question. According to Kolberg although there were signs of dismantling the medicalization model he suggests that medicalization serves political purposes: high official unemployment rates are unacceptable in Scandinavian social democracies where every individual has a right to a job.[26] Demedicalization would precipitate growing caseloads overstraining public expenditures. The medical criteria of admission would also serve the latent function of restricting the number of clients to be given income protection. Thus arguments of equal treatment, growing structural unemployment and problems on the periphery of medicine may explain the hesitant process of demedicalization of disability determinations.

New Zealand's Accident Compensation Act

New Zealand's disability rehabilitation policy is considered a landmark in social legislation among different welfare states and it is claimed to have had an impact on government action in Australia, Malaysia and Great Britain. There were two occasions in the history of New Zealand that led to the restructuring of the system of social provisioning. The first of these was the great depression of the 1930s; the result was the welfare state. The second was the work of a Royal Commission on Personal Injury (1967) also referred to as the Woodhouse Report.[27] The Report identified serious national problems in the provision for victims of personal injury by accident; it provided an analysis of the roots of the problem in existing institutional arrangements and pointed to far-reaching remedies. The Report laid out a set of principles, which defined an entirely new stance toward injury and rehabilitation. By implication it was a challenge to the prevailing principles of welfare state and social security. The Woodhouse Report led to the Accident Compensation Act of 1972. The uniqueness of the Act was the genuine invention and new philosophy it was based upon-- that of community responsibility. In simplest terms its premise stated that accidents were a chance and undesired by-product of the normal operation of society i.e. production, distribution and consumption of goods and services. Hence the plight of the victim was a social cost of a basic social good, of the very processes that defined society itself. With society as a whole - the community - is the only possible answer to the question of where responsibility lies. The toll of personal injury was regarded as a disastrous incident of social progress and the accident victim was equated as the returned veteran - his service and any adversity attendant upon it were demanded by the state, and the state now had an obligation to restore his situation no matter what cost this might entail. The implications of this approach led to the concept of entitlement, and to policies of rehabilitation and compensation.

However the major criticism of this novel rehabilitation policy and act was that those disabled through accident were more advantaged than those disabled through other means. The Woodhouse Commission recognized that such a distinction could not be made on logical grounds. It also recognized the greater organizational complexities and problems of financing a scheme that included those incapacitated by illness as well as accident victims. According to Kronick, Vosburgh & Vosburgh, in attempting to resolve this conflict, it opted for accident compensation as a first step in the form of social provision for the disabled.[28] The differential treatment of the two categories created pressures on the government to rationalize the situation. A partial answer was offered in the Disabled Persons Community Welfare Act (1975). This Act addressed the provision of care, facilities, training and employment for all disabled persons not covered under the Accident Compensation Act. However the new law followed only some of the principles underlying the Accident Compensation scheme. Those disabled by illness were still to be dependent on a means-tested benefit rather than the real compensation payable to earners disabled through an accident.

Soviet Welfare

Services for the aged, disabled and handicapped have continued to follow the pattern laid down in the early post-Revolutionary years; the only innovations have been shifts in emphasis. These services till the late 1960s included economic support in the form of pensions and benefits, institutional placement, medical care, training and retraining and job placement. Nearly about 98% of the aged, disabled and handicapped lived at home on pensions.[29] For social services they depended upon on welfare workers and indigenous nonprofessionals from the Republic Ministries of Social Welfare, their own collectives usually being trade union committees.

The Soviet government did not publish statistics about the disabled - "invalids" - separately: they were shown together with the retired aged as "pensioners". The greatest difficulties in developing training facilities for the disabled arose in the early post-Revolutionary years, mainly because economic poverty and chaos precluded the allocation of resources. Efforts to improve this situation were stepped up in the 1930s to meet the demands of the first five-year plan. The Decree of 1930 directed the ministries of social welfare to strengthen assistance to invalids and their families "considerably" by providing remunerative work. While all persons needing vocational rehabilitation were entitled to be trained the emphasis was on training for war veterans and workers in state establishments. In the period after World War II training for workers and employees who became disabled was offered in three types of facilities: sheltered workshops, training producing enterprises run by deaf and blind societies and state enterprises in which the disabled person sustained injury. Cooperatives of the disabled were formed. As they gained in resources and prestige, they pressed for better training, cultural and educational opportunities and more adequate insurance benefits. From these efforts the disabled learned that they gained more by relying on themselves and working through their own collective of their capacities than by relying on governmental or societal help. Apparently the latter would come to their assistance only if they demonstrated their capacity to be productive.[30] However with regard to disability the Soviets from the very beginning adopted the principle of compensating for the loss of wages sustained rather than for the physical or mental trauma involved. The underlying strengths of the Soviet Rehabilitation services was considered to be the philosophy of "socialist humanism" which imbued the vocational rehabilitation services with humane and individualized approach which helped to meet the needs of the disabled more effectively.[31]

Analysis of the rehabilitation policies

According to Gary Albrecht's critical assessment of cross-national rehabilitation policies, the perceived salience of disability as a social problem, the accumulation of surplus capital and the growth of the welfare state have contributed to the development of extensive rehabilitation polices rationalized in terms of the national interest.[32] Any thoughtful analysis of these national rehabilitation policies is sensitive to the social history and political economy of individual countries that make them unique. With due respect to such individual differences comparative policy analysis forces abstraction in terms of the development of general principles and theoretical models.

Making comparisons across national health care systems, Albrecht argues that since national programmes and policies are situated within, and reflect the organization, ideologies and resources of the larger national medical system, it is important to consider the larger system underlying rehabilitation. Most cross-national policy analysts assume that a health system refers to the coordination and utilization of resources to promote, protect, or restore the health of the people .[33] In operational terms De Miguel argued for example that a health system is 'the set of relationships among institutions, social groups, and individuals that is directed towards maintaining and improving health status of a certain human population'.[34]

The definition of health problems and the form of intervention also reflect the dominant political and economic interest of the nation. Heidenheimer, Helco and Adams point out that conservative monarchs introduce a national hospital system to maintain the health of soldiers and ex-soldiers and then extended the services to the general population (Sweden in 18th and 19th centuries). Conservative politicians introduce public insurance programmes in an attempt to deprive rising socialist parties of an appealing issue (Germany, 1883). Liberal parties on the other hand introduce health insurance partly in an attempt to keep organized skilled workers from defecting to either conservative or Labour Parties (Britain, 1911). Social Democratic governments take the lead in transforming health systems partially financed through public sources into comprehensive, integrated public systems that supply almost all the health care in the country (Britain, 1948 and Sweden, 1970).[35] To these policies which types of governments have pursued in the context of health care services Albrecht adds that it is the form of American-style medical practice and health benefit programmes which is now dominating the medical profession, insurance companies and hospitals, which express private, entrepreneurial interests.

Health care in less developed countries usually reflects the system brought from a dominant industrial country and imposed on the developing country. Less dominated countries like China evolve their own system, based on past traditions and current world practice and modified by their available resources and political organization. The particular, fragmented (Rwanda), specialized but coordinated (Yugoslavia) or centralized (UK) form of health care system mirror the political structure of the nation.[36]

In conclusion it can be stated that there are general principles and models in the development of health service systems of a nation. Yet their utility is limited by the many intervening variables that affect health policy implementation. Hence an understanding of cross-national rehabilitation policies is dependent upon an appreciation of the corresponding national health systems designed primarily to diagnose and treat potentially disabling conditions. Disability benefits are generally contingent on the individual's ability to perform social roles. However with the definitions of disability expanding the scope of the rehabilitation services for the population at risk has also to be enlarged proportionately. The progressive disenchantment with the medical model of rehabilitation led to the development of the social service model of rehabilitation. Presently, the integration of the disabled into mainstream society is the main plank of the crusade. Although in most of the developed countries nutritional and communicable disease problems are solved, while this is not so in the developing countries, the effects of chronic illness are become increasingly apparent in both sets of countries. The problems and available solutions of industrial countries are different from those in less developed countries therefore different interventions are required. However with changing political, economic and social conditions, examined in the next section, nations will be forced to make social choices concerning the identification and treatment of disabilities.

Collapse of the welfare functions of the state

According to Marshall the Welfare State was born into a world of austerity – of rationing, price control, coupons, and rent restrictions. It was not that these restrictions on the free market were regarded as good in themselves and desirable elements in the new social order.[37] But they provided a background to welfare legislation a society committed to 'fair shares' and to distribution of income which could be rationally justified and was not the unpredictable result of the supposedly blind forces of a competitive market, in which everybody was entitled to take as much as he could get.

By the mid 1950s and early 1960s the 'Austerity society' had passed away and the Affluent society was taking its place. The restraints on self-enrichment and competitive consumption were removed and sensational stories were told of astronomic salaries, limitless expense accounts and fabulous speculative gains in real estate and elsewhere (some of the things the Indian media has circulated in the last few years as part of the promotion of the liberalisation model). Prices rose, wage demands became an annual event and inflation deprived some of the welfare benefits of their original value. It was in these circumstances that the basic principles of the Welfare State came under attack. The main objectives of the attack were the principle of universality and the provision of certain services free to all.

A series of parallel developments and complementary processes were unfolding in the United States of America. At the end of the Second World War, the US emerged as the sole hegemonic capitalist power, dominant in the economic, political and military spheres. Under the US leadership a set of international institutions were developed to provide viable international trade. The rapid growth of world trade, spread of MNCs and the development of international credit resulted in a close interdependence of the capitalist nations on one another – but all through the centralisation of the state structure was visible.

But towards the end of the 1970s the boom of post war economic growth came to a halt and caused global recession. The growth in the welfare state globally came to an abrupt end in many countries. Simultaneously the collapse of the Soviet Union and the nations of the socialist block in the late 1980s led to the reshaping of the capitalist world and a possibility to pressurise for a return to the laissez faire liberalism by reducing state interference to a minimum. The theoretical perspective of the neo-liberals gained prominence and advocated the rejection of the welfare state principle. This was the period of the neo-liberals' first electoral success with the election of the Reagan and Thatcher governments in the US and Britain. Their right wing economic polices reflected the ideological commitment to unbridled market principles, ignoring the remarkable role of state directed economies in these countries, wherein state involvement in public health had been central to the strategy to stabilise the economies in a move to help capital growth and technological change. Thus by the 1980s the welfare model was being countered globally and echoed nationally. Public expenditure was cut back and within this total, social expenditure suffered the most.

Neo-liberalism has been described as the right-wing solution to the current crisis of capitalism. According to Gough an attack on certain aspects of the welfare state is coupled with a monetarist economic policy which would rely on 'market forces' to discipline the working class, enhance profits, along with more repressive measures directed against the labour movement.[38] The basic premise of neo-liberalism is that public institutions and interventions are necessarily inefficient and wasteful and markets are the best for economic growth and development.

The economic crisis of the 1970s brought into prominence the role of the World Bank as a 'helping and bailing out' agent for many countries especially for the developing countries. The World Bank and other such economic organisations have been used by the neo-liberals to propagate their agenda. One of the major areas of influence and one that is considered profitable is the health sector. Privatisation is the main thrust for the welfare sector. Prior to state intervention health care was primarily dealt with privately, particularly at the family level. But with the emergence of state intervention and social policies regarding health care, health of the people became the responsibility of the state and the services provided by it. However this new wave of neo-liberalism and reform strategies for health care has resulted in privatisation of health care and the commodifying of health. The main arguments for privatisation are cost-efficiency and that since individuals are rational beings they should be allowed to make the choice that they most desire in the larger democratic interest. Due to the emphasis on state withdrawal from the welfare sector in general a major consequence of privatisation is that the state has also abdicated its responsibility to the welfare of its people. In the health sector this led to two major effects: one that the caring of the patient has landed on the family or what's called the familialization of health care; and second the costs of curing have to be borne solely by the individual. The implications of such a situation for most third world countries which have not achieved or ensured the basics of food, clean water, health, education and employment for all, the scenario of state withdrawal will have a cumulative effect on the health of the people as shown in many studies from Latin America and sub- Saharan Africa.

Another feature of privatisation is the development of and encouragement given to the NGO sector. The NGOs are considered to be a far better conduit for the distribution of multilateral and bilateral aid in the area of social and economic development. The origins of the development of the NGOs may be traced back to around the 1970s. The growth of the NGOs is attributed to factors such as the role played in Catholic and Protestant churches by liberation theology or as a response to the severe curtailment of political rights in Latin America. In India NGOs emerged as a response to the larger retreat of institutional politics and these organisations were viewed as political interventions within the mainstream.

The Reagan-Thatcher popularisation of free market, anti state policies, the fiscal and administrative crises of underdeveloped countries, the overall retreat of the state, and the end of the Cold War are all seen as processes which gave rise to renewed prominence to the roles of NGOs. The NGOs, as an alternate sector, were supposed to rectify state failure with their interventions and were seldom seen as a means to correct market failure. According to Alan Fowler the NGOs are thought to be more cost effective in service delivery, to have greater ability to target the poor and vulnerable sections of the population, to demonstrate a capacity to develop community based institutions, and to be better able to promote the popular participation needed for sustainability of benefits.[39]

The major criticism of the NGO sector is that the NGOs are largely donor driven and generate patron-client relationships within an unequal power situation and enter only particular sectors. Tendler has provided evidence, which indicates that the NGOs function as topdown, non-participatory and uninnovative.[40] Replicability and sustainability, two criteria that define the success of NGO projects, have also not been fulfilled in many cases. Because of their limited scope and reach, NGOs are no alternative to the state. Thus many studies have revealed that regarding NGOs as an alternate development paradigm has been grossly exaggerated. According to Zaidi NGOs, at best, are providers of a minimal amount of 'band aid social welfare'.[41] The only alternative to state failure is the state itself because it is only the state, which can provide continuity of services. In sum, in third world countries a different form of state, based on a different equation with 'civil society', which is decentralised, delegatory and democratic, may perhaps be the only alternative to state failure itself.

Conclusion

The case for the market providing services is being ably presented by economists who argue that services collectively organised by the State are seen as a temporary economic phenomenon peculiar to a specific historical phase in the development of large-scale industrial societies. They were needed as social supports when the masses were poor; in times of war; and when the future of capitalism was uncertain. These conditions, it is argued, are no longer prevalent and the 'welfare state' should wither away and people should resort to a self-regulating market. Private responsibility should replace public paternalism. In the area of health the American model of health care is regarded as the most superior, efficient and cost effective model and is spreading its tentacles in both developed and developing countries. In this model people are viewed as consumers, health is regarded as a commodity and profit maximisation is the aim. However as we have seen the debates are narrowing down to a single model without recalling the range of options explored by states and societies in the past. A unipolar economic world is being accompanied by the offer of a single ideology – that of the market. The question that confronts us is: will the experience of widespread social distress that such a society is bound to generate lead to another or a revised phase of a welfare state.

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RECORDING DISABILITY:
CENSUS AND NATIONAL SAMPLE SURVEY DATA

> *On aggregate, 0.6 percent of the disabled children,*
> *less than 3 percent of the total of physically disabled,*
> *under 1 percent of the total of mentally disabled are*
> *estimated to have access to rehabilitation of the state*
> *or voluntary agencies. NSS reported that over half*
> *the disabled people they identified had never*
> *seen a qualified physician for any purpose.*
> *- Barbara Hariss-White*

The study of any population requires an insight into their demographic, social and economic characteristics. The Government of India conducts both the Census and the NSS. The Census and the National Sample Survey (NSS) provide the basic information regarding the disabled population in India. While the Census is conducted in a decadal sequence, the NSS is undertaken as and when the need arises for an in-depth analysis of an issue. The fundamental strength and value of the Census comes from its universal coverage and its freedom from sampling error. However the Census can have problems of under-estimation.

The collection of data on disability through the Census in India dates back to 1872 when the practice of Census began. The questionnaire of the 1872 Census included questions not only on the physically disabled but also on the mentally disabled. The practice was discontinued in 1931 and then information on disability was not collected in the subsequent Census of 1941, 1951, 1961, and 1971. It was in the year 1981 that the first Census on disabled persons was undertaken in Independent India. The reason for collecting data in 1981 was that the UN had declared it as the International Year for Disabled Persons but the practice was discontinued in the 1991 Census. The 1981 data was a mere eyewash of a Census enumeration. There were many lacunae in it, the main one being that only three categories of the disabled were considered, namely the totally crippled, totally blind and totally dumb. Two major categories namely, the hearing and mentally disabled were left out. Other major drawbacks were that the definition of disability was restrictive in the sense that the use of the word 'totally' left out the categories of the partially disabled persons who do form a part of the disability sector. The other drawback is the definitions and use of the terms crippled and dumb which are indicative of the level of ignorance with regard to disability. It was in 1995 with the passage of the Persons with Disabilities Act that there was lobbying by the disability sector for the disabled persons to be included in the Census. The various reasons given by the Census Commission for not including the disabled in the Census since 1941 ranged from difficulties in enumerating the disabled due to the lack of gadgets or tests to assess the disability, to the difficulty for the enumerators to elicit information about disability as people would hide their disability, or families would hide the disabled members due to the stigma attached with disability. Although the intention of the Census Commission was to leave out the disabled persons in the 2001 Census the lobbying by the disability sector along with the passing of the 1995 Act which emphasized the rights of the disabled created pressure and the Census Commission had to include the disabled persons. The results of the 2001 Census are awaited. In the following section the main findings of the 1981 Census are presented.

The Census of India 1981 was entitled Census of the Physically Handicapped. It was conducted by the Government of India. The Ministry of Education and Social Welfare requested the enumeration of the physically handicapped. The ministry provided the following definitions on the blind, the deaf and the orthopedically handicapped.

The Blind - the blind are those who suffer from either of the following conditions:

a) total absence of sight;
b) visual acuity not exceeding 6/60 or 20/200 (Snellen) in the better eye with correcting lenses;
c) limitation of the field of vision subtending an angle of 20 degrees or worse.

The Deaf - the deaf are those in whom the sense of hearing is non-functional for ordinary purposes of life. Generally a loss of hearing at 70 decibels or above at 500, 1000 or 2000 frequencies will make residual hearing non-functional.

The Orthopedically Handicapped - those who have a physical defect or deformity which causes an undue interference with the normal functioning of the bones, muscles and joints.

The definitions indicated that detailed inquiries regarding the handicapped would not be possible; hence it was decided to limit the enquiry to elicit information on the aggregate numbers of those who are totally blind, totally dumb and totally crippled. Further enquiries regarding sex, age or other characteristics were left out because it was felt that these would not be within the capacity of the enumerator.

In the following Tables I, II and III, three states with the highest percentage a specific disability within the disabled population have been presented for All India, Rural, and Urban, according to the 1981 Census for the Physically Handicapped.

TABLE I - THREE STATES WITH HIGHEST PERCENTAGE DISABILITY-WISE (1981) ALL INDIA.

TYPE OF DISABILITY	NAME OF STATE WITH HIGHEST PERCENTAGE OF A DISABILITY TYPE		
Totally blind	Rajasthan (58.05%)	Uttar Pradesh (56.89%)	Madhya Pradesh (52.47%)
Totally crippled	Gujarat (47.35%)	Kerala (38.82%)	Jammu & Kashmir (36.38%)
Totally dumb	Sikkim (78.17%)	Manipur (38.95%)	Himachal Pradesh (38.22%)

Source: Census of India, 1981.

TABLE II - THREE STATES WITH HIGHEST PERCENTAGE OF PERSONS DISABILITY- WISE (RURAL) 1981.

TYPE OF DISABILITY	NAME OF STATE WITH HIGHEST PERCENTAGE DISABILITY WISE		
Totally Blind	Rajasthan (59.54%)	Uttar Pradesh (57.94%)	Madhya Pradesh (53.23%)
Totally Crippled	Gujarat (46.14%)	Kerala (38.45%)	Jammu & Kashmir (36.21%)
Totally dumb	Sikkim (78.58%)	Nagaland (61.38%)	Manipur (38.98%)

Source: Census of India, 1981.

TABLE III - THREE STATES WITH HIGHEST PERCENTAGE DISABILITY-WISE (URBAN) 1981.

TYPE OF DISABILITY	NAME OF STATE WITH HIGHEST PERCENTAGE DISABILITY - WISE		
Totally Blind	Rajasthan (46.55%)	Uttar Pradesh (46.10%)	Haryana (45.21%)
Totally Crippled	Gujarat (51.94%)	Bihar (43.83%)	Kerala (40.58%)
Totally Dumb	Sikkim (68.04%)	Nagaland (42.65%)	Manipur (38.75%)

Source: Census of India, 1981.

NATIONAL SAMPLE SURVEY (NSS)

The National Sample Survey Organization (NSSO) made its first attempt to collect information on the number of physically handicapped persons in the 15th round (July 1959 - June 1960). The enquiry was exploratory in nature and was confined to rural areas only. However in the 16th round (July 1960 - August 1961) the geographical coverage was extended to urban areas. The subject was again taken up in the 24th round (July 1969 - June 1970) and in the 28th round (October 1973 - June 1974). The objective of these early enquiries was only to provide estimates of the number of persons in the country who suffered from certain specific physical handicaps. However the types of physical handicap covered in all those rounds were not always the same. For reasons of economy, information on the physically handicapped was collected in the early rounds in survey schedules meant for other subjects. Therefore there was little scope for collecting information on cause, specific nature and other details. In the year 1981 which was declared the International Year of Disabled Persons by the United Nations, at the request of the Ministry of Social Welfare the NSSO in its 36th round (July - December 1981), undertook an exclusive and comprehensive survey of disabled persons. The objective was to provide a database regarding incidence and prevalence of disability in the country. However the survey was done only on the physically disabled persons, namely those with visual, communication (speech & hearing) and locomotor disability. The physical disability to be covered under the enquiry was distinguished from morbidity. Morbidity covers cases of illness or injury of recent origin not resulting in the loss of ability to see, hear, speak or move. The latest NSS survey on disabled persons was conducted in the 47th round (July - December 1991). The basic framework of the survey including the concepts, definitions and operational procedures were the same as in the 36th round. However there were some minor modifications in the content of the enquiry schedule based on the experience of the 36th round.

In both the 1981 and 1991 NSS the sample was a two stage stratified design. The first stage comprised villages in the rural sectors and urban blocks in the urban sector. The second stage comprised of households in both the sectors.

The results or findings of the surveys of 1981 and 1991 have been placed under different headings making the comparison of the latest two rounds of the survey difficult. For example in the 1981 survey visual disability was further classified as 'with light perception' and 'with no light perception' whereas in the 1991 survey there was no such sub-classification. Another example of inconsistency in the presentation of the results is the specification about age in terms of 'age at onset' or just as 'age'.

For the purpose of the survey, a person was treated as physically disabled if the person had at least one of visual, communication (hearing and/or speech), and locomotor disability. According to the 1981 NSS for the country as a whole, prevalence of physical disability was estimated at 18 persons per 1000 for the rural sector and 14 persons for the urban sector. At the all-India level, the prevalence of physical disability amongst males was estimated at 20 for the rural areas and 15 for the urban areas. The corresponding rates for females were slightly lower, 16 for rural and 13 for urban for the all-India level. The prevalence of physical disability for the rural population was slightly higher than for the urban population.

In 1981 for the rural areas, the prevalence rate per 1000 population was highest in Punjab (26) and the lowest in Assam (8). In the urban sector the highest rate was estimated at highest for Tamil Nadu (21) and the lowest in Assam (8). The prevalence rate of the same level for rural and urban areas was seen in the states of Assam, Kerala and Tamil Nadu. In the remaining States the prevalence of physical disability amongst the rural population was higher than amongst the urban population.

The 1981 NSS results indicate that in the rural areas the prevalence was highest in Punjab for males (30) and in Andhra Pradesh for females (23). In the urban areas the highest rate was in Tamil Nadu for both males (23) and females (19). In both rural and urban areas the lowest rate (8) for both males and females was estimated in Assam. The prevalence of physical disability amongst males was higher than amongst females in both rural and urban areas.

In this study the main focus is on the 1991 NSS results as those are the most recent data available for disability. However wherever required the 1981 NSS results has been referred to. The findings of the 1991 survey conducted in 16 major states and India as a whole are presented in terms of rural and urban residence. At the all-India level 39,271 rural and 17,489 urban households were surveyed from 4373 villages and 2503 urban blocks. The number of disabled persons enumerated were 42,400 and 18,833 in rural and urban sectors respectively. According to the survey estimates the number of physically disabled persons in the country was 16.15 million during July-December 1991; they formed about 1.9% of the total estimated population (using the 1991 census population projected for 1st October 1991).

About 12.73 percent of these physically disabled persons suffered from more than one type of the following disabilities - visual disability, hearing disability, speech disability and locomotor disability. The aggregate estimates of the physically disabled in rural and urban sectors have been given for each sex and type of disability. It is observed that among the different types of disabilities the number of persons having locomotor disability was highest in both rural and urban sectors followed by the number of persons with visual disability and hearing disability.

Data has also been collected of households by number of disabled persons in a household for rural and urban sectors of the 16 major states and all India. It was found that about 10.77 and 2.67 million households or about 9 and 7 percent of the total estimated households respectively in rural and urban sectors reported to have at least one disabled person in the house. The average size of these households estimated to be 5.8 persons in both sectors. Among these households about 92 percent had one disabled person, about 7 percent had 2 disabled persons and less than 1 percent reported 3 or more disabled persons both in rural and urban sectors. In 1991, according to Barbara Harris-White at least 32 million of the total population of 844 million was likely to have been disabled. Their families and those working in caring institutions, people affected indirectly by disability would have amounted to perhaps four or five times as many.[1]

A comparison of the estimated number of disabled persons by type of disability in rural and urban areas for 1981 and 1991 NSS Rounds are given in the following Tables 1 and 2.

TABLE 1 - ESTIMATED NUMBER (IN '00) OF DISABLED PERSONS BY TYPE OF DISABILITY IN RURAL & URBAN AREAS (1981) ALL INDIA.

Type of disability	Rural			Urban		
	Male	Female	Persons	Male	Female	Persons
Physical Disability	5496	4176	9672	1300	967	2267
Visual disability:	1193	1715	2908	249	317	566
With no light perception	443	706	1149	105	110	215
With light perception	747	1001	1748	144	206	350
Hearing Disability	1366	1111	2477	288	254	542
Speech disability	870	496	1366	255	133	388
Locomotor disability	2814	1328	4342	679	406	1085

Source: *Sarvekshana* - Journal of NSSO, Vol. VII, No. 1-2, July-Oct 1983, Government of India.

TABLE 2 - ESTIMATED NUMBERS (in '000) OF DISABLED PERSONS BY TYPE OF DISABILITY AND SEX IN RURAL AND URBAN AREAS (1991) ALL INDIA.

Type of disability	Rural			Urban		
	Male	Female	Persons	Male	Female	Persons
Physical disability	7442	5210	12652	2078	1424	3502
Visual disability	1539	1796	3335	308	362	670
Hearing disability (5 yr. & above)	1409	1164	2573	339	330	669
Speech disability (5 yr. & above)	942	557	1499	298	169	467
Hearing &/or speech disability	2009	1490	3499	557	426	983
Locomotor disability	4396	2411	6807	1370	762	2132

Source: *Sarvekshana* - Journal of NSSO, Vol. XVIII, No. 2, Oct.-Dec. 1994, Government of India.

Prevalence and Incidence Rate of Disability

According to the 1991 NSS data estimates the prevalence of physical disability (number of physically disabled per 1 lakh persons) have been investigated. In the country as a whole the prevalence of physical disability was 2.0 percent in the rural population and 1.6 percent in the urban population. Between the two sexes, the prevalence of disability was marginally higher among the males than among the females. The rate for males was 2.3 and 1.8 percent while for females it was 1.7 and 1.4 percent in rural and urban sectors respectively. The inter-state variations in prevalence were significant in both the sectors. In the rural areas the percentage ranged from 1.2 (Assam) to 2.9 (Punjab). In the urban sector the percentage ranged from 1.1 (Rajasthan) to 2.0 (Orissa). The prevalence rates among the males were higher than among females in all states.

The incidence rate of physically disabled is the number of persons who suffered physical disability (by birth or otherwise) during the specified period of the previous year (365 days preceding the date of survey) per 100,000 persons was also investigated. At the all India level 90 per 100,000 were born or otherwise became disabled during the reference year in the rural sector. In the urban sector this figure was a little lower 83 per 100,000 persons. The incidence rate is also observed to be higher among males than among females. The rate among males was 99 and 90 in rural and urban sectors respectively as against 81 and 75 respectively among females. The states also exhibit a similar feature. The state-wise differences are quite high ranging from 30 to 171 per 100,000 persons in rural sector and from 46 to 144 in the urban sector. Assam reported the lowest incidence rate and Tamil Nadu the highest rate in both the sectors. The states other than Tamil Nadu, which showed high incidence rate in rural areas, were Punjab (156), Andhra Pradesh (132), Madhya Pradesh (121) and Maharashtra (107). In urban areas Orissa (141), Maharashtra (98) and Andhra Pradesh (94) had a relatively high incidence rate. Contrary to the general pattern rural areas of Andhra Pradesh and Madhya Pradesh and urban areas of Assam, the Orissa and Tamil Nadu reported a higher incidence of disability among females than males during the year.

Since the incidence rate of physically disabled persons as a whole is not available for the NSS 36th round, only the prevalence rate as obtained from these rounds are presented for each sex in the rural and urban sectors. The results reveal that in both sectors the prevalence of physically disabled persons for males and females increased marginally over the period 1981 - 1991. The rural-urban as well as male-female pattern in the prevalence rate is found to be similar in both surveys.

A comparison of the prevalence rates of physically disabled persons for the 36th Round (1981) and for the 47th Round (1991) is given in the following Table 3.

TABLE 3 - PREVALENCE OF PHYSICALLY DISABLED PERSONS PER 1,00,000 PERSONS OBTAINED FROM NSS 36TH AND 47TH ROUNDS.

Sector	36th Round (July-December 1981)			47th Round (July-December 1991)		
	Male	Female	Persons	Male	Female	Persons
Rural	2045	1632	1844	2277	1694	1995
Urban	1532	1297	1420	1774	1361	1579

Source: *Sarvekshana*, Vol. XVIII, No. 2, Oct. - Dec., 1994, Government of India.

Prevalence rate for a particular disability

$$= \frac{\text{estimated number for disabled persons}}{\text{estimated total population}} \times 1,00,000$$

1991 NSS RESULTS

Degree of Disability

According to the 1991 NSS for determining the degree of disability of a disabled person, self-care such as ability to go to the toilet, take food, get dressed etc were taken into account. Irrespective of whether or not a person had 'single' or 'multiple' disability he/she was classified into one of three categories - those not able to take self-care even with aid/appliance i.e. cannot function without aid/appliance; those able to take care of self without aid/appliance i.e. can function only with aid/appliance and those who can function without aid/appliance i.e. can function without aid/appliance. For the all India pattern among the physically disabled about 25 percent in the rural sector and 20 percent in the urban sector were observed to be severely disabled as they could not function even with aid/appliance. The corresponding percentages for males in the rural and urban sectors were 23 and 19, and for females it was higher 28 and 23 respectively. The all-India pattern is reflected in the states also. The percentage of disabled persons who cannot function even with aid/appliance is seen to be highest in the rural areas of Uttar Pradesh (32), Madhya Pradesh (31), and Rajasthan (30). In the urban areas it is Himachal Pradesh (31), Uttar Pradesh(29) and Bihar (26). Tamil Nadu has recorded the lowest percentage of severely disabled persons in both sectors about 16 and 12 in rural and urban sectors respectively.

VISUAL DISABILITY

A person was treated as visually disabled if were in any of the following categories - persons who have no light perception; persons who have light perception but cannot count fingers at a distance of 3 metres even with spectacles; and those who normally use spectacles and normally do not use spectacles.

Prevalence of visual disability :

The estimated number of visually disabled persons per 100,000 population is the prevalence rate. The prevalence was 302 in rural and 525 in urban sectors. The prevalence among females was 548 and 346, which is higher than among males, which were 471 and 263 in rural and urban sector respectively. Among the states Orissa (820), Andhra Pradesh (806) and Himachal Pradesh (629) reported the highest in the rural sector. In the urban sector the rate was high for Assam (451) and Orissa (444). Bihar reported the lowest prevalence rate in both sectors (341 and 225 respectively).

Age at onset of visual disability:

Some are born with the disability and some acquire it after birth in the course of life. In order to study the pattern of age at onset the cohort of persons of 60 years and above who acquired visual disability were considered for rural and urban sectors. A majority of them-- about 69 percent acquired visual disability at the age of 60 years and above. The next age group was 45 -59 years. It was noted that both in the rural and urban sector percentages are marginally higher in the first three age groups (0-4, 5-9 and 10-14 years) than in the later age groups. The survey results suggest old age and early years of life manifest the most cases of visual disability.

Cause of visual disability

The information on probable cause of disability was collected with respect to those who acquired visual disability. The cause was not known for about 16 and 13 percent of the visually disabled in the rural and urban sectors. About 27 to 21 percent reported "old age" as the cause in rural and urban sectors respectively. Cataract, the incidence of which is generally high in old age, was found to be cause for 24 and 28 percent in rural and urban sectors respectively. Comparing the prevalence and incidence rates of visual disability of the 36th and 47th rounds, in the country as a whole the prevalence and incidence of visual disability decreased marginally over the period 1981 and 1991 (See Table 4, p.98). This is also observed for each sex.

HEARING DISABILITY:

For the purpose of the survey hearing disability was judged taking into account the ability of the better ear. Thus if one ear of the person was normal and other ear had total hearing loss the person was judged as normal in hearing. A person was treated as having severe hearing disability if the person could not hear at all, could only hear loud sounds, could hear only shouted words. Moderate hearing disability was considered by asking the person to repeat the words spoken by the speaker. Enquiry about hearing disability was conducted on persons of 5 years and above.

Prevalence of hearing disability

The prevalence rate was higher in the rural sector for both males and females. The prevalence of hearing disability was higher among males' (498) than females' (435) in the rural sector while in the urban sector it was higher among females' (355) than for males' (325). A similar pattern was noticed for the states as well. In rural areas the highest rate was reported from Himachal Pradesh (1108), Tamil Nadu (723), Orissa (698) and Andhra Pradesh (660). The highest rate in urban areas was reported from Orissa (548), Tamil Nadu (518) and Andhra Pradesh (501). It can be noted that in the urban areas of Himachal Pradesh which reported the highest prevalence rate in rural areas, the rate was as low as 237 in the urban areas. No other state has shown such a large rural-urban difference. Rajasthan has reported the lowest prevalence of hearing disability for both sectors 271 and 196 rural and urban respectively.

Degree of hearing disability:

At the all-India level about 23 and 21 percent had very severe hearing disability in the rural and urban sectors respectively. In the states the percentages of the very severely disabled persons in the rural sector are Himachal Pradesh (41) Bihar and Karnataka (30), while in the urban sector the states are Bihar (36), Kerala (27) and Orissa (26).

Age at onset of disability:

It can be seen that at the all-India level about 61 and 65 percent reported the onset at ages 60 years and above in the rural and urban sectors respectively. The results indicate that hearing disability is mainly a problem of old age. The state level results generally conform to the all-India pattern.

Cause of disability:

In about 26 and 21 percent cases in rural and urban India the informants were ignorant about the cause of hearing disability. About 23 to 26 percent reported 'old age' as the cause. Of the other reasons illness and ear discharge were identified as the cause by a comparatively large proportion of persons with hearings disability.

Comparing the prevalence and incidence rates of the 36th and 47th rounds it has been found that the prevalence has decreased considerably but the incidence rates have remained more or less stable (See Table 4, p.98).

SPEECH DISABILITY

Speech of a person was judged to be disordered if the person's speech was not understood by the listener, drew attention to the manner in which it was spoken and was aesthetically unpleasant. Persons with speech disability were categorized as: persons who could not speak at all; persons who could speak only in single words; persons who could speak unintelligibly; persons who stammered; persons who could speak with abnormal voice like nasal, hoarse, or discordant voice; and persons who had speech defects such as articulation defects. The information was collected only for persons 5 years and above.

Prevalence of speech disability;

It was found that 273 per 100,000 persons in rural India and 237 per 100,000 in urban India had a speech disability. The male-female difference was considerably high and a higher proportion of males had speech disability than females. Out of 100,000 males 333 and 285 males in rural and urban areas respectively and 208 and 132 females in rural and urban areas respectively had speech disability. The states also reveal a similar pattern. The prevalence was highest in Himachal Pradesh (457), Kerala (414) and Karnataka (353) in the rural sector. In the urban sector the highest prevalence rate was observed in Andhra Pradesh (359), Kerala (327) and Tamil Nadu (306).

Age at onset of disability:

At the all-India level about 59 and 57 percent in rural and urban sectors respectively reported that they were affected by speech on reaching the age of

60 years and above. The onset of speech disability was proportionately more in the first three age groups than in the latter groups.

Cause of speech disability:

The results show that in rural and urban India about 20 and 17 percent respectively did not indicate the cause of speech disability. Among the reported causes paralysis and other illness were the major causes. Only 2 percent reported old age as a cause.

Comparing the prevalence and incidence rates of the 36th and 47th rounds the prevalence rate seems to have decreased in each sector and sex. The decrease was more in the rural areas and among males. The incidence rate remained almost stable over the period 1981-1991 (See Table 4, p. 98).

LOCOMOTOR DISABILITY

Persons having loss or lack of normal ability to execute distinctive activities associated with moving both themselves and objects from one place to another were treated as persons having locomotor disability. Locomotor disability included such lack of normal ability that could be due to paralysis of limb or body, deformity of limb, loss of limb, dysfunction of joints of the limb, and deformity of the body other than the limb.

The survey estimated 8.94 million persons as having locomotor disability in the country. Of them 6.81 million lived in the rural areas and 2.31 million in the urban areas. Further about 2 percent of those who had locomotor disability reported to have multiple disabilities (two or more locomotor disabilities) in rural and urban areas.

Prevalence of locomotor disability;

Compared to other types of disability the prevalence of locomotor disability per 100,000 was higher. The rate was as high as 1074 and 962 in rural and urban areas. Among the males the prevalence was much higher than among females: 1345 and 1170 for males as against 784 and 728 for females in rural and urban sectors respectively. The all-India pattern is reflected in the states as well. The prevalence was highest in Punjab (1974) in the rural sector and Kerala (1203) in the urban sector. The lowest prevalence was reported from Assam (419 and 424) in both rural and urban sectors respectively. Assam is the only state where the prevalence of locomotor disability was proportionately more, though marginally, among the urban population than that among the rural population.

Age at onset of locomotor disability;

As was observed in the case of visual and hearing disability for locomotor disability also the highest percent 54 and 59 persons were found to have acquired the disability at the age of 60 years and above in rural and urban India. There is also a relatively higher incidence of locomotor disability in the early ages.

Cause of disability:

Polio was found to be the major cause of locomotor disability. About 33 and 35 percent reported "polio" as the cause at the all India level in the rural and urban sectors respectively. The next highest cause was "burns and injuries" accounting for 23 and 24 percent in rural and urban sectors respectively. Contrary to the results of the other disabilities of "old age" as a major cause of disability only 4 to 5 percent reported it as a cause for locomotor disability.

Comparing the prevalence and incidence of locomotor disability of the 36th and 47th rounds it can be seen that the prevalence rate increased substantially in both the sectors. The increase was more in the urban sector (See Table 4, p.98). The prevalence rate also increased for both the sexes over the decade. But the rate was not uniform. While the rate among rural females was higher than among the males the picture was the opposite in the urban sector. The incidence rate remained the same overall. It remained stable for both males and females in the rural sector. In the urban sector the rate among males increased marginally and for females it decreased slightly. However the observed differences in the rates has not been identified.

TABLE 4: PREVALENCE AND INCIDENCE RATE (PER 100,000 PERSONS) OF DIFFERENT DISABILITIES OBTAINED FROM 36TH AND 47TH ROUNDS FOR RURAL AND URBAN SECTORS.

Disability/ Sector	36th Round (July-December 1981)			47th Round (July-December 1991)		
	Male	Female	Person	Male	Female	Person
Visual	Prevalence Rate					
Rural	444	670	553	471	548	525
Urban	294	425	356	263	346	302
Visual	Incidence Rate					
Rural	32	45	38	22	28	28
Urban	23	38	30	15	25	20
Hearing	Prevalence Rate					
Rural	595	510	573	498	435	467
Urban	386	395	390	325	355	339
Hearing	Incidence Rate					
Rural	20	18	19	16	14	15
Urban	14	15	15	11	14	12
Speech	Prevalence Rate					
Rural	379	228	304	333	208	273
Urban	342	207	279	285	182	237
Speech	Incidence Rate					
Rural	6	2	4	6	4	5
Urban	7	3	5	5	4	5
Locomotor	Prevalence Rate					
Rural	1047	597	828	1345	784	1074
Urban	800	544	679	1170	728	962
Locomotor	Incidence Rate					
Rural	64	42	53	64	42	53
Urban	61	47	54	64	39	52

Source: *Sarvekshana*, Vol. XVIII, No. 2, Oct-Dec. 1994, Government of India.

Literacy among the Disabled

A literate, for the purpose of survey were those who could read and write a simple message with understanding. Those who were unable to do so were considered illiterates. The different levels of general education of those who were considered literate were ascertained. In rural India about 70 percent of the physically disabled persons were found to be illiterate as against 46 percent in urban India. Only about 4 percent of the disabled in rural India have reported an educational level of "secondary and above" as against 12 percent in urban India. The urban bias in literacy is more pronounced because of the availability of better educational facilities in general and the existence of special schools for the disabled. Kerala has marked the highest literacy level. The lowest literacy level is found in rural Orissa and in urban areas of Uttar Pradesh.

Along with the general educational level information relating to whether they had completed any vocational course was also collected. The data have been tabulated for age 5 years and above. The vocational courses have been broadly divided into two - engineering and non-engineering courses. Out of 1000 physically disabled persons in rural India only 12 have completed any vocational course. In urban India a comparatively higher number 31 per 1000 disabled persons have completed any course. Of them about 20 to 27 percent have completed courses in engineering trade and 73 to 80 percent in non-engineering trade. The state-wise estimates show some variance. In rural Himachal Pradesh 54 per 1000 disabled persons (the highest in the rural sector of the major states) have completed any vocational course. In the urban sector Maharashtra (58 per 1000 disabled persons) reports the highest. The lowest in the rural sector are reported from Orissa and Madhya Pradesh (6 per 1000) and lowest in the urban sector is reported from Haryana (11 per 1000 disabled persons).

For disabled children in the age group of 5-14 years the enrolment status in general as well as special schools have also been investigated. The enrolment ratio for children in the urban areas was found to be higher than for the rural areas - 552 and 458 respectively. The ratio was also higher among males than females in both sectors. Of those who were once enrolled in an ordinary school but were not currently enrolled, 43% were found to have discontinued due to onset of disability in the rural sector and 39% in the urban sector.

Disability and Employment

Employment has been covered under the heading "usual activity of the disabled". The usual activity status of an individual is the activity situation obtained for a person in respect of his/her participation in gainful or non-gainful activities during the reference period of 365 days preceding the date of survey. Three major activity status areas were identified:

(i) Working or being engaged in gainful activities (work) - employed (sub categories being self employed in agriculture, in non-agriculture; regular employee and casual labour)

(ii) not engaged in gainful activities (work) but available for work - unemployed;

(iii) Not engaged in work and also not available for work - out of labour force (sub categories include attending educational institution, domestic duties, begging and others).

The distribution of disabled persons by activity status shows that 29 and 25 percent of the disabled persons were employed in rural and urban areas respectively. Of the persons considered as employed 60 percent were self-employed, 7 percent were regular employees and 33 percent were casual labour in rural India. The corresponding percentages were 48, 30 and 22 in the urban areas. The percentage of disabled persons seeking and/or available for work was higher in the urban areas (1.7%) as compared to the rural areas (0.7%).

Onset of disability and its effect on work activity of the disabled - Onset of disability in a person who was usually working (gainfully employed) may sometimes lead to loss of work or change of work. For those who were usually working before the onset of the disability, information relating to loss or change of work was collected for disabled persons of age 5 years and above in terms of the proportion (per 1000) who were working before the onset of disability. In the rural and urban sectors about 40 and 29 percent of disabled persons 5 years and above were working before onset of disability. In the rural sector 47 percent had lost or had discontinued their work due to onset of disability. The figure was 42 percent in urban areas. About 13 to 15 percent had to change their work. Most of the states exhibit a similar pattern. In rural areas the highest percentage of disabled persons who were working before onset of disability was in Himachal Pradesh (60) and the lowest in Kerala (30) and Gujarat (31). In the urban sector the highest was in Himachal Pradesh (57) and lowest in Gujarat and Kerala (22 and 23 respectively).

Living Arrangements for the Disabled

Information on living arrangements was collected in terms of living alone, with spouse only or with spouse and other members of the household. The results reveal that at the all-India level 4 and 6 percent of the disabled persons were living alone in rural and urban sectors respectively. These persons did not have other members of the household to take care of them. About 4 to 5 percent lived with their spouses only. But a large majority about 90 percent lived with their spouse and/or other members of the family. The state-wise estimates do not show any uniform pattern. In the rural sector the percentage of disabled living alone was highest (6 to 7) in Tamil Nadu, Orissa and Andhra Pradesh. While in the urban areas the highest was in Maharashtra (14) followed by Himachal Pradesh and West Bengal (6 to7).

Treatment Taken

Although the NSS has data on the type of 'treatment taken' what is significant is the data on 'reasons for taking no treatment'. The most common cause revealed for taking no treatment is 'treatment is expensive' in both rural and urban areas as well as in both the 36th and 47th rounds of the NSS. While the percentage of persons who were not aware about the availability of treatment is very small. (See following Tables 5 and 6 for details).

TABLE 5: DISTRIBUTION OF THE PERCENTAGE OF PERSONS NOT TAKING TREATMENT BY REASONS - RURAL & URBAN AREAS (1981).

Type of disability	Reasons for taking no treatment									
	Treatment expensive		Other reasons		Treatment not necessary for: Economic Independence		Personal Independence		Place of treatment not known	
	rural	urban	rural	urban	rural	urban	rural	urban	rural	urban
Visual:										
No light perception	46.0	53.7	24.6	27.0	16.3	10.6	8.2	6.3	4.9	2.4
With light perception	49.9	41.5	16.9	24.0	17.3	16.6	10.4	15.6	1.9	2.3
Communication:										
Hearing	36.6	31.2	19.4	25.6	18.0	15.2	16.8	22.9	9.2	5.1
Speech	28.7	18.0	19.6	20.3	18.0	16.6	17.7	29.9	16.0	5.2
Locomotor:										
Paralysis	49.2	31.0	18.7	26.6	13.2	7.9	3.7	4.7	8.2	7.1
Deformity	37.0	27.2	21.6	29.8	12.6	10.3	9.7	11.2	11.9	8.7
Dysfunction	47.5	37.4	14.9	25.9	15.5	11.9	8.5	8.8	6.2	3.4

Source: *Sarvekshana*, Vol. VII, No. 1-2, July-Oct. 1983, Government of India.

TABLE 6: DISTRIBUTION OF THE PERCENTAGE OF PERSONS TAKING NO TREATMENT BY REASONS - RURAL & URBAN AREAS (1991).

Type of disability	Reasons for taking no treatment									
	Treatment expensive		Other reasons		Treatment not necessary for: Economic independence		Personal independence		Treatment not available	
	rural	urban	rural	urban	rural	urban	rural	urban	rural	urban
Locomotor	50.2	44.8	34.7	37.5	6.9	9.5	5.0	5.7	3.2	2.4
Hearing	48.8	50.7	36.5	33.4	7.6	6.8	4.8	8.2	2.3	1.0
Speech	42.1	34.5	41.4	37.2	8.1	7.0	5.3	8.9	3.1	12.4
Visual	No data available									

Source: *Sarvekshana*, Vol. XVIII, No. 2, Oct.-Dec. 1994, Government of India.

Although the NSS results present only a sample data they are of a more in-depth nature than the Census results obtained for disability. However since both the Census and the NSS have only covered the physically handicapped, (though the 1991 NSS also tried to conduct the survey for mental disability for the age group 0-14 years) the data has not been able to provide an adequate baseline of disability in the country. Unfortunately due to the limited nature of the results they have not been used for any policy formulation for the disabled persons. The number of studies that have analyzed the data are also very few. However the results do indicate that disability is a complex social category rather than a medical condition. The hope is that the 2001 Census will provide the much needed baseline data about the disabled persons and the data will be used in subsequent policy formulations since the last decade has witnessed the passing of two Acts for the disabled, the 1995 Persons with Disabilities Act and the 1999 National Trust Act.

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[1] B. Harriss-White, 'On to a Loser: Disability in India', in *Illfare in India: Essays on India's Social Sector in Honour of S. Guhan*, New Delhi, Sage, 1999, p. 138.

STATE, SOCIETY AND DISABILITY IN INDIA

> *The state shall, within the limits of its economic capacity and development, make effective provisions for securing the right to work, to education, and to public assistance in cases of unemployment, old age, sickness, and disablement and in other cases of undeserving want*
>
> *(Article 41 of the Indian Constitution)*

> *Within five decades of the conception and inception of the welfare state in India, its boundaries have got blurred.*
>
> *- Ali Baquer*

After India achieved Independence in 1947, the new government of the country accepted, in good faith, the philosophy of a welfare state from the British and from the socialist strands within the national movement which was committed to reducing existing inequalities among the people. Conceptually, Indian planners recognized the need for tackling problems such as unemployment, malnutrition, and social inequalities, along with providing integrated health services to cover the entire population. In the field of health, an important feature of health policies, plans and programmes in India was that they originated during the national movement against colonial rule. The National Planning Committee of the Indian National Congress was set up in 1938. The Health Survey and Development Committee referred to as the Bhore Committee (1946) was greatly influenced by the aspirations of the national movement. Its recommendations are considered the blue print of the health policy and services in India. According to D. Banerji, in following the policy frame for health services, which had begun to take shape during the freedom movement, independent India embarked, step by step, on implementation of a comprehensive rural health service through Primary Health Centres and health planning as part of socio-economic planning.[1] Some of the medical professionals such as Dr. B. C. Roy, Dr. A. R. Ansari, and Hakim Ajmal Khan were inspired by the welfare state movement and socialized health services in the Soviet Union and they demanded a more egalitarian health service system and made this an important plank in the anti-colonial struggle. Thus even as early as the 1940s, India's leaders had envisaged a people-oriented health service. However, the government's commitment to the provision of basic health services to all, within not too long a period, necessitated a fundamental shift in the approach to these problems and concurrent radical changes in the approach to health service development which unfortunately never really took place. On the whole, the growth of the health care services in the country has been haphazard and unrelated to the needs of the poor and the rural people who stand most in need of health care.

The socio-economic development of the country is largely based on the five-year plans drawn up periodically. According to Banerji, the plans have been directed towards the broad objective of achieving a 'socialist pattern of society', the basic determinant being greater equalization of income and wealth and reduction of private profit.[2] It is in this context that we need to briefly examine the health services provided by the planners in the last five decades.

Health Services

After Independence major investments were made in education and health. Although health is a state subject according to the Indian Constitution, it is the central government that defines policies, provides financial resources and specified services for medical education. The structure of the health service system, as it developed, has been pyramidal, with the sub-centres at the bottom catering to a population of 5000 each, above it are the primary health centres with a population of 30,000, above them are the community health centres with a population of 100,000 and at the apex is the District hospital.

The major operations in the health sector planning were to build infrastructure, provide basic medical care, maternal and child health services, health information and education, referral services, to develop specific national health programmes, to control communicable diseases, provide family planning services and control severe forms of nutritional deficiencies. A support system for these tasks was also developed including education, training, research and drugs and equipment production.

One of the landmarks in the history of primary health care was the Alma Ata Declaration (1978), which presented a radical new strategy as part of the target of achieving Health for All. This strategy was a response to the growing recognition that the development policies of the 1950s-60s had failed to improve the condition of a vast majority of the world's population. The assumption that global economic growth would lead to the enriching of the poorest through a 'trickle down' effect was not happening. The concept of Primary Health Care (PHC) was different from the Basic Health Care as it attempted to operationalize the latter within a socio-economic, political and cultural context. Hence Primary Health Care emphasized accessibility, participation of the community, cost effectiveness, subordination of technology and overall social and economic development of the community. However within a year of signing the Alma Ata Declaration an alternative approach called Selective Primary Health Care (SPHC) gained prominence. The SPHC approach argued that PHC was not cost-effective and, in fact, it was too expensive. According to the proponents of the SPHC a more effective method was in the selection and prioritization of a limited number of diseases to be tackled emphasizing the use of technology. The acceptance of the SPHC by the World Bank was probably the first trace of health sector restructuring in developing countries.

Soon however the multifactorial approach to health got lost in the mechanical model. This also had its effect on the health service system. Among the poor and developing nations, India occupies the 'enviable' position of possessing a health service system, which has an extensive infrastructure; an army of trained personnel and well equipped institutions for research and education. According to Qadeer, an overview of the system however reveals that despite its professed commitment to serve all - specially the poor - it is riddled with unevenness and inequalities.[3] The inequalities are in terms of resource distribution, access, participation and health status. Apart from the inequalities, the health services system has certain distinct characteristics such as that it is based on the use of inappropriate technology, top heavy organization with a top-down approach of working, and a hierarchical structure that matches the social hierarchy of the larger society. Therefore the heavy bias in favour of curative services and the dependence on sophisticated centralized technology along with the thrust of the government to involve voluntary and private institutions in the name of 'self care' is an indication that "the welfare state that India was to be, became an unrealistic myth after the euphoria of the first two decades".[4]

Analyzing the shifts in the health programmes and the health services system what emerges is the highly unstable nature of the programmes and the inability of the health services system to handle the shifts because of the inherent problems in the service system right from its inception. A second problem is regarding the prioritization of the programmes. The programmes appear to be following the course of those issues or problems, which are getting funds from the donor agencies; these then are placed higher in priority in relation to other programmes. A third problem is the fact that the people's participation and needs are totally lost in the implementation of the programmes and in the service delivery mechanism. In fact such a situation has led to a retreat of the state from any responsibility for the health of its people. What is also striking is the fact that right through the initiation of health programmes and shifts in the programmes, disability is not factored in anywhere even though one of the aims of both health programmes, as well as health service systems, is to prevent illness and disability and provide rehabilitative services.

THE DISABLED IN INDIA

The Indian Constitution established that people with disabilities are entitled to the same social, economic and political rights and privileges as other citizens of India in the Fundamental Rights and Directive Principles of State Policy. Article

41 of the Constitution is the only article explicitly to mention disabled people but it appears under Part IV of the Constitution i.e. under the Directive Principles. Unlike Fundamental Rights these Principles are not directly enforceable through the law even though they are 'fundamental in the governance of the country' (Article 37) and it is the duty of the state to apply these principles in making laws. Article 41 reads: "the state shall, within limits of its economic capacity and development, make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement, and in other cases of undeserved want".[5] The mandate of the state under Article 41 envisages a comprehensive social security system, which would enable the lives of disabled people to be fulfilled. However, the Constitution did not make any specific legislative provisions about the rehabilitation and total integration of the disabled in society and there was no law to protect them from discrimination in their daily lives. Moreover the mere provision in the form of discretionary office memoranda does not guarantee entitlement. Unfortunately, according to the Supreme Court, 'it is not possible to compel the state through the judicial process to make provision by statutory enactment or executive fiat for assuring the basic essentials which go to make up a life of human dignity'.[6]

Most of the approaches adopted towards disability until 1947 were based on the concept of charity. During the first three five year plans (1955-69), the sole support to disabled people comprised grants-in-aid to NGOs and the establishment of national training institutes. It was in the first Five-Year Plan that an attempt was made to change the emphasis of programmes for the disabled from charity to rehabilitation. The second plan emphasized education and employment with schemes for scholarships and setting up of special employment exchanges for the disabled. In the third plan the state encouraged development of facilities for vocational training and expansion of employment opportunities for the disabled, and better coordination between public and private organizations. Upto the close of the fourth plan most of the programmes were curative or ameliorative in nature. From the fifth plan onwards emphasis has been on the promotion of preventive and developmental services. The later Five-Year Plans encouraged development of facilities for vocational training and job opportunities. The later plans showed how support for the disabled people declined in real terms as social development priorities, programmes and projects emerged. The main thrust of the welfare programmes for the disabled have focussed on prevention of disabilities and development of functional skills. Under the Seventh and Eighth Plans prevention was stressed upon. However the number of disabled persons benefiting from such initiatives remained negligible seen in the context of their total population.

According to Barbara Harriss-White, in India, plan allocations for the disabled population have been pitifully small, and have increasingly been subsumed under expenditures devoted to general anti-poverty measures.[7] The disabled have been systematically given the go-by. Reviewing the performance of Tamil Nadu with regard to social security, Guhan observes that: 'compared to other types of pensions, the coverage of PHP (Physically Handicapped Pension) is very unsatisfactory, especially since identification of the physically handicapped poses no serious problems'.[8] A significant part of Harriss-White's indictment of the Indian State is that there little in the way of constitutional provision to safeguard the special rights of the disabled, emanating from their special needs.

SCHEMES AND PROGRAMMES OF THE GOVERNMENT

The government has implemented certain schemes and programmes for the disabled, mostly as part of the health schemes. For instance under the Central Government Health Scheme (CGHS), expenses incurred on Intra Ocular Lens, Hearing Aids and Pacemakers and artificial appliances have become reimbursable.[9] There are other examples of the various government schemes and programmes which are concerned with disability. Central Government has, for example, taken certain steps to combat communicable, non-communicable and other major diseases, which cause disability not only to improve the health status but also to prevent and control disabilities. These come under the

National Health Programmes. The following are among the various programmes that have been undertaken: National Leprosy Eradication Programme; National Programme for Control of Blindness; National Iodine Deficiency Disorders Control Programme; National Mental Health Programme and National Filaria Control Programme.

Apart from the above listed health schemes addressing the disability issue, there have been schemes and programmes under different departments of the government. For instance there are the Family Welfare Schemes for maternal and child health which are concerned with disability some of the examples being the following:

- Universal Immunization Programme - includes immunization; surveillance of vaccine preventable diseases; impact on Infant Mortality Rate.
- Oral Rehydration Therapy (ORT) for Diarrhoea control among children under 5 years of age.
- Prophylaxis Schemes against anaemia among pregnant and lactating mothers and against blindness due to Vitamin A deficiency among children under the age of 5 years.
- Child Survival and Safe Motherhood Programme - this programme includes:

(a) Sustaining and strengthening the ongoing immunization, ORT, and Prophylaxis schemes.

(b) Improving maternal care at community level by providing training to the Traditional Birth Attendants and supplying disposable delivery kits to the pregnant women.

(c) Expanding in a phased manner the programme for control of Acute Respiratory Infections for children below 5 years of age.

(d) Setting up a network of sub-district level First Referral Units for improving emergency obstetric care in certain states of India.

However the various schemes have not been proposed just to prevent or provide intervention for disability; in fact the disability component seems incidental to the scheme. For instance the scheme for polio eradication is concerned only with providing the vaccine. The programme does not go into the means by which the causes for the occurrence of polio and its consequences can be addressed. That would include improvement of water and sanitation facilities, better health care facilities, better 'rehabilitation'; and training and aids facilities for those afflicted by polio. Further, most of the programmes seem to run on the agenda of the donor agencies rather than being based on the long term needs of the people requiring these programmes.

LEGISLATION

In the field of legislation pertaining to the disabled no clear perspective which can be attributed to a welfarist perspective can be discerned. For example the British had introduced the Lunacy Act in India in 1912, which dealt with two entirely different disabilities, namely mental illness and mental retardation within one Act. According to Baquer the objective of this Act was not to reform 'these' people but to protect society from 'such' people.[10] This Act prevailed for almost 65 years. And when there were pressures to change the outdated laws, the mentally retarded were simply left out of the Mental Health Act, which was passed in 1987. Similarly the Government of India had made a quota system for the disabled as early as 1971 for education and employment. At the same time the provisions of the Hindu Marriage Act of 1956 permitting mental illness or leprosy as sufficient grounds for obtaining divorce or separation, because both these disabling conditions were regarded as incurable, also stood. The only act appearing to accord the disabled person positive rights of entitlements is Section 28 of the Hindu Succession Act of 1956, which prevents disqualification from succession to property on the grounds of any disease, defect or deformity.[11] With the exception of this last Act, which indicates the importance of family property for the resource base of disabled people, the net effects of the acts was to limit the freedom accorded to disabled people. How were the disabled to be enabled and how were others in a relationship with the disabled to be provided 'relief' against certain forms of disabling conditions remained unresolved in the legislations relating to disability.

Responsibility for monitoring the implementation of limited government orders giving certain entitlements to disabled people is vested in officials monitoring the reservation laws for scheduled castes and tribes. An office memorandum of January 1986 urged such officers to renounce their prejudices against the physically disabled people.[12] Another in August 1987 deplores the lack of significant progress in implementation of reservations for the disabled, pleading for 'changes in attitude'.[13]

Efforts to have a law for the disabled have taken a long while to emerge and until recently there was no comprehensive law for persons with disabilities. According to Miles, 'To have a formulated disability policy is a recent notion'.[14] But the policy agenda is, and long has been, formed by forces other than that of the hegemonic policy discourse of international and national administrators: by the media, by professional and business centres, religious orders, academics, politicians and institutions of civil society.

The first attempt was the draft legislation known as Disabled Persons (Security and Rehabilitation) Bill, 1981.[15] The Bill was intended to provide security, employment, education, training and rehabilitation of the disabled persons. It recommended the establishment of the Central and State Councils to promote the welfare of the disabled. All institutions for the disabled were expected to obtain a license from the government. The person or persons in charge of the care of the disabled had to ensure the well being of the disabled person/s and to prevent physical pain, humiliation and mental suffering of the disabled in their care. Unfortunately the Bill was never enacted by Parliament.

In 1987 Rajiv Gandhi appointed a committee under the chairmanship of Baharul Islam to consider legislation for the handicapped, especially for their employment.[16] The committee made certain recommendations, such as, it made amendments to ensure equality of opportunity for the disabled citizens and that no one would be discriminated against on grounds of disability. It made it obligatory on the part of the Central, State and Local governments to provide facilities for prevention and early intervention. However, before the Baharul

Islam Committee's recommendations could be translated into law, the Congress government lost power in 1989 and the report never saw the light of day.

While at the national level attempts to provide for a comprehensive policy for the disabled had been aborted, there was a growing concern with the rights of the disabled at the international level. Movements for the disabled had resulted in legislative changes in many countries and had been incorporated into the United Nations Charter. Thus, by this time the UN agencies were demanding the implementation of Human Rights for people with disabilities. The passing of the 'Americans with Disabilities Act' and the emergence of a number of organizations in different countries to create awareness and popular support for the rights of the disabled together contributed towards creating a political and moral pressure for purposive action in India. Hence measures such as the Rehabilitation Council Bill 1990 intended to regulate the training of rehabilitation professionals and the maintenance of a Central Rehabilitation Register was made into an Act in 1993.

In India the welfare of the disabled is a state subject. The Economic and Social Commission for Asia and the Pacific (ESCAP) held its 40th Session in Beijing in 1992. In the course of the session ESCAP passed a resolution which proclaimed the period 1993-2002 as the Asia Pacific Decade of Disabled Persons. This resolution was passed with a view to give impetus to the implementation of World Programme of Action in the ESCAP Region beyond 1992. India was a signatory to the ESCAP Resolution. The Resolution laid emphasis on enactment of legislation aimed at equal opportunities for people with disabilities, protection of their rights, prohibition of abuse and neglect, and discrimination against them. This led the Indian Parliament to enact a comprehensive law for persons with disabilities. As a result the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 was passed and came into effect from 1996. The Act has 14 chapters and aims to:

- Spell out the state's responsibility towards prevention and early detection of disabilities.

- Ensure every child with a disability has access to education.
- Ensure there is a percentage of jobs to employ the disabled.
- Initiate schemes to provide aids and appliances to the disabled.
- Ensure the protection of the rights of the disabled through non-discrimination.

The latest legislation for the disabled passed in India pertains to the formation of a National Trust arising from the need for care of some categories of the disabled who require long-term care. This need has taken the form of the "National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities", Act (1999). The National Trust is a statutory body under the Ministry of Social Justice and Empowerment, Government of India. The Local Level Committee (LLC) is the instrumental organization to carry out the directions of the National Trust Act and is considered to be the unique character and substance of the Act. The scope of the LLC includes a range of activities from primary awareness creation, campaign on causes of disability, service needs and provisions, inclusive education, promotion of positive health, skill development, job training, rehabilitation services, marriage and social inclusion, rights awareness, family support, guardianship and any other issue or concern which helps to translate the objectives of the National Trust into action at the Local Level. The basic aims and objectives of the National Trust are:

- To enable and empower persons with disabilities to live as independently and fully as possible within and as close to the community to which they belong.
- To strengthen facilities to provide support to persons with disability to live within their own families.
- To extend support to registered organizations to provide need-based services during period of crisis in the family of persons with disability.
- To deal with problems of persons with disability who do not have family support.

- To promote measures for the care and protection of persons with disability in the event of death of their parent or guardian.
- To evolve procedures for the appointment of guardians and trustees for persons with disability requiring such protection.
- To facilitate the realization of equal opportunities, protection of rights and full participation of persons with disability.
- To do any other act which is incidental to the aforesaid objects.
- The two main schemes under the Trust are: establishment of Relief Institutions for providing institutional care and training of cares givers.

An assessment of the recent Acts of the Government concerning the welfare of the disabled persons in India suggests that many people, professionals as well as some of the disabled persons who are aware of the Act, have welcomed the passing of the two Acts summarized above. However there are certain issues that require considered attention. Regarding the Persons with Disabilities (PWD) Act, 1995, it is widely felt that it is the implementation of the Act which is crucial more than having an Act which could end up being confined just to paper. According to Anuradha Naidu, CAPART, the Act talks of inclusion at various levels and it is those provisions that would have to be worked on. Similarly, Poonam Natarajan, Director, Vidyasagar, points out that the main features missing in the Act are precisely the clauses for implementation; further the Act makes no mention of the allocation of resources to be used for achieving the clauses of the Act. On a more hopeful note Rama Chari, NCPEDP, argues that although the big challenge is the implementation of the Act, the Act itself is a landmark for the disability movement for it brings to the fore the importance of the rights of the disabled.

ENTRY OF NGO/VOLUNTARY SECTOR

The evolution of specialized state services for disabled people have not served the various classes of disability without bias. Till January 1989, the National Institute of Mental Health funded 450 institutions providing services to 18,000 mentally retarded people out of an estimated maximum of 4 million eligible; 30,000 mentally disabled children (under 1% of the 'eligible') are catered to in some way by this system. On an aggregate, 0.6% of disabled children, less than 3% of the total of physically disabled and under 1% of the total mentally disabled are estimated to have access to rehabilitation services of the state or of voluntary agencies. The National Sample survey reported that over half the disabled people they identified had never seen a qualified physician for any purpose.[17]

Given the dismal response of the Indian state regarding the welfare provisions and services for the disabled the desperate families of the disabled were led to seeking other means of dealing with the situation. Hence a number of parents set up organizations depending primarily on the needs of their child. These organizations were different from those run on the idea of charity. The parents started more specialized units such as a school for spastic children with high cognitive ability, a school for spastic children with varied mental abilities, and a school for autistic children. Some parents who had the idea of starting an organization to provide better services but did not have the requisite resources to do so formed parents associations, which then set up an organization to cater to adolescent and adult mentally handicapped persons. Hence in the absence of any state support many organizations have come up with newer methods of handling the disability issue in order to provide a more meaningful life to the disabled than the charity oriented organizations of the past.

The setting up of organizations marking the entry of the parents into the NGO sector reiterates the fact that in the eyes of the government and society the care of the disabled is primarily the responsibility of the family. The other striking aspect of the NGO sector is the gendered nature of the professionals initiating and sustaining the requisite services for the disabled: it is either the mothers of the disabled person, young girls or older women in their mid-40s who have emerged as professionals in the field of disability. They are the main force involved in the running of any organization (See Chapter One and Five). Although many of the organizations are well run, and even sensitively run, none of the organizations have formed themselves into a pressure group or lobbied for the rights of the disabled as citizens. Most of the NGOs, barring a few, do not consider the role of the state as important in providing for the disabled. Also the level of intervention that these organizations provide in terms of not just identification, intervention, and training for the disabled person, but they are a very strong emotional crutch for the parents. As a result, parents do not see the state as having a role to play, or as abdicating its responsibility to the disabled as citizens with entitlements, because they have never seen the state in operation in the field of disability. Thus while the quality of service that an NGO provides cannot be ignored, the NGO model cannot be replicated to a larger area of operation because of the lack of funds and limits to its reach. As Harriss-White succinctly puts it, despite the wide scope of the NGOs, as the second alternative to the state in terms of institutional responses, they suffer like markets from certain debilities.[18] First, they have relatively small and insecure funding. Second, their provision is unsystematic and discretionary. Third, they are minimally regulated; redress by disabled people for incompetence is practically impossible to obtain. Neither the market nor NGOs allow universal claims based upon social welfare rights. Thus the state, however imperfect, is the only institution capable of creating and implementing such rights, and capable of acknowledging a general obligation.

REHABILITATION AND CARE OF THE DISABLED

In the past couple of decades in most countries of the world there has been a growing realization that institutional care for the disabled is not entirely suitable for their individual needs, independence and dignity. The institutional model is therefore now being replaced by a relentless advocacy for community care. However the call for community care is not only based on humanitarian considerations but also because the western model of institutional care has been found to be too expensive to run in poorer countries like India. Hence it was the economic considerations that guided both the emergence and decline of institutional care and provides the rationale now for community care which is being persuasively offered as an alternative to institutional care.

One of the major programmes of community care was launched by the UNDP called the Community Based Rehabilitation (CBR). Einar Helander, who proposed the concept of the CBR, argues that the CBR calls for flexibility on account of social, economic and cultural situations, the circumstances of the disabled and existing services in individual countries, priorities and policies. CBR is defined as "a strategy for enhancing the quality of life for the disabled people, by providing more equitable opportunities and by promoting and protecting their human rights".[19] The pre-requisites for CBR to become a reality have been described as "full and coordinated involvement of all levels of society" and "integration of the interventions of all relevant sectors - education, health, legislative, social and vocational - and aims at full representation and empowerment of disabled people".[20] According to Baquer such an approach favours reducing the role of statutory services as providers, without going into the causes of their failure.[21] Such a model demands little or no growth in public expenditure on services for the disabled and at the same time uses a language of human dignity, participation, involvement, self-help and family support. This approach promises to shift emphasis from 'every thing for a few' to 'something for everyone' in terms of being cost effective and comprehensive in coverage, without demanding further commitment of resources from the government; it also does not provide any clarifications about the nature or quality of care.

The WHO spearheaded the CBR in India and made it popular idea after its successful foray into Primary Health Care. CBR is one of the major forms of non-institutional rehabilitation service delivery methods. According to Maya and M. J. Thomas, however, today CBR has moved away from being merely a delivery of service to a method of community development.[22] It aims to promote 'community participation' and ownership in programmes, with the active involvement of the disabled persons and their families in all issues of concern to them instead of they being passive recipients. The CBR programme was primarily meant to be a service vehicle for poorly developed countries, with sparse service delivery systems in most of the regions. Significantly, family members of the disabled themselves generally delivered it through home based interventions and community volunteers using simplified training packages. The original ideology of the CBR was to provide adequate coverage of rehabilitation services to a population with no services, at an affordable cost, in a participatory model, within the given unique circumstances of culture and tradition. However, according to Thomas, the initial surge of donor funds for CBR initiated a set of projects that could not be replicated due to the indifferent attitudes towards documentation and monitoring.[23] Its impact was limited due to a lack of emphasis on results, replication and cost-efficiency, all factors important for sustainability. Further, according to Thomas, in the case of CBR, sustainability does not seem to be a major issue because donors are usually more concerned with the visibility of starting the project in an underdeveloped country rather than seeing them through.[24] Additionally, South Asian governments do not view disability as a priority. With the growing political confusion in many of these countries, and in the absence of collective bargaining power of the disabled people, it is unlikely that the subject of disability will be accorded priority. Governments are not willing to spend large amounts of money on CBR unless they are convinced about its impact.

Yet there are variations in the kinds of CBR programmes in existence. According to M. J. Thomas for instance there are home based services provided by families for their disabled relatives; self-help projects run by the disabled persons themselves; out-reach projects run by a rehabilitation institution; and NGO projects run by paid CBR workers. CBR also functions as an ideology, which promotes inclusion of disabled persons in developmental projects or in institutional programmes located in a village.[25]

CONTEMPORARY INDIAN SCENARIO

Given the above background and the fact that not much documentation is available regarding the disabled in terms of the presence of a disability movement, the role of the professionals, parents and the disabled themselves, a critical evaluation of policies and legislation for the disabled is yet to be undertaken. Hence an attempt is being made here to understand the disability issue in India through discussions with professionals, the disabled persons and parents who are also professionals. Interviews were conducted with six persons working in or involved with the disability sector.* Some of the themes that emerged from the interviews on a wide range of topics pertaining to disability in India are grouped together under a number of different heads in the section below:

Disability awareness - According to Renu Singh, the awareness about disability is more noticeable nowadays because of the media although even today the real issue of disability continues to remain within the families, which are affected. The awareness is yet to reach the wider community level. In her view the larger society is not sufficiently sensitized. She regards the PWD Act as having a major role in terms of carrying forward this awareness to the community since there is legislation at least today which will generate its own discussion. And since it is the role of the NGOs to ensure its implementation there will be an increased awareness as the implementation is carried through.

According to Javed Abidi, there is a very definite trend that can be traced with regard to the increased awareness about disability today. The issue-based coverage around disability was never present earlier. All that existed in the past was that there would be the odd event, which might be reported in the newspapers like some minister inaugurating a school, or a home, for the disabled. This trend continued till 1994. From 1994 onwards the Media was contacted to provide more serious coverage because they were not doing much to focus on the disabled. But sadly, the issue of disability still doesn't get as much attention as women's issues or the environment, or even AIDS in Abidi's

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* Renu Singh, Spastics Society of Northern India (SSNI), Delhi, (Professional & Director). Javed Abidi, National Centre for the Promotion of Employment of Disabled Persons (NCPEDP), Delhi, (Director & Disabled Activist). Rama Chari, NCPEDP, Delhi. Anuradha Naidu, Council for Advancement of People's Action and Rural Technology (CAPART), Delhi, (Professional & Head of the Disability Unit). Anita Ghai, Delhi University, Delhi (Developmental Psychologist & Disabled Activist). Poonam Natarajan, Vidyasagar, Chennai (Parent, Professional & Director).

view. On a scale of 1 to 10 he would rate the coverage of the disability issue at 7.5 but only in the English media. In terms of increasing the general awareness in the community Anuradha Naidu considers that an important factor is the development of certain activities symbolic in nature, which is unifying for the disabled as well as works to convey a message to the masses. Such an example is provided by occasions like celebrating the World Disability Day or observing the Year of the Disabled and so on.

In contrast to the views cited above, and perhaps because Poonam Natarajan was a parent of a disabled child apart from being a professional in the field; she looked at the question of 'awareness' more in terms of medical awareness. In her view the doctors today are much more informed about disability than they were two decades ago. Consequently, they have found that the number of referrals has increased dramatically over the last decade.

Disability movement: There is a unanimous feeling amongst the various categories of professionals and disabled activists that India never really had a disability movement per se. But there are others who qualify this viewpoint. According to Rama Chari, NCPEDP, the disability movement has not been totally non-existent. For instance the blind were a very strong lobby but only for themselves. The 1990s have seen a cross-disability movement emerging.

Defining her understanding of a movement Renu Singh, SSNI, stated that a movement should be a "unified thing" and she strongly believes that a disability movement should be headed by persons with disability. The movement has to start from the grassroots level. It has to start with empowerment of persons with disability. Commenting on how the NGOs can be of assistance to the advancement of the movement, she says that NGOs are not only into "awareness raising" but primarily into service delivery because one has to look at interventions for the disabled first and awareness raising follows thereafter-- it is a by-product of the delivery. Ultimately it is when services get opened up that all existing barriers such as barriers to services, to information begin to break down. We have to "open society up", for example through mainstreaming, for sensitization to actually begin. In her view there is also a need to move more towards inclusion and to stop building special schools.

According to Anuradha Naidu, CAPART, a Disability movement is a question of whether persons with disability have say in decisions about themselves or not. This does not mean that institutions for the disabled have no role to play in the disability movement. There are a lot of institutions which have and will be providing services but it doesn't mean that they are not part of the movement because they are now taking on a second way of looking at things - they are beginning to see the disabled person as a citizen and trying to build the required needs and programmes to see how they can adapt to keeping in mind this shift of perspective. For instance the SSNI and Vidyasagar in Chennai have started the CBR model, and Prajna, an organization which is seeing the need for persons with disability to be organized, is developing on that theme. So such organizations do have a role in the disability movement and see themselves as allies even though they may not be directly involved in the movement.

However, according to Anuradha Naidu, one can't really talk of a disability 'movement' as such because a large number of persons have not left their homes, have not had access to facilities and haven't entered into the 'public space'. At most they have come to the institution for some kind of training because their family has brought them to it; this is true especially in the case of the multiple handicap person. Therefore families and professionals who are like minded have a role to play in the disability movement in her view. For instance, persons with disabilities may not be able to advocate rights for themselves so how would their issues be raised if not by the families and other professionals working with them, she queries.

According to Javed Abidi, NCPEDP & Disabled Activist, a Disability movement is happening now, taking 1994 as the starting point. There was no disability movement before 1994. There was only the movement of the blind among the disabled prior to 1994. He considers 1994 as the origin of the disability movement in the true sense because there is now a cross disability focus. According to Abidi a basic criterion of a movement is sustainability. He feels that progress is being made and things are being achieved though the movement is only at a nascent stage.

Regarding the role of the non-disabled in the disability movement everyone is of the view that in every sense it should be the disabled who should be in the lead. And it wouldn't qualify as a disability movement if the disabled were not leading it. According to Abidi, this is where the philosophy of the Disabled Persons International's slogan comes in which says "nothing about us, without us" i.e. decisions cannot be taken about us (the disabled) without our participation or consideration. However no movement is complete unless it reaches out to others. So no disability movement would be complete if it did not have the parents, the professionals and just about anybody else. It cannot be just restricted to the disabled: according to Abidi, "a microscopic view that has been prevalent in India is that it is our little island - consisting of the disabled, their parents and the professionals. But what about the others such as the architects, doctors, designers, and the media?" he questions. Summing up the nature or character of a disability movement in the true sense of the term, he says, "the disability movement has to be based on cross-disability, sustainability and have a national character to it".

According to Anita Ghai, an academic who writes about disability and is a Disabled Activist, there has not been a disability movement in India. At times there has been an upsurge of activity and one sees a certain collectivity. But if that is to be compared with other movements, "the way one defines movements - a people's movement at least," she doesn't think the disability movement can be classified as such. There are many reasons for this situation. Basically, for the disability issue to come to the fore there is a need for a collectivity to emerge, and to show itself spaces need to open up for the disabled to be able to use them. And spatially she doesn't think the disabled have had accessibility. So in the name of a disability movement if a conference, to which only 100-150 people manage to come because they have access to some kind of private transport- whom she'd call the elite disabled, or who can travel by air, etc., then this is not enough. So many of the disabled are left out because they do not have the same means of even reaching the conference: how then could such a conference be regarded as part of a movement? Thoughtfully she states, "I'm not very sure in my mind whether I can say that there is a disability movement today-- but there is a disability consciousness emerging strongly".

Anita Ghai also dwelt on the formation of the Disability Rights Group (DRG). She said that if one were to sketch the DRG historically, one finds that there are different people in it at different times. While this would lead to a lack of continuity the turnover can be looked at positively too. But her own experience with the DRG is that it is 'male centric, and person centric and urban based'. Elaborating on what would be more justifiably regarded as a movement, Ghai argues that a movement would be one where a majority of the disabled can at least find a voice, and be a way of bringing their concerns to the fore. However "the utopia that is created is scary (of menu's in five star hotels in Braille, of lifts into aircraft, and so on), and it is that utopia that individually we are fighting for. In reality however we are not fighting - there is no fight really going on. A fight has to be a concerted effort, a continuous effort, and it has to be for everyone. It has to be to get the bare minimum for everyone". She considers that the participation of various categories of persons in the disability movement would depend on which vantage point one is talking from. For instance if one needs the basics then one will go along with anything that is happening. She feels that "Professionals are, beyond a point, not very bothered about the movement or anything. On the other hand parents groups are genuinely concerned".

In terms of the relationship between one set of discriminations and another, those working in the field of disability, or experiencing discrimination stemming from their own disability or of those close to them, often compare the disability movement with the women's movement in terms of conceptualizing discrimination and strategies adopted for initiating change in policies. At another level the expectation that existing movements for change, and against inequalities and discrimination would actively incorporate disability into their agendas has been belied. Parents of the disabled, or the disabled themselves who have participated in movements can suddenly find themselves, and the issues they seek to highlight, abandoned by the movements they had been part of. According to Poonam Natarajan, politically the issue of the disabled has not been taken up by any other movement. The Left does not think that the disabled can be part of a movement like the women's movement in her understanding; this was explicitly stated to her by a leading woman activist of an established left party. A deep sense of betrayal is often experienced and is dealt with at greater length in Chapter Five. Ultimately then it is the disabled, and those connected with the disabled, who are left to struggle by themselves.

Rights of the disabled - according to Rama Chari, the awareness about the rights of the disabled has been emerging more in the last one decade with the disabled people themselves coming to the fore and talking about their rights. Earlier the disabled were hardly seen. Even at the governmental level there was the Ministry of Welfare which was giving welfare measures to the disabled people. There were special schools set up, and the NGO sector came into operation mainly with the idea of charity such as distributing wheelchairs. Some provided special education, or therapy, or vocational training. Finally some disabled people felt that there should be some attempts at working in the area of rights.

According to Renu Singh, one thinks of different disabilities, different categories but often forgetting the issue is that of their rights. No matter what their disability is and where they are placed, equality and opportunity is important and has to cut across all boundaries.

Javed Abidi describes how the question of rights of the disabled came up as an issue in India. It was in 1994 that some people in the disability sector were upset with what was going on, or rather not happening, that led to the formation of the Disability Rights Group (DRG). It was the first time that an advocacy group was formed and a cross disability perspective was taken. Thus began the fight and demand for the rights of the disabled. The DRG did work in a systematic way. Since the DRG was not politically affiliated to any party the group members met with the ministers of the Congress and the BJP regarding the rights and policies for the disabled.

According to Anita Ghai, from her personal experience she has picked up the position that the 'personal is political'. But she is strongly of the opinion that one should work for that particular cause which is going to benefit the maximum number of people. She feels that the vision in the disability sector in India is lacking. She attributes it to the fact that is there isn't much understanding of disability as a concept. The demands are just in terms of 'concessions' even if it is couched in terms of rights.

Role of the state

According to Rama Chari, the year 1981, the International Year for Disabled Persons, was not the beginning of the movement. In 1981 there was pressure on the government because of the UN declaring it the International Year for Disabled Persons and therefore some schemes were started, and the NSS and Census were also conducted. According to Chari, the government can do a lot because it has the largest resources, and the largest reach, and NGOs are really just small islands both in terms of reach and resources. She believes that the government has a lot of money that is unutilized or misused. She also feels that the NGOs at best can work as pressure groups on the government rather than provide the entire range of services.

According to Renu Singh, the major problem is that there are different ministries involved while dealing with the various issues such as education, health or employment for the disabled. However none of the ministries are looking at disability. Thus there is policy fragmentation and this is the first barrier operating in the field of disability; further by "adopting the segregation model we are still following the charity model", she believes because disability has not been integrated as a part of overall policy formulation.

While focussing on the funding aspect of the state, Anuradha Naidu argued that the ministry is distributing funds but much of the money is being used for setting up centre based services. Commenting on the argument often given by both the government and non-government organizations regarding the lack of funds, she held the view that there are government funds and money for work in the area of disability except that it is going into a model that is not going to be cost effective in the long run.

According to Javed Abidi, India is very much a welfare state since India says it more categorically than the US or the European countries. India has a "huge number of welfare schemes". According to Abidi what is unfortunate is that disability doesn't find a place in that welfare frame. In 1995 the resource allocation for the disabled at the central level was 47 crores rupees. Presuming that at that time the number of disabled was about 5 crores, the stated amount works out to Rs. 9 per disabled person per annum. Abidi questions angrily why is it that the resources allocation for the disabled was so low and was never questioned by those in the disability sector. An argument often given is this is so because India is a poor country, but thankfully it is not an answer that is given now. Abidi's explanation for the poor resource allocation for the disabled was that when a minister goes on tour of some place he announces many packages for the people as a political and vote seeking gimmick. Fed up with this game he began to question the ministers by asking them that if there was money for everyone how come there is none for the disabled. The budget of the welfare wing in the early 1990s was about 1000 crores rupees out of which the bulk was distributed between the SC/ST and Minorities and the leftover of 47 crores was given to the disability sector. Abidi says that the answer to his question about why is there no money for the disabled is 'hidden' in the allotment itself-- because the others are a vote bank whereas the disabled are not. Since the disabled have never united and fought this injustice Abidi argues that there is no point in placing the entire blame on others for the low priority being accorded to the disabled. Arguing with the ministers has had some effect and this year the resource allocation for the disabled is somewhere near about 1000 crores.

Poonam Natarajan personally believes that the government wants to come and talk to those who are involved in the field of disability. According to her people should be willing to do consultancy for the government because it is these people who are working in the field and getting all that 'rich experience' while the policy makers are just bureaucrats. According to her it is very different working with the government today than it was earlier. Today people's field experience does influence bureaucrats and 'they listen to you', she says. They also genuinely want to know what the field situation is because they realize that they don't know what is happening on the ground. For instance if you tell them that the wheelchairs don't work, or that what the government is making in a certain factory is not working, they close down the production in that factory and go on to planning to make something better. But this is not to state that governments are "not dumping everything on the NGOs ", which they are.

According to Anita Ghai, "What people do not realize is that the state in its attempt to promote the NGOs is actually giving up its responsibility". The issue of rights is emerging but she questions, "for how many?" Rights are not emerging for everybody. According to Ghai there is an issue-based mode of fight. An example is the hunger strike to be counted in the census, or demanding air travel concession or income tax reduction or exemption. She considers this to be a 'concessional' approach and not a question of rights. According to Ghai the welfarist agendas are not looked into because they do not serve the purpose of those claiming to fight for the rights of the disabled. On the other hand there are some of the disabled who are allowing themselves to be co-opted by the government; in any case why should the disability movement be perceived as one wherein all those within the disabled community will automatically have good intentions. It is a field like many others where there will be a range of the kinds of people who are involved.

Legislation and Social Policies - According to Rama Chari, groups started forming regarding the rights and policies for the disabled and created a pressure for legislating the rights of the disabled. The Disability Rights Group (DRG) was one such group. The disability movement initiated by this group led to the fight of getting the 1995 Persons with Disabilities (PWD) Act passed. It was a landmark for the disabled people. But according to Chari the much bigger challenge that still lies ahead is its implementation, as pointed out before.

Renu Singh, was sceptical of surface changes; as she put it the government may change the name of the ministry but that does not really mean a change in the ideology under which it operates, which is still very much grounded in the medical model. If one sees disability in the context of the social model then one has to bring a change in society and the environment.

In the context of the Acts Anuradha Naidu's view is that financial allocations have not been made in the PWD Act and she too believes that the Acts are difficult to implement. Another difficulty is that now that the Act is in place the trouble is "that things do not naturally fall in place"; for instance getting a disability certificate should be given in the routine course of matters, but there is no psychologist appointed to sign the certificate. So then the fight now moves on to demanding the appointment of a psychologist. The positive side of the Act is that it talks of inclusion at various levels and if those could be put in place it would certainly be a step ahead. Naidu personally feels that the Act has made a difference - it is like a watershed point - now the state has the responsibility and needs to look at people with disability as citizens and work towards inclusion. The problems now are at the administrative level, as things do not flow as a natural consequence of the law coming into existence; one has to fight for the implementation of every little step in the long road to entitlement.

Ghai struck a less positive note on the Act. According to her, an Act can only become meaningful if there are possibilities of enactment. Resource crunch is the reason given for non-implementation but there could be other reasons as well for the lack of will in implementing the Act.

Tracking the development of the 1995 Act Javed Abidi considers 1994 as the cut-off point because it was at that time that the discussion about the disability Act was picking up. In 1993 the government had organized a national seminar about disability in general-- not particularly to formulate a law. But people at the seminar said that if the government is actually serious about doing something for the disabled then it should implement the recommendations of the Baharul Islam Committee i.e. bring about a comprehensive law and not do something in a piecemeal manner. And that is how the 1995 Act originated. However regarding the evaluation of the various laws, Abidi states that there are problems. And as time passes a law fades and needs amendments. For a law comes into existence at a particular moment in time and when that moment passes changes need to be made and so is the case with these laws.

Evaluating some of the new policies Poonam Natarajan pointed out that the DPEP has a component catering to children with special needs. However her organization studied what the DPEP schools were doing it was found that the programme was very ineffective. Similarly evaluating the ICDS and the Anganwadi project it was found that the worker should have been trained in handling all children, including disabled children, to make the programme a more comprehensive and purposeful venture. But instead the Anganwadi workers refer the disabled child to the PHC and nothing more is done to include the disabled child in the programme. Natarajan and a few others have therefore been lobbying with the government on the point that since the Anganwadi worker is meant for all children of a particular locality then why should the disabled children be excluded from her purview. (Anganwadi workers are generally women).

Another fact that Natarajan points to is that the Government and Municipal schools are supposed to take in children with disability. So while on paper they are to include the disabled, in practice the response is that the disabled children are sent to the hospital. On the question of resources Natarajan pointed out that of the education programmes, the 'Sarvashiksha Abhiyan' has allotted Rs. 1200 per annum per disabled child. According to

Natarajan this is enough money for any aid or appliance a disabled child needs but the common complaint one continues to encounter is that there is no money; in most cases the money is not the real problem, the issue is actually planning a cost effective and purposeful utilization of funds. Natarajan cited the well-meaning example of the collector of Nilgiris who is regarded as one of the most dynamic collectors in the country. With the money from the National Trust, she is setting up homes for special children from the ages of 6 to 16 years. The claim being made is that this measure will help to provide training to the children and that once the training is over they will go back to the family. The question Natarajan raises is why have homes for training? History reveals that the emphasis of many people in the disability sector the world over, and in India too, has been to work against setting up residential institutions or homes within which the disabled are confined and training is imparted to them away from their families and society. Further Natarajan points out that even if the reasoning regarding training the children to be independent adults is accepted sending the children back to the family later is going to be very difficult; they would have become adolescents by the time they finish their training and social adjustment at a later stage becomes much tougher. Hence Natarajan feels that with this kind of 'mindless' planning going on we may come back a full circle and probably to a worse scenario considering the amount of time one would have lost in the process. Although the National Trust Act does fund homes, Natarajan thinks that the collectors are not the ones who should set them up. The parents of the disabled and the disabled themselves should decide upon a measure such as this.

Natarajan points out that the main problem with the National Trust Act is that its schemes are not going to work. For instance the National Trust gives money to train caregivers. But after the training the parents are supposed to pay about Rs. 1000 per month to the caregivers. The pertinent question to be answered is how many can actually afford to give 1000 rupees every month? Hence instead of subsidizing the salary of the caregivers too, the Trust is only restricted to giving money for the training of the caregivers. A further problem with the National Trust Act is that it is a 'guardianship' Act. Therefore if there is a case of a CP person who needs support but not guardianship then there are no schemes for that kind of specific situation wherein support will be provided without taking over the autonomy of the person.

With respect to the PWD Act, Natarajan said that her institution, among others, had in fact lobbied against it because it did not have any time frame for enactment and there were no financial allocations in the Act. Their position was seen as inimical to the disabled and they were told by the DRG not to oppose the Act. Finally the Act was passed "just to show the world that even India has an Act for the disabled".

Earlier the state only used to give grants and aids. But now there are different ministries under which disability is entrusted. However the government still only wants to fund centre based activities. There is a demand to have disability under one ministry. Additionally there is a demand that every ministry should have a disability component. There also seems to be major confusion operating in the minds of policy makers, for on one hand there is talk about inclusion and on the other the RCI is saying that all persons working with disabled persons must be licensed. This leads one to the question of how is the normal school teacher going to get the license without qualifying the training criteria of the RCI.

Rehabilitation Models-- Sketching out the course of how the SSNI shifted from a centre based model to a CBR model, Renu Singh said that the SSNI started with only CP children. But in retrospect, today, they realize that they need to move away from this institution-based model to a community based model. However unknowingly in the rural programmes, right from day one, even 20 years back they were looking at all children with disability within the framework of the community because they realized that they had to work with everybody. They found that they could not restrict their work with just one category of people. What they had not realized was that the same framework could be applied in the urban set up too. But today in the city they are trying to move towards incorporating the disabled into the community, calling it integrated services. The aim is to work towards 'convergence' with the existing structures instead of building new structures, which are segregated. Therefore, they have plans to tie up with a NGO working in the area of development in an urban slum area. The SSNI proposes that no segregation is required and they will offer technical expertise to the NGO thereby cutting across all disabilities automatically. According to Singh it is with this kind of thinking that they've grown in their own perception and find that this approach is more holistic.

The majority of the organizations catering to the disabled persons today are institution based, especially the new institutions that are coming up. The issue is how many mainstream schools are willing to take the disabled into their programme? According to Singh, even the DPEP, Anganwadi and Balwadi projects are really not opening up to include the disabled children. Singh argues that what needs to be carefully examined is what services the programmes are providing to all children, including the child with disability. If public services are not catering to the disabled then the situation will inevitably lead to special schools coming up, since that is the only alternative. Even mainstream schools, which are opening up a section for the disabled, are building up only in terms of resource centres in which there will be special educators. Further the inclusion of the disabled is only in certain activities of the school. But there is no social inclusion at all. Therefore the talk of inclusion by such schools is a just a myth.

According to Singh what is needed is a support system for the disabled. For this the NGOs, professionals and the disabled, all will have to collaborate. Instead of giving a one to one instruction the need is to give training to the mainstream teachers.

Regarding the kind of rehabilitation model that should be followed, Singh feels that in a country like ours we need to learn from the west i.e. deconstructing the special schools and services they have created. And one needs to work towards convergence. Reflecting on the ultimate aim of any service, Singh cites the following example: some of CP persons who pass out with 90% marks from SSNI call themselves 'special school survivors'. This perception exists even after 25 years of providing special services, regarded as excellent service and considered one of the best offered in the country. Singh says "the experience has made us rethink our strategies; ultimately at the heart of all this is the person with disability. If that person after all this input is unable to find a place in society, we need to take a relook at our strategies and think about how do we work through the community. Especially in a country like ours, where there is shortage of resources, working towards inclusion should begin from day one and bring about a change in the general quality of services by catering to the disabled."

Regarding the need for institutions for the severely disabled, Singh feels that there would always be a category, which would require institutions to take care of them, but they are hoping that schools would start including such cases. Singh argues that if one talks of Education for All, 'Sarvashiksha Abhiyan', then it should be for all children, disabled and non-disabled, instead of specialized services outside the existing structures. This requires one to look at policy, which should discourage the setting up of special institutions. And although it is believed that there will always be people who would need only vocational training or sheltered workshops, Singh questions why can't the corporate sector take on persons with disabilities? "After all even they have a social obligation," she says forcefully. Emphasizing once again the need for inclusion Singh states that one needs to examine the existing structures and see how one can work towards convergence. But till the structures open up there is bound to be a reliance on institution-based services.

On the same subject of working with the community Poonam Natarajan say that one of Vidyasagar's methods is to set up networks with different NGOs working in different regions. Thus when a particular NGO requests their help in the area of disability they help them in the planning. In this way according to Natarajan, "we don't have to go and create the need". Most of the work is top-down in these NGOs. Also many of the NGOs have varied concerns and are not working specifically in the area of disability. Therefore, to whatever is the NGO's agenda disability is also included as one of the components. Setting up

Self-Help Groups is one of the main activities that many of the NGOs take up. Each self-help group defines its own concerns. The idea of self-help groups came about because in the west the rehabilitation professionals had completely taken over the lives of the disabled persons. This made them mere passive patients who could neither do anything nor think for, and by themselves. Thus, as a mark of protest and to emphasize the need for independence in decision making, the disabled led the move to the formation of self-help groups.

Commenting on the concept of CBR, Anita Ghai raised certain crucial questions: "The community in India is not so simple to understand. And there is really not community participation. There are no such homogeneous communities". The major problem with the programme is that it is top-down in approach not bottom-up. For instance when you talk of education it is couched in terms of special education - why? It is true that some of the disabled will require special aids. Employment comes when there are basic skills. If no attention is paid to that, and only employment by itself is emphasized, then one will again remain in the charity mode. One needs to develop capabilities. Inclusion does not mean that you throw someone into the water without a tyre. Inclusion means that you will provide the tyre (assistance) that is required.

According to Javed Abidi, the 'Mafia' of the disability sector are the people in the service delivery sector. They should also take up advocacy--issue-based advocacy and generic advocacy. One should be acutely aware of all issues that concern the sector. Unfortunately there are lots of issues and one can't be working on all of them, simultaneously, all the time. Therefore according to Abidi, "you have to play the role of a juggler and have to constantly be bouncing balls. I believe I should do this because I have one life and limited time". But on the contrary it could also be argued, according to Abidi, that it is equally meritorious to work in one area such as education and dedicate one's life to nothing but education. Abidi clarifies "I'm not anti service delivery, it is required. But there has to be a balance between delivery and advocacy" and he seems to be focussed on the latter.

On the other hand the concerns raised by Javed Abidi relate more to how he would launch the crusade towards building a disability movement. Abidi is a strong advocate of the use of the media to bring out the issues of the disabled. However his use of the media has not been welcomed by many of his 'fraternity'. This he counters by stating, " I come on the media as a social activist for a cause. And the cause is not just my personal matter but for all my fellow disabled brothers and sisters. People don't understand the difference between publicity and public relations".

Abidi was one of the founders of the Disability Rights Group. They are building up a lobby where there is a distinct kind of division taking place between the service delivery and what he calls "our kind of people". He concedes however that such a distinction would be fuzzy for some years because, at present, there are no hardcore advocacy groups on the scene.

Further Abidi states, "for myself I've decided to take up various issues from time to time, juggle them and make some progress every where. Then leave it to the others to pick it up and move forward. For example access is not just an urban issue. It has to start from somewhere and so why can't others simultaneously take it up in other regions rural or urban". Such a position he states "is a bit of a chicken and egg question because there are comments such as what's the point of a ramp in the village post office or panchayat ghar if there are no wheelchairs".

Regarding the paucity of work in the disability sector in India, Abidi says, "Our leadership/Mafia has been so inward looking and lethargic that 55 years have been wasted. If the disabled in the rural areas don't have wheelchairs then what do you want to work on first, getting the ramp, or the wheelchair or both? It is a puzzle and one has to work at it constantly. And juggle as many pieces as possible so that you can achieve as much as you can in a shorter period of time".

Commenting on the difficulties encountered vis-à-vis organizing the disability movement from 1994 onwards Abidi said that initially his slogan was "unite the sector" and the effort was to unite and bring everyone together. But he found that it was not working. Around the year 2000 he decided to divide the sector into two - one being the service delivery minded ones and the other who he called "people like us" or those who lobbied for rights. Abidi then decided to build up the movement from there and he finds that it is working well this way. His other criticism of institutions working in the area of disability is that barely 10 of the many institutions in Delhi are involved in the movement. He however says that he does not care about their non-involvement because the movement has not suffered due to their non-participation; "have the disabled not been counted in the census?" he queries citing the example of the census. For Abidi inclusion in the census has been an important victory marking a shift in government policy.

Anita Ghai has raised several other issues that need to be addressed: among some of the issues of concern, thrown up mainly by the disabled persons according to Anita Ghai, are those that need attention not just from others or non-disabled around but by the disability movement itself. For instance, at the time of the Orissa cyclone, New Delhi Television (NDTV) did a clip of how all the disabled persons in the village were left behind while their families fled the village. This was not taken up as an issue by the disability movement. Recently in the Gujarat carnage, so many people have been disabled. But this too has not been taken up as an issue to be worked on by the disability movement. Ghai feels that for any movement to be far reaching it must not just address its own narrow concerns, emanating from the life experiences of the individuals leading the movement, but should also raise a voice regarding other social issues which have consequences for other segments of society. From a different position Ghai critiques the apathy of the non-disabled towards the disabled. She believes that non-disabled people feel a threat when they meet a disabled person because there is a chance of becoming ' like that'; it reminds them of their own vulnerability to death, disease, and incapacity and so they go into a kind of denial and fail to confront the issues arising from disability.

The themes and concerns discussed above bring to the fore the fact that a welfare state concern has been absent all along with respect to the disabled in India. One of the reasons for very little being done for the disabled can be the economic factor about value attached to 'able-bodied labour'. In India there is so much surplus labour, as well as cheap labour, that replacing the labour of a disabled person has been easy. As a result there was no need to rehabilitate the disabled labour in order to return it to the labour market for further use. Another factor is the long-standing dominance of the charity mode of provisions for the disabled. The charity orientation overshadowed the concerns of the disabled as any other marginalized group's demands for rights. As Abidi pointed out, unlike the SC/ST and Minorities, the disabled have not been looked upon as a vote bank, hence they get the least of the packages, which too are misutilized.

A fuller understanding of why the disabled never came under the purview of the Indian welfare state model can be obtained from why the need for a welfare state ever came up in Nirja Jayal's analysis of the Indian welfare state. In the United Kingdom and other countries of the industrialized world recovering from the economic and personnel havoc created by the Second World War required government assistance and benefits to recover the economy and provide livelihood to the categories of people most affected. Similarly in India given the social, economic and political situation and the numerous human problems resulting from the partition of the country and the mainly agriculture based economy, there was an increased demand requiring urgent attention in the necessity of types, quality, quantity and level of services determined by the availability of resources.

However the implementation of the welfare state model in India seems from the outset to have been overburdened with contradiction and frustrations. According to Jayal, in the twin context of challenges to the welfare state in the west, and the policies of economic reform initiated in India, it is widely believed that the Indian State is reneging on its welfare promises, and thereby compromising its fundamental defining ideals.[26]

Reexamining whether India is, or ever was, a welfare state in the sense in which western political theory and practice define it, Jayal states that indeed it is true that India does not fulfill many of the definitional criteria associated with the welfare states of the west. In the world of its origins, the institution of the welfare state was historically inspired by the intention to provide a corrective mechanism, compensating for market-generated inequalities; in India, according to Jayal, the assumption by the state of welfare tasks - however narrowly defined - paralleled the embarkation on a state-directed and essentially capitalist path of development. Thus the Indian State can be characterized as an interventionist and developmentalist state, with only a limited welfarist orientation.

In the Indian context, the arguments for the rolling back of the state have in recent times generally echoed a variant of the efficiency argument. The critique of the public sector has primarily targeted its inefficiency and wastefulness. Not only, it is argued, do the benefits of welfare schemes not reach their intended beneficiaries, but also the concern for social justice has itself led to faulty economic and planning policies.

The second point that Jayal raises is that the moral aspect of the neo-liberal critique of the welfare state in the west has been altogether absent in the Indian context. She argues that rights-claims have not been a component of the neo-liberal agenda in India, not least because rights have never been central to the philosophy of welfare that underpins the welfarist initiatives of the Indian State. Since welfare is not expressed in terms of rights, its abandonment could arguably be a relatively simple matter. A right that has never been conferred is self-evidently difficult to claim or defend. Thus the question of rights is altogether external to the debate, not only in the form of libertarian notion of rights, strictly ruling out state interventionism, but also in the possible form of a radical notion of social rights in which claims to welfare may be conceivably be grounded.

It is suggested that the Indian State may be more appropriately characterized as an interventionist rather than a welfare state. Interventionism can subsume a welfarist orientation. The primary purpose of interventionism and its inspiring and guiding force was developmentalist. This was not a state that self-consciously and deliberately took on the responsibility of providing for its citizens, in clearly defined areas which bore some relationship to the idea of needs, especially basic needs.

Instead the paramount concern of the post-colonial Indian State was the project of modernization. The developmental initiatives of the state were largely directed to the industrial sector. In the strategy of development planning the economic component of development was privileged over its social and political aspects. The gradualist approach to democratic social transformation necessitated the acceptance of structural inequalities.

There are two relevant grounds for a philosophy of welfare: a needs-based conception of justice and a theory of rights and obligations. In terms of the theoretical distinction, the philosophy of welfare adopted by the Indian state has two notable aspects: the first is that of the rights enshrined in the Fundamental Rights given in the Constitution, whereas welfare rights are in the form of non-justiciable Directive Principles of State Policy. This has resulted in a disjuncture between liberty rights and welfare rights in the Constitution. Second the Indian State adheres to a needs-based conception of justice in theory, but in practice follows a philosophy of welfare manifestly based in ideas of charity and benevolence. The idea of a *right to welfare* is precluded. Hence the question of welfare is not subject to political negotiation.

According to Ali Baquer, the concept of a benevolent, all-embracing and all-providing welfare state has undergone substantial change.[27] This is not only in India but also in the most advanced countries where resources are not desperately scarce and population is "not multiplying at an alarming rate outstripping all programmes aimed at expediting social change," as he puts it. Governments in various countries unable to maintain an acceptable standard began to dismantle the myth that a welfare state was created as perfect, flawless and the ultimate answer to the needs of all people in an attempt to promote social justice, human dignity and equality. Within five decades of its conception and the inception of the welfare state, its boundaries have got blurred, according to Baquer.[28] From the ideology of the state being the only provider of services, the shift has been towards the values of market and commercial concepts of cost-effectiveness.

The shift away from the state as provider of services has been accompanied by the advocacy of NGO based service delivery and more recently by the CBR paradigm. An in depth examination of a CBR programme in India may be useful at this point and one such example of the development and evaluation of the CBR project has been provided by Ajit Dalal.[29] According to Dalal, probably in the history of social services no other concept has become so popular in such a short time as community based rehabilitation (CBR). It began as an international movement with the growing realisation that institution based services cost prohibitively higher and does not integrate people with disability into society. CBR was regarded as a new approach in which families and communities are given the responsibility for the welfare of their members with disabilities. The success of CBR lies in encouraging people with disability, their families, and the local community to join the programme.

According to Dalal in developing countries like India, the prevalence of disability, particularly polio and blindness, is at least four times more among those who are below the poverty line than those above it are.[30] The success of preventive and rehabilitative measures is largely dependent on the success of community development programmes. In this context improving the quality of life of people with disabilities and their families would also benefit a large disadvantaged section of society. The emerging view today is that CBR programmes need to draw their resources from existing community development programmes and should get integrated with them.

It was with the above ideological framework within which the Sirathu CBR project took shape. Sirathu tehsil consists of five villages and is about 70 kms from Allahabad City. It is one of the most backward regions of the Allahabad district. Barring a few high caste families, most of the inhabitants belong to lower caste, are illiterate and work as agricultural labourers.

Two features of the region worth noting were the high degree of caste consciousness among the two groups who do not trust each other and compete for scarce resources. The other feature is the prevailing ethos of dependency on external agencies for rehabilitation. The culture of dependency has been built up over the last forty to forty-five years and is sustained by the practice of 'welfare' camps. In these camps, aids and appliances are distributed free of cost by government and non-government agencies. Self-reliance is least appealing in this set up and any initiative to mobilise local resources is viewed with scepticism.

Ajit Dalal and others were part of a project, which was looking at the setting up, working, and evaluation of CBR projects across South Asia. The Sirathu project was part of that study. The Sirathu project did achieve moderate success despite many constraints and compulsions. The project also threw up questions for the CBR approach.

Firstly it is presumptuous to imagine that village communities are cohesive and motivated. In reality they are often faction-ridden with different interest groups operating at cross-purposes. CBR programmes are highly vulnerable to local influences. Experience indicated that rehabilitation programmes succeed where local leadership is strong and has a high moral standing.

Secondly a major challenge for a CBR programme is to bring about attitudinal change. In a culture where suffering is accepted as Karma, where people below subsistence levels have learned to be helpless, any talk of CBR is a distant dream. According to Dalal one has to give serious consideration to see how CBR can work in a community which is oppressed and exploited for centuries.[31] The rehabilitation work in such a situation can not be divorced from the larger concerns of socio-economic development.

Thirdly in a resource starved underdeveloped village only a low cost CBR is viable. The dictum is self-sustenance rather than self-reliance. According to Dalal, "it is tragic that the many government schemes for disabled people remain out of reach for those who require them. Success of any community effort is to be assessed in terms of revival of these defunct schemes. For this, the communities should be motivated to work as a pressure group to claim benefits for their disabled members and their families".[32]

The above discussion about CBR and the example of a CBR project in backward village in India has brought to light some of logistical difficulties with the CBR approach. However one thing that the discussion did not highlight is the role of the family especially the mother/ woman who would be doing most of the looking after of the disabled person under CBR and we need to bear in mind the features of the gender biases in the ideologies of caring that was discussed in Chapter One.

Summing up, a survey of the policies, the legislative interventions and the interviews with professionals and disability activists suggests that the state has failed to create a coherent agenda for disabled people in terms of the implementation of the legal frame of obligation and the institutional means by which needs can be translated into practical claims. According to Harriss White there has also been a consistent trend of real decline in the resources allotted to alleviating disabilities, to which a miniscule fraction of those needing support actually gain access.[33] The state also fails to regulate both the private sector and NGOs with any consistency. Hence the inevitable impact on state underfunding and of the dispersed and joint responsibilities of state and a variety of NGOs with limited, self-defined briefs has been made public in a series of case studies of the arbitrary sterilization of mentally retarded girls committed by courts to a segregated institution in Maharashtra; in a situation of inadequate, undertrained and under-remunerated staffing, water shortages, underfeeding and insanitary conditions, sexual harassment, a recourse to arbitrary and technically illegal surgical interventions was used as a technical solution to social problems.[34]

Thus according to Harris-White, "in setting its current welfare priorities, the state has ducked responsibility for disabled people and is currently unwilling, rather than unable, to substitute for the market or the various charitable institutions proxying for the 'community'."[35] Given the wider framework of the political economy in which the state is retreating from its earlier welfarist obligations, which may not have ever been put into practice but were recognized at least at the conceptual level, the debate on disability is tending to be confined to a state versus NGO, and an institutional versus CBR paradigm. However the issue being missed out is that from the point of view of the disabled the state and the NGOs, or institutions and CBR, are not contradictory but complementary to each other. The stability of state resources, the framework of rights, and the capacity to reach widely into the countryside which only the state has, is a necessary component of any disability programme even when the NGOs are a part of the service delivery system and CBR facilitates the incorporation of the disabled into their communities.

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[3] I. Qadeer, 'Health Services System in India: An Expression of Socio-Economic Inequalities', *Social Action*, Vol. 35, July-September, 1985, p. 204.

[4] Ibid., p. 220.

[5] B. Harriss-White, 'On to a Loser: Disability in India', in *Illfare in India: Essays on India's Social Sector in Honour of S. Guhan*, ed. B. Harriss-White & S. Subramanian, Sage, New Delhi, 1999, p.148.

[6] In the case of Bandhua Mukti Morcha, cited in B. Harriss-White, see n. 5, p. 150.

[7] B. Harriss-White & S. Subramanian, *Illfare in India: Essays on India's Social Sector in Honour of S. Guhan*, ed. B. Harriss-White & S. Subramanian, Sage, New Delhi, 1999, p. 25.

[8] S. Guhan, cited in B. Harriss-White & S. Subramanian, see n. 7, p. 26.

[9] A. Baquer & A. Sharma, *Disability: Challenges Vs. Responses*, www. healthlibrary.com

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[10] A. Baquer, *Disabled, Disablement, Disabilism*, Voluntary Health Association of India, New Delhi, 1994, p. 23.

[11] B. Harriss-White, see n. 5, p. 149.

[12] B. Harriss-White, see n. 5, p. 152.

[13] Ibid.

[14] M. Miles, cited in B. Harriss-White, see n. 5, p. 146.

[15] A. Baquer, see n. 10, p. 26.

[16] Ibid., p. 27.

[17] A. Sen, cited in B. Harriss-White, see n. 5, p. 152.

[18] B. Harriss-White, see n. 5, p. 137.

[19] A. Baquer, see n. 10, p. 21.

[20] Ibid.

[21] Ibid.

[22] M. Thomas & M. J. Thomas, 'Planning for "Community Participation" in CBR', *Asia Pacific Disability Rehabilitation Journal*, Vol. 12, no. 1, 2001, pp. 44-51, p. 44.

[23] M. J. Thomas, 'Community Based Rehabilitation in South Asia: At the Crossroads?', *CBR News*, 13, January-April, 1999, p. 4.

[24] Ibid.

[25] Ibid.

[26] N. G. Jayal, 'The Gentle Leviathan: Welfare and the Indian State', *Social Scientist*, Vol. 22, Nos. 9-12, 1994, pp. 18-26.

[27] A. Baquer, see n. 9.

[28] Ibid.

[29] A. K. Dalal, 'CBR in Action - Some Reflections from the Sirathu Project', *Asia Pacific Disability Rehabilitation Journal*, Vol. 9, no. 1, 1998, pp. 1-5.

[30] Ibid.

[31] Ibid.

[32] Ibid.

[33] B. Harriss-White, see n. 5, p. 153.

[34] P. Bidwai, cited in B. Harriss-White, see n. 5, p. 152.

[35] B. Harriss-White, see n. 5, pp. 152-153.

NARRATIVIZING DISABILITY

Knowledge of suffering cannot be conveyed in pure facts and figures, reportings that objectify the suffering of countless persons. The horror of suffering is not only its immensity but the faces of the anonymous victims who have little voice, let alone rights, in history.

- Rebecca Chopp (The Praxis of Suffering)

Narrative 1: **<u>"The Story between the Lines"</u>**

One bright sunny winter morning I find my way through the bylanes of an east Delhi middle class residential colony to reach Dolly's house. I ring the doorbell and after a few seconds a tall, wiry, bespectacled girl, or rather a young woman, for Dolly is 21 years old, opens the heavy metal door. Dressed in a synthetic salwar kameez and a light beige sweater she asks me, with a smile, to come inside. I climb a couple of steps and am inside the house. Before my eyes can adjust to the dark inside of the house the main door is shut blocking out the little light that entered the corridor. From the dark interior, and amidst a cold damp atmosphere, I hear a lady asking me to walk in further. Not knowing which direction to go in I blurt out, "which way?" she replies, "this way" and I start walking in the direction of the voice only to brush against some hanging wet clothes. In the meantime the lady switches on a tubelight in the room-- the light is very dim probably because of low voltage. By now my eyes have adjusted to the darkness of the house and I enter into the faintly lit drawing room. The room is small and cramped with a three-piece sofa set and a heavy wooden bed. Dolly's mother looks a typical Punjabi middle class woman in appearance - middle aged, plump, dressed in a cotswool salwar kameez; however she has an expression of perpetual anxiety and worry. She scrutinizes my credentials--the papers that I carry, and it is only after she sees the letter from Spastic Society introducing me that she loosens up a bit. But she is not yet comfortable about my recording anything, she says to me. Dolly's mother remained hesitant and reluctant to part with information throughout the interview, which seemed somewhat unusual in my experience since I had found parents of disabled children more than willing to share their experiences with me in most other cases. In the meantime from a door on the left side of the room emerges a tall but slightly bent, thin man wearing pajamas and a shirt. He has bushy eyebrows, his eyes are sunken, his cheekbones are prominent and in a gruff voice he greets me. He sits on the divan crossing his legs with great difficulty. I am told that he is not well.

We begin the interview with the following case history: Dolly was a 'Full Term' baby through a Normal delivery in a Hospital in Delhi. She did not cry at birth and was put on oxygen for two-three hours. The doctors did not say anything about any future developmental delays. However the parents realized something was the matter when the baby was late in sitting, crawling, walking, etc. since they had had experience of handling a baby earlier as Dolly's older brother is not disabled. But the parents did not do much about their fears telling themselves that some children are late beginners.

As Dolly grew older and it was time to send her to school. The parents sent her initially to a government primary school in the neighbourhood, getting her admission through an "approach"; a government school fees is all that they could afford. They had realized by then that Dolly was 'not like other children', and they feared that she would be "caught out" sooner in a private nursery school than in a government school. They also reasoned that, generally, children are not thrown out from a government school. However by the time Dolly reached class 2 or 3 the teachers realized that the child was having problems in 'coping' because she couldn't keep pace with the other children academically. Further, the teachers couldn't manage her in terms of studies as well as in terms of her 'behaviour'. The final decision regarding taking Dolly out of school arose when there were objections being raised by other parents about Dolly going to the same school as their 'normal' children. It was claimed by the teachers that they were incapable of handling the situation of ostracization by the community of a handicapped child, even as it might be argued that such a child has an equal right, as any other child, to an education.

For some years Dolly stayed at home. In course of time the parents came across a girl in their neighbourhood who had had polio and the Spastics' Society had helped her to get a wheel chair. This family informed the parents of Dolly about the Society and suggested that they take their daughter there. Dolly was admitted initially in the Home Management programme and now she is in the Vocational Programme of the SSNI.

The first formal information regarding Dolly's condition the parents got was when they took her to SSNI. The experts there diagnosed Dolly's condition as Cerebral Palsy: armed with this information the parents started her intervention programme through the Home Management department. The mother took Dolly to the SSNI as and when she was asked to do so. At the SSNI the mother was trained to handle Dolly and came to understand the exercises that were a must in order that Dolly could become physically mobile. Both the parents worked hard with Dolly but the mother was much more so as she was always at home while the father went to work. The mother's only help while bringing up the child was her husband and, occasionally, someone from her family. The mother's reluctance and hesitation in revealing information in terms of feelings, emotions and periods of depression she went through, indicated that there was at present still somewhat of a distressed situation in the family which was affecting her. The father does not work any more. He seems to have developed serious psychosomatic disorders - he has severe inexplicable pain in his legs and the doctors are not able to diagnose the reason for it. The physiotherapist claims nothing is the matter and that the legs are perfectly fine. The pain gets aggravated at night and invariably he has to take a sleeping pill.

Dolly's father is a believer in the founder of the Radhaswami sect. He said he became a believer of the 'sant' not because he was expecting a 'miraculous cure' for his daughter but to gain emotional strength to deal with the situation - his daughter's disability. The fear and dread of his daughter's condition is apparent in terms of him still groping around for the 'cause' of his daughter's disability. Although he's been given the medical explanation for her condition, he still feels that past deeds are responsible but he did not want to elaborate how it applied in his case. The father has developed a method of explaining things in the form of stories, which, if one reads between the lines, reflect his anxieties. For instance both the parents are very fearful and anxious about their daughter's future. The nature of the anxiety was revealed through a string of stories about how they know people who have ill-treated a disabled person in their respective families. One of the stories that led to the question of Dolly's marriage was the story of a blind girl who was married off to a person who didn't take any dowry as such but treated the wife as a servant for the household. This led the parents to jointly emphasize that they did not want to 'sell' their daughter to the highest bidder. However later, the mother told me that some of the stories the father recounted were true though some were not, revealing the workings of his imagination about the bleak and dark future of his daughter. The anxiety of the parents is compounded by the fact that the older brother is not particularly fond of the sister, at least in their opinion. (I did not have the opportunity to meet the brother because he was away on official work). However, the brother contributes financially to the home. An instance of his major financial contribution was at the time of Dolly's treatment and surgery for a broken jaw. This led the parents to narrate their distress about the way even the medical profession treats the disabled. Dolly had fallen down and broken her jaw. They took her for surgery to one of the big well-known government hospitals in Delhi. There the doctors performed two rounds of surgery under general anesthesia but were unsuccessful in treating Dolly. The parents were advised by a local doctor to take Dolly to another big government hospital. As soon as he read the report of the previous hospital the senior doctor at this hospital refused to treat the child. Not knowing what to do the parents just hung around the ward when a young doctor came up to them and took a look at the case and discussed it with the senior doctor. The senior doctor dissuaded the junior doctor from taking up the case. However seeing Dolly's traumatic condition and the plight of the parents the junior doctor assured the parents that he would treat Dolly. Going against the orders of his senior he went ahead with the surgery under local anesthesia and brought back Dolly's ability to eat, speak, and most important of all for the parents, smile.

While the father was more articulate about his anxiety for the daughter's future, the mother could not verbally articulate her fears; her facial expression and continuously fidgeting hand gestures however indicated her deep anxiety. In order not to discuss the topic any further she cut the conversation off by getting up to make tea. And yet, it was evident that while the mother could reveal her grief to her family members the father could not discuss his anxieties with anyone because he had also developed a suspicious nature and did not trust people easily. Apart from the anxiety about his daughter's future the father also suffered from a deep fear of his own death, which he revealed in terms of visions he had about his soul leaving the body. He feared that if he revealed too much about his and his daughter's condition to anyone, or communicates his anxieties, there would be people out to take advantage of the situation and harm his daughter. As a result the family also had a very restricted social life and interacted only with their close relatives. But wherever they went they always ensured that Dolly went with them, if not only one of them went.

The parents have realized that a social life for the daughter was very important. Something to keep her occupied was also necessary because, in their opinion, 'such children' do not know how to entertain themselves, or keep themselves occupied over the weekend, and especially during vacations. They hope that the SSNI would develop some programme whereby children like their daughter can have opportunities to interact with their peers even on non-working days or during vacations. However Dolly's parents did not see themselves as active participants in the process of organizing a group or do something to get the social interaction programme started. They seemed resigned to the fact that the organization knew best the way to handle the situation of Dolly and people like her. The parents were willing to go along with whatever decisions were taken by the SSNI without voicing their opinion particularly because in their view 'at least here was an organization willing to help out such children'.

The daughter's future was an important concern of the parents. Apart from the question of who would look after her physically once the parents were gone, the parents hoped that the SSNI would be able to train Dolly and find employment for her such that she would be independent, financially at least. According to the parents they had not been able to make any financial provisions for Dolly because they did not have enough resources to save up, and whatever money they get from renting one portion of their house is spent in the daily living expenses.

The running anxiety about the daughter's future and provisions for her brought in the question about the need for governmental intervention, or help from other support systems outside the family. The father was dismissive about the present government's policies claiming that the government provisions did not really help deal with the situation because all the responsibility of care fell on the family itself. He also felt that it was ultimately the family, which needs to cope with the situation, because it is within the family that the handicapped persons have to stay. Both the parents ended by saying that they wished a future for their daughter that would not be cruel for even 'such children' are human with feelings and emotions and once one understands them they are like any other person, if not better.

NARRATIVE 2: **"NO MIRACLE WOULD HAPPEN"**

Making my way through the evening hustle and bustle in the crowded by-lanes of an east Delhi middle income colony I reach the residence of the Nijhawan's. Upon entering the house I hear the loud excited voice of Surinder, "madam agayee, madam agayee". The father explains that Surinder has been waiting eagerly for my arrival as he does for any guest about whom he is informed as coming to their house.

Surinder belongs to a family comprising his parents and a younger brother. Surinder is 21 years of age and has profound cerebral palsy. He is home bound and totally dependent on some one not only for all his daily living needs but also for moving him from one place to the other. After years of shifting from one rented accommodation to another the family has finally managed to purchase a house of their own. They were driven to such a situation of buying their own place because, as stated by the father, "we had a lot of problems in renting an accommodation with such a child. No one would happily accept our situation. The maximum we could stay in one place was a year." Initially the house would be rented to them on sympathetic grounds or whatever. But then they would start facing humiliating and oppressive remarks such as "kahan se bimari utha le aye", and many would not like their children, or other family members to interact with their children, or with them. Describing the situation the father said, "We have tolerated so many things... At least here we don't have that kind of torture to bear with now".

At the time the mother was expecting Surinder she had malaria in the 8th or 9th month with high fever, about 107 degrees. She was taken to a nearby Primary Health Centre in a village in Haryana. The doctor gave her some medicine and an injection. On hindsight they attribute Surinder's present condition to the medication and the fact that the doctor did not advise them to go to a hospital in the city in the given condition. None of the doctors they met informed the parents that there could be some adverse effect on the child.

In describing their immediate reaction upon the realization that their child is handicapped, the father replied, "we were not much depressed, for we didn't realize it would be a lifelong thing." The parents thought that Surinder's condition would prevail only for some time and that in the course of time he would get cured. Since Surinder was very small they had faith that there would be some treatment available with new advancements in medical technology. Since Surinder was the first of their two children the parents did not have much experience about the developmental milestones of children in general and hence, when Surinder was not walking, they did not think it was a moment of alarm when he did not do so at any particular age or contact the doctor for an opinion. When the parents took him for his immunization routine, the doctors in a children's hospital informed them that something was the matter with Surinder and a lot of exercises needed to be done with him. However, despite the regime of exercises there was no significant improvement in Surinder's condition.

Describing their initial years of coping with their situation, the father tried to understate their efforts in order not to portray their efforts as 'heroic acts of service'. However the parents said that they both got involved in trying to get the maximum number of sources and occasions to get Surinder's exercises done since that was the primary "treatment", as instructed by the doctor's at Kalawati Hospital, of making Surinder a little functionally independent. They tried not to spend too much time being emotionally upset about the situation. The father's way of coping with the situation was to ensure the routine of exercises was not disrupted so he not only took the child for exercises, he even hired a physiotherapist to come home in the evenings to do the exercises. While the mother did have emotional outbursts and spells of nonstop crying, her family and her in-laws were very supportive in helping out with the physical looking after of the child since she was also working in a job.

All this was before they enrolled Surinder in SSNI. The parents were grateful to the Spastics' Society for being helpful in the initial years; in the course of their parent counselling sessions the parents were told, almost in the beginning itself, that they should not think that there will be a miracle and that their child would become 'normal'. This statement made them change their outlook and they stopped looking for a cure, which did not necessarily mean that they had stopped 'hoping' for a cure. The counselling at SSNI helped them tremendously in understanding Surinder's situation - that it was going to be a lifelong condition and the fact that his strengths and potential needed to be tapped rather than focussing on what he could not do. With this in mind they have struggled over the years, and put in a great deal of hard work to get

Surinder to walk, talk, eat by himself, dress himself and be toilet trained. However today, at the age of 21 years, Surinder only speaks a few words. He does not walk, despite all the exercises. His legs have got crossed and rigid making the carrying of him more difficult. The father can no longer carry him because of his severe back problem and also because Surinder has become bigger and heavier over the years. Surinder had been toilet trained. However he still needs someone to feed him and dress him up. Surinder is also on medication for fits. Until a few years a go Surinder was going to SSNI but on realizing that there was nothing much Surinder could do in terms of vocational training the school asked the parents to remove Surinder and make place for another child who would benefit more from the vocational training. The parents had no objection to removing Surinder and making place for another more capable child who would benefit from the training but what the parents feel upset about and found difficult to handle is that there is no longer a routine for Surinder; more than that there is no interaction with the outside world. At least when Surinder used to go to the SSNI he used to be in the company of people and he used to really enjoy his schedule. Surinder may not be able to express his joy verbally but there was a visible difference 'if one looked closely into his eyes and even at his spastic body'. Now that he is not going to SSNI anymore, the parents have put him in a nearby crèche where he goes for a few hours; although there is nothing much he learns at the crèche but going there is an outing for him, which he looks forward to. In the evenings the parents again try, as much as possible, to take him out to the market and he in turn insists on helping them by holding the vegetables or shopping bags in his wheel chair. Surinder is not able to express himself verbally but the parents can feel the restlessness of a youngster in Surinder and the frustration and anger he feels at not being able to go out or do something to help the parents in many more ways. Thus the parents feel if only there is some means of organizing outings and other kinds of social interaction for 'such children' it will benefit them (both children and parents) greatly.

In the last 5 years or so the parents have undergone various spells of ill health; first the father developed severe back pain, rendering him incapable of lifting Surinder from one place to another or even onto the wheelchair. Then the mother was diagnosed as having breast cancer. Those were really trying days when the mother had to go for chemotherapy and the father was laid up in bed for almost a month because of his back problem. Both the parents neglected the children but family support was strong. This situation was very grim and depressing for both parents. On probing about how they handled situations of helplessness or depression - the Mother said: "I can't explain it to you but at such times God gives some kind of inner strength, but I can't describe it to you. So with God's grace, and the help of some of our relatives and some people in my office, we overcame our difficult times. " The Father stated, "we are God-fearing people so as the difficulties came their solutions or ways to handle them also emerged." Family support from both sides helped them tremendously. Even now both of them, but especially the mother, do go through moments or phases of depression and anxiety about the future - " But looking at other 'such children' we console ourselves and feel he is better off than many others who are worse off than him. What else can we feel? There is nothing much we can do, and there is no treatment".

The family has had quite a few negative experiences with regard to social interaction with neighbours and relatives. For example, the parents were told quite bluntly not to bring Surinder to a relative's wedding. Even though they felt upset the parents still went to the marriage, without Surinder, out of a sense of obligation. However, similar experiences in terms of reactions, and in some cases problems of accessibility to people's houses has restricted their social life considerably. The only places the family visits are the brothers and sisters of the parents. When they have to go to a relative's place, out of compulsion, they do not take Surinder or sometimes one of the parent's stays back to be with him. At first they used to feel very bad about this kind of exclusion of one family member, but they have learnt now to "adjust" to such a situation. The family does not travel out of station because of the hassles of taking the wheel chair and the inaccessibility of the toilet.

These observations led us into a discussion of the role of the government and its policies and provisions for the disabled. The parents of Surinder were very dismissive of any government action in terms of policies. They brought up the fact that even though there may be certain provisions for the disabled, it is only the disabled such as the blind, or someone who does not have an arm or leg, who gets the benefit of the reservations. The father also referred to the extent of ignorance of the policy makers with regard to the degrees and types of disability. As a result of inadequate government action some of parents of CP children decided to form an association to try and build a residential block of flats for their children to live in once the parents are no longer there, or if the parents have to go somewhere in an emergency they would be able to leave their child there for a few days. In order to get some assistance in setting up this project some parents went to the ministry of social welfare and found that the minister was ignorant about the fact that there are different types of disabilities, which are not cases of polio or a consequence of amputation! The father was very upset that even though this was the capital city, and despite the ministry being situated here, it had such few provisions for the disabled; clearly then the condition would be much worse in rural areas. He quoted a government official who came to lay the foundation stone of the proposed residential flats for the disabled as saying that he was ashamed of the fact that the government had crores of rupees to spend on elections but did not spare some money for the care of the disabled children.

The discussion then slid into the question of Surinder's future: the parents expressed their extreme anxiety about what would happen to Surinder after they died and who would care for him thereafter. They acknowledged the possibility, and the hope that his younger brother, who is very fond of Surinder, would look after him but they were also worried about how he would manage. Somewhere at the back of their mind they were also anxious about the possibility that the younger brother, or his future family, could become resentful of looking after Surinder. If Surinder was regarded as a "burden" what would be his fate. The parents seemed to feel that no one could look after a disabled child as well as the parents would. But at the same time it is the protective instinct of the parents for the 'other' child which makes them feel concerned about their expectation that, in the absence of the parents' support, ultimately it was this child who alone would have to shoulder the "burden" of looking after their disabled child. They hoped that the proposed residential complex would be ready soon so that they would be somewhat reassured about Surinder's future.

NARRATIVE 3: **"She too has the Right to Live"**

Living in a haveli type house in one of the quieter lanes of a crowded central Delhi wholesale market is Anjana. She is 25 years old and is the second of four children of Madhu. Madhu is a widow who lives in her husband's house. Apart from them her sister-in-law lives in one portion of the house, and in another lives a tenant. Anjana has severe CP and is spastic; she is dependent on some one to attend to her daily needs. Her speech is affected severely too yet she is able to communicate her needs and emotions. Though she has a wheel chair it has to be wheeled by someone. Till a couple of years ago she was going to SSNI. However assessing her functional abilities as dependent on someone else and the body's inability to perform any vocational skill the SSNI did not think it feasible to keep her any further in the programme. She now goes to a crèche for handicapped children run by the Railway Hospital. She does not learn anything much there and it is only a means of spending her time in a safe environment while her mother goes to work as there is no one to look after her at home.

Anjana is the second daughter of Madhu. As the first child was a daughter the mother-in-law had wanted the second child to be a son. She brought Madhu some medicine claiming it was a medicine to ensure the birth of a son. Madhu resisted taking the medicine initially but soon emotional pressure from her husband and sister-in-law compelled her to take it. Every time she took the medicine she vomitted-- this was in the third moth of her pregnancy. One fine day Madhu decided to stop the medicine due to the side effects she had developed. Time passed, she had a normal delivery in the hospital and Anjana was born. Soon after her birth Anjana had high fever for 7 - 10 days. She was taken to a local doctor who for no apparent reason advised them not to admit her in a hospital. Since there was no improvement in her condition the parents took her to Kalawati Saran hospital where the doctor informed them that she had pneumonia and should be admitted. Having only heard of horror stories about hospitals, along with superstitions related to children dying in hospitals, a relative advised them not to admit the child in the hospital. Instead the family took the child to another doctor near their house. That doctor prescribed some medicine which, when they went to purchase, led the chemist to remark with astonishment: 'such a heavy dose for a small baby is too much!' The parents however followed the instructions of the doctor and in two days the baby was absolutely fine.

By about 3-4 months the mother noticed that the baby was not holding her neck. People around started expressing surprise that Anjana hadn't yet started holding her neck. They took her to yet another local doctor who told the parents that had they not brought Anjana at that point the chances of her survival would have been bleak since Anjana was also a very weak baby. He was the first person to explain Anjana's condition to them: 'whatever she does will be delayed and the progress is going to be very slow' he said. Time went by but Anjana still wasn't sitting, walking, etc. so her parents took her to Kalawati Hospital where a special chair was made for her and the mother was also taught some exercises to do with her. When Anjana was about two years old there was an advertisement in the papers that a school had been opened for children who didn't hold their neck. This was the SSNI ad and the parents immediately took Anjana there. She was the third child to be admitted to the SSNI. "After that day, and to this date I have not taken her to any doctor or hospital", said the mother.

Before the SSNI advertisement, Madhu's mother had taken Anjana to AIIMS where they asked for an X-ray of the brain which, her mother didn't agree to saying that such a small child didn't need a brain X-ray. Thus, according to the mother, Anjana's case typifies in some ways the lack of information passing for knowledge among the medical profession, compounded by closed mindsets in a joint family set-up 20 years ago. However she feels that today there is much more awareness, not just about disability but also about being alert with respect to the development of one's child. Further, the child is no longer regarded as something that is a natural consequence of marriage and that they just grow up in the course of time. The responsibility and care that is required in bringing up a child is highlighted nowadays, especially in the context of disability. The disability campaigns of today emphasize that disability is nothing to hide, or feel ashamed of, or to be ostracized by society. People are also made aware that one is not alone in the pain and helplessness in the process of bringing up a disabled child. To start with, for instance, Madhu just could not sit through the parents' workshops, which were held in the SSNI. The moment the parents started to talk about their problems Madhu would have tears in her eyes and would want to walk out from there. She felt so helpless and underconfident of her capacity to cope with Anjana's situation. The teachers would try to explain to her and help her a lot in overcoming the feelings of helplessness and underconfidence. "But see the situation today", she remarks, " Now I go about helping and explaining to other parents, building up their confidence to handle the situation."

The long journey of 25 years in bringing up not only Anjana but also the other children has not been easy for Madhu. Soon after her husband died of cirrhosis of the liver, the family fell on bad times financially. It was Madhu's parents who came to her aid and helped her financially in bringing up the children. Madhu decided to take up an office job in a government setup which did not last very long because the organization closed down. Then she took up another office job, this time in an NGO for the disabled persons. The NGO does not pay very much but it brought her into contact with parents of other disabled children and in many cases the children were more severely or profoundly affected, or were parents who had two or three handicapped children, a situation much worse than hers. Madhu also developed a good rapport with other staff members and the NGO became her strongest emotional support--more than her own family.

"What was the family's response to Anjana's disability?" I asked. Madhu said that the mother-in-law had passed away before Anjana was born. The rest of the family did not know much about disability and thought the child had some illness, which would be cured with the help of medicines. Once Madhu was told the nature of Anjana's disability and her interaction with the SSNI staff and parents grew, she found emotional sustenance and strength to cope with the situation from there and never went to the medical professionals for any kind of assistance. Madhu never shared her emotional grief with her family because they were helping her financially and she did not want to burden them further. But Madhu does share some intense moments of anxiety and worry about Anjana's future with her sister, but never in front of Anjana. Often feelings of pity and sympathy regarding Anjana and the life she was going face ahead used to come to her mind. However, she knew that just pity and sympathy were not going to help Anjana and there have been some instances in her life, which gave her renewed strength to deal with the situation. One such instance she described was the following: after her husband passed away, Anjana was sitting in her wheelchair near the front door. Within her hearing the neighbour across the house lamented, " Oh, it is not the father who should have gone; it would have been better if something had happened to this girl instead." This upset Madhu terribly and she thought to herself that this was no way to think and she said to me - "my daughter has also come into the world like everyone else: doesn't she too have the right to live?"

Anjana is a very sensitive and perceptive young woman and according to the mother she has had this quality right from the very beginning. She is not at all demanding, or fussy, and tries to manage things for herself as much as possible. However Anjana does have her moments of frustration and anger at her helplessness; when she was younger she used to flay her hands and bang them against the wall. However according to the mother now she has 'matured' from that phase, and can work out things more reasonably. Anjana's mother and her siblings have never treated Anjana as a special child in terms of pampering her or giving her a special position in the family-- for instance she has been scolded when she has done something wrong and been praised for something extraordinary that she may have done.

Anjana's mother is anxious about her future, but then she feels that Anjana's condition is much better than that of many others. Further, she believes that since the relationship of her children between them is good, they will look after Anjana. Madhu is part of an association of parents, which plans to set up some accommodation for disabled persons so that they can live independently. However she expressed the hope that her other children would take responsibility for looking after Anjana for she feels that it is ultimately the family which can provide the protection and loving care that is needed by someone who is disabled.

This led to a discussion on the role of government policies and interventions in the field of disability. The mother shrugged her shoulders and said that if in 50 years the government has not done anything, now with all the lobbying she didn't expect anything much to come about. However she did think that NGOs had a crucial role to play in not only disseminating information but also in terms of providing services because the care and personalized services that an NGO set up gives no government institution could provide. However she was also critical of the SSNI that the amount of help the institution had extended in the initial years of coping, and coming to grips with the situation of handling a child with disability, they have not been able to provide in the same measure as the children grow older. She did not mind the fact that children like Anjana are not so functional as to be able to learn any vocational skill in the institution but that did not mean that these young adults have no need for being occupied and have social interactions. They had once followed a routine, which no longer exists and have to spend the rest of their lives at home. The parents/family do not have the resources to engage these children meaningfully at home without the assistance of organizations. The argument Madhu was making was that the parents were willing to set up some kind of social interaction occasions for such children fortnightly or so, however they do not have the space to hold such occasions and organizations are not willing to give them the physical space!

The mother concluded by stating that she has overcome the feelings of distress and depression about Anjana's condition though her anxiety for her future still worries her. Elaborating the nature of her anxiety she narrated the following instance: Initially there was a male helper for Anjana; once he touched Anjana and she immediately 'knew' that it was a wrong touch, and that it wasn't a touch by mistake. It did not happen just once but quite a number of times and Anjana used to come and complain to her siblings but they overlooked the matter and felt that she was just 'trying to seek attention'. Then she started telling the mother, and also complaining to the teachers. This led the mother to have a talk with the staff in SSNI and they said that there could be something the matter otherwise why would Anjana keep repeating the same thing. The mother then had a meeting with the crèche people and they also said that they had noticed the helper's peculiar behaviour and finally chucked him out. Similarly, once earlier, in their neighbourhood there was a boy who had misbehaved with her. The family didn't know about it. But whenever this boy would come home, Anjana would start yelling and asking him to get out. The mother would try to calm her by saying that he's like her brother. However she loudly protested and angrily said NO! Because she knew that he had not behaved in a 'brotherly' manner. Later she told the mother explicitly that he had wrongly touched her once when she was sitting outside the house on the street side. It put the mother in a difficult position and she didn't know how to confront the boy, but the boy of his own accord stopped coming to their place. Probably he had realized why Anjana used to get angry. The mother said that although this showed how mentally aware and sharp Anjana was, since no one had taught her what is a right touch or a wrong one - it had never occurred to us to teach such things consciously to her, but she picked it up. It is such instances of future abuse and vulnerability the daughter may be subjected to which worries the mother. And there are no mechanisms available by which children like Anjana can combat their situation, or express their distress, and seek help.

The family has never hidden Anjana's condition from any person within or outside the family. They always take her with them wherever they go and she is part of all the happy and sad times the family has had. They have not come across any situation when they have been prevented from bringing Anjana with them. She is part of their family and they are proud to have her.

NARRATIVE 4: **"The Mother's Burden"**

I make my way through the line up of the latest cars in one of the posher colonies of south Delhi to reach the address of Mrs. Bose. She had instructed me that the entrance to her place was from the rear of the house. The rear roads of the houses in some of these colonies are the service lanes; they are generally filthy and dusty. So was this service lane. Finally I find the house or rather the small dark room where the Bose family lives. The father is not present and the people I meet are Mrs. Bose, their son who studies in an evening college, and Superna, their daughter.

Superna is 21 years old; she is short and stout and bursts into a fit of giggles when something is asked of her. She has moderate CP and is mobile only when placed in a wheel chair, she has no speech and only communicates with sounds and gestures, she is dependent on someone for her daily living activities though she can manage to eat by herself when served. She is in the vocational training centre of the SSNI.

Mrs. Bose is a thin woman, with thin, long heavily oiled hair; she has prominent cheek bones and sunken tired looking eyes, and also has bent shoulders as if they are carrying a lot of load, she speaks very softly, looks drained of energy, yet resilient. In a matter of fact manner she invited me into the room, which looked decrepit with the paint peeling off, a tubelight which was blinking because it was near its end. It could not be put off because there was no other light point and no source of natural light in the room. The room was crowded with a double bed piled with bedclothes, which smelt musty because it was winter and books and paper were scattered, which the boy was reading, while there was a TV blaring away. There was a loft stuffed with things, some of which came crashing down during the interview. Just outside the room is a little kitchen, which also has no ventilation, so when any cooking is done the fumes come into the room resulting in a coat of gray.

After taking down the preliminary details of name, education, profession of both parents. When I enquired about the occupation of the husband, the mother replied in a tone -----, "he's an alcoholic". Then she started talking about the husband's problem of alcoholism, which has not been controlled despite various treatments from hospitals and de-addiction centres. As a result he has been unable to keep a job and consequently is not supporting the household financially. Due to his alcoholism there is also a lot of tension and fights in the house not only with the mother but physical fights with the 17year old son too. This has resulted in affecting the son's studies. The mother was thankful that at least the father did not raise his hands to hit the daughter.

Superna is the older of the two children. At the time of her pregnancy the mother had paratyphoid and she attributes Superna's condition to the medicines she had taken. At the age of 10 months she took Superna to Holy Family Hospital for a routine check up where she was informed that there was something the matter with her daughter. Although she had taken Superna at 3 months, the doctors did not detect anything then. The doctors did not exactly tell the mother the nature of Superna's condition, but prescribed some medicines and asked her to bring the little girl for some exercises, which she did.

When Superna was a little older a teacher in Mrs. Bose's school told her about SSNI. She took her there and the child was admitted in the home management programme. The problem was that the mother had to take her every three days to SSNI which she did for sometime but then it became difficult because she was working in a school to make ends meet. She couldn't manage juggling both responsibilities and she stopped going to SSNI since earning a living was the priority. However Superna's name was not struck off the SSNI list and a few years later they sent a letter admitting her into the regular school programme.

The mother started working because her husband didn't have a job due to his alcoholic condition and he could not retain any job for long. He used to and still gets into a crazed state and is out of control when he is drunk. The mother has tried all sorts of treatment but nothing has helped or worked. Even now after so many years his problem is continuing. The mother has got no support from the husband's family and feels cheated that despite the family knowing his condition had got him married with the warped reasoning that marriage would 'cure' him. After the husband's mother passed away - she was the only one who could control him - the problem has got more out of hand and none of his other family members care to interact with him or help her handle the situation, financially or emotionally. Apart from extending no support to the mother, the husband's family has been taking advantage of the husband's condition and are harassing the mother and children to leave the house or rather the tiny dark room so that they can appropriate the entire property and render Superna and her family's homeless. The extent of the harassment meted out to the mother by the husband's family has led the mother to start imagining that the family is doing 'black magic' on them. She narrated instances of the family having done black magic. Although she seems to have gotten over that fear, when the pile of things came crashing down from the ledge, she said that even now the fear is present.

The mother is very grateful the SSNI for their support and she said "Whatever strength I have got to manage the situation is from the help of some of the SSNI staff." One of the teachers even took her son home for tutions. She describes her situation before she came in contact with the SSNI as one where, "I only used to cry and feel helpless and scared of this man." Out of compulsion to get the home fires burning she had to take up a job, but her husband used to lock the door and not let her go in the morning. Or when she returned from work he would not open the door instead hurl abuses at her. He would also indulge in character assassination loudly. She has had to, and still puts up a brave battle against the physical and emotional torture the husband inflicts everyday on her.

In such a scenario when she discovered her daughter's condition, the mother said that as far as she could remember there was no adverse reaction on her part. For her, combating the problem of her husband's alcoholism and the violence that followed was, and still is, upper most in her mind. She did not see her daughter's disability as any major problem. This is not to say that she has not tried to get treatment for her daughter whether it was medication or the exercise schedule. Even though she stopped going to the hospital to get the exercises done, she continued them at home whenever she found the time. The realization that her daughter is disabled only strikes her when the husband holds her responsible for the daughter's condition. "Superna is very sensitive and she speaks up for me against her father when he fights with me." At times of extreme tension, after the father walks out of the house it is Superna who extends a shoulder for the mother to cry on and consoles her and gives her support to go on and live life. The mother confesses that Superna is the emotional anchor in her life that makes her go on. The mother has, at many times, thought of leaving the house, but either did not have the courage or has not found it a viable option especially with a disabled daughter. She did not consider it an option earlier because the daughter was young; now because the daughter has reached a vulnerable age and because the mother does not trust the world, and reasons that a known devil is better than an unknown one she stays on. Another reason for staying on in this house is just the physical security that since they own that room they cannot be thrown out of it; further there is no guarantee that the husband will not follow them to trouble them anywhere else.

The mother went through long periods of depression on account of her husband's condition, his treatment and the future of the children. Once she came in contact with SSNI they helped her immensely emotionally to gain strength to deal with the situation. She says, with a look of exhaustion that just the narration and going over her life brought on - "that stage has passed when I had to console myself. I have spent so much money and energy that today I no longer think about the situation." She has realized that the reins of her, and her children's lives were in her hands once she became financially independently by getting a job. She has pinned all hopes of getting out of this grim situation with the help of her son, who studies and simultaneously works. The 17-year-old son realizes the tremendous task he has ahead of him in life; he looks a bit unsure but is also resolved in getting out of this situation. The son is a loner and though he has a couple of good friends, he does not spend much time with them. The mother for her part doesn't have the time to indulge in any kind of social interaction once she gets back from work. Hence the family really does not have any social network.

When asked what she thought of government provisions for the disabled, her train of conversation veered towards the need for government assistance to deal with chronic alcoholics who disrupt not only their life but also that of the family.

Regarding Superna's future, the mother just shrugged her tired and burdened shoulders and said, "future, what future?" she hoped that the SSNI would be able to train Superna in a vocational course that would make her somewhat economically independent. Regarding her physical and emotional care in the future, the mother said resignedly that till she is alive, she would look after her: after that she doesn't know.

NARRATIVE 5: **"Dedicating Oneself to Seva"**

Making my way through the uniformly built government quarters near one of south Delhi's posh colonies I reach the address of Manav Kakkar. I ring the bell and there is a loud 'satsang' song that starts. I wonder whether I had reached the wrong place, that instead of a house I had reached an ashram, but soon the music stopped and the door was opened by a middle-aged woman, Manav's mother. The father is in a government job. Manav is the only child of his parents.

The mother is very soft spoken almost inaudible, her tone was that of a person who is grieving or is in mourning. Narrating the time when she was expecting Manav she said that she had no problems during her pregnancy or after delivery. Manav was born in a hospital through a normal delivery process. He attained his developmental milestones of sitting and walking with support. When he was about a year old, the family went to the holy city of Hardwar and on their return to Panipat Manav had high fever and fell unconscious for two days. They took him to a private clinic in Panipat. The doctor was incompetent and did not give any proper diagnosis and prescribed some medication. However there was no significant improvement in Manav's condition so they brought him to Delhi after a week or two. Although the fever was no longer present, Manav seemed to have forgotten how to sit, stand and walk. After some examinations the doctors told the family that it might be a case of encephalitis. In Hardwar at the time of their visit there was an outbreak of encephalitis. It was reported in the news that some children had died and those who survived had severe brain damage. They were not given any more information regarding delayed milestones or retarded mental development and they returned to Panipat. However by the time Manav was 3 or 4 years he had still not started walking. This alerted the family and they went to Delhi's Kalawati Hospital for Children. It was there that they were informed that there was no medical treatment or cure for and that he should be admitted to a special school. They started looking for a special school and came across SSNI, a school for CP persons and Sahan, a school for the mentally handicapped. Although Manav was enrolled in the home programme of SSNI he never got admission in the school or the vocational centre. He got admission in Sahan. Thus they shifted their residence from Panipat to Delhi. For 1 year the mother lived alone with Manav in a rented room without her husband or any family support, though there were a couple of friends who helped out. The mother did not recall any adverse problems that she faced living on her own.

Today Manav is 21 years old. He is a thin tall, lanky young man with a rigid gait, stiff arms and fingers. He has an enlarged tongue as a result of which his mouth cannot close and due to lack of adequate speech therapy there is constant drooling. Although there is nothing much that Manav is learning at Sahan in terms of a vocational skill. He still goes there because the mother wants to ensure a routine for him otherwise at home he develops behaviour problems because of the lack of adequate things or work to keep him occupied. Though the mother always engages him some kind of housework within his capacity such as carrying in the washed clothes, she still regrets the fact that he never went to a school for CP children where he may have learnt much more.

Regarding their immediate reaction on getting to know that their child was going to be handicapped the mother, in a resigned sort of tone, described it as, "then we left our life's boat in God's hands and wherever He wishes to take us with Manav we are willing to go. So we readied ourselves for the hard work of looking after Manav". The mother 'sacrificed' all of her interests, for instance she wanted to be a teacher, but she buried that ambition in order to do what she described as 'seva' for her child. In the initial years of bringing up Manav, she was very upset about his condition, about his future and their collective future and about the inability to cope with the situation. But over time she has come to rationalize her situation and feelings in spiritual terms as "now we are in 'God's line' so there is nothing to be upset about." In fact she went further and said that if there is anyone who wants to leave even 'ten such children' with her she was willing to look after them as she has developed so much patience over time. And it is patience and loving care along with a capability to keep them occupied that is important. She launched into a long discussion on the importance of social interaction for such children, their ability to pick up good and bad things just as normal children did and how even they feel frustration and anger at not being productively occupied in doing something; not knowing how to express themselves leads to severe behaviour problems. In the initial years her husband was upset and did not know what had hit the family and how to cope with the situation. She narrated an instance of how one of her husband's friends felt sorry for him and took him to a Sadhavi who said to her husband "name the thing that you want?" her husband replied, "I have not come to ask for any material thing, I have only come to ask for strength to deal with my 'dukh'." The Sadhavi was it seems stunned by this answer for she only knew how to appease people's cravings for material things or sermonizing that material things should be sacrificed for gaining salvation.

But both parents over time became spiritual minded and both of them have taken Diksha to serve their child and any such child who they come across.

There was never any negative response from the extended family vis-à-vis Manav. But there was a lot of pressure on the parents to have another child. However it was the joint decision of the parents not to have another child because at that time they felt that 'ab sirf iski seva karni hai'. Many friends and relatives told them to have another child because they believed in the notion of a normal child and thought it would also help Manav to interact if there was a normal child around. But the parents were not for it. And today when they look back they feel their decision was correct. The reason for feeling that their decision was correct, according to the mother, is because if they did have a normal child their attention would have been divided and they may have even given that child much more attention, better diet, better education, for he would be the one from whom they would have expectations. The mother philosophically said that it is the expectations from people that make one unhappy. But now "from him we have no expectation and he is everything for us and we are not dissatisfied with life."

The parents and the rest of the family include Manav in all their social activities. They never leave him out and are not embarrassed about his condition. They do come across outsiders who feel sorry for their situation but that does not bother them. The rationale given by the mother is, "once the parents have accepted their situation there is nothing which can hurt them, or weaken their determination to look after the child. When parents themselves are disappointed with what they have, it is then that what others say hurts or affects them."

Regarding government provisions for the disabled the parents were aware of the job reservation, tax rebate, travel concession, etc. They did not think the government was really keen on doing anything for the disabled because if it were something would have been done. Before Manav became disabled they only considered that disability came about through accidents, or that some one born disabled was a freak or a rare instance. Despite the fact that Manav became disabled due to an illness and that the doctors did not inform them early enough about his condition being lifelong, they seemed to show no anger at the incompetence and lack of ethics of the medical profession in revealing truthfully the nature of the case, or confessing ignorance about certain conditions. The idea of such a feeling was brushed aside by the remark "what had to happen has happened". The only concern of the mother regarding government provision was that there should be doctors who would be willing to diagnose and give medicines to such children whenever they have minor colds or sore throats. Most of the doctors the parents encountered, especially in private clinics or nursing homes refused to help out or would be sacred of handling such a case and they would have to travel to one of the bigger government hospitals for treatment.

This led to the question about Manav's future, the parents seemed resigned as if to their 'fate'. The anxiety upper most in their minds was who would look after Manav after the parents are no more. They think probably if God wills it some relative will look after Manav. But this anxiety, when it becomes overpowering often leads the mother to think that all three should die together. According to the mother it is only the parent who can look after their child in the best possible way. She further elaborated that since looking after such a person is considered "ganda kaam" (dirty work) by society hence parents are the best caregivers.

NARRATIVE 6: "A Way of Handling Stigma"

Nidhi is 22 years old and belongs to an upper middle class family. She lives with her brother and widowed mother in a rented accommodation in a low-income colony tucked away in the depths of a posh south Delhi area. They shifted to Delhi recently, in fact just a couple of years back from a kasba (small town) in UP.

Nidhi was a premature baby, born in the 7th month and weighed 1.5 kgs. After 6 days she was diagnosed with jaundice, her weight fell to 700 grams and she was put in an incubator. However soon after she was put in the incubator she started frothing from the mouth and was given oxygen. She was in hospital for 40 days and gradually her weight increased to 1600 grams. Although Nidhi is diagnosed with mild CP her main problem is in walking and maintaining her balance, hence she walks with the help of a walker. After she was discharged from the hospital they returned to their small town.

Nidhi's paternal grandfather was some kind of a big shot in the kasba and when Nidhi was small her condition did not really matter in his social interactions with people around. However as Nidhi grew up and reached the walking age, the grandfather started imposing restrictions on Nidhi going out or being taken out. He feared his reputation would be at stake and that people would point their fingers at him and talk about his granddaughter's condition. However since Nidhi's growth was delayed, she went to school only till the 5th standard because physically she started looking older than the other children. The grandfather was obviously a patriarchal and authoritarian personality for Nidhi's father did not have much say in bringing up his daughter in any other way than was dictated by the grandfather. After Nidhi's father passed away due to tetanus and soon after the grandfather also passed away, Nidhi's mama suggested that they shift to Delhi to make Nidhi capable of doing something.

Nidhi is a short and tubby, very sharp, alert and aware girl who loves talking and is capable of expressing herself fluently. Once they shifted to Delhi they looked around for a school for the disabled. Today she is in the vocational unit of the SSNI. The mother very proudly remarked that Nidhi is very intelligent and understands things well. It was because of her grandfather who was in a high post in the village or rather a very small town (kasba) that he didn't want his reputation to be affected by people talking about his granddaughter being disabled. At the most he would explain her condition as she couldn't walk but would not say anything about her mental slowness. Hence she attended the town school only upto class 5. However since she started going to school late, by the time she reached class 5 she was around 14 years old and her menstruation started and not knowing how she would be able to handle the situation in school they pulled her out of school. Although while at home there were enough people to occupy Nidhi her energies were only channeled within the family circle as a result she is an extremely social person and loves chattering away and can talk nineteen to a dozen. Her manner of talking is also that of a very mature adult. She always wants to please people and is extremely self-willed, a trait the mother attributes to the grandfather for spoiling and pampering Nidhi.

When Nidhi was born and her condition discovered the parents and especially the mother, never thought it was going to be a lifelong condition. But a lot of support was given in bringing up Nidhi. Since the grandfather was very concerned about his reputation, he ensured that all sorts of help in the form of: medicines and aids were available to make Nidhi comfortable. The mother does resent the control imposed by the father-in-law over Nidhi, and how her development was impeded by his attitudes. However she covers up by saying what could be done, it was a small town, and theirs was a conservative family where girls were not allowed outside the house, so at least he allowed Nidhi to study upto class 5.

The mother did not recall much hardship in bringing up Nidhi or dealing with her disability. Except for a problem in walking and in holding objects, Nidhi's mind was very active and that covered up for any 'defect' anyone might notice. Although the mother stated that Nidhi is a bit slow mentally, her nonstop chattering is a symbol of an active mind and seems to compensate for her physical disability. The mother feels the move to Delhi has been good, since many more of Nidhi's abilities have been tapped. Also a peer group for social interaction has done her lot of good.

The mother, in what appears to be a rational and practical attitude to handling the whole situation, stated that she is not someone who easily displays her emotions. For instance she came to grips with her husband's death, by one fine day telling herself that moping around is not going to help and that she needs to pick up strength to look after her children as well as she can. Though she does not deny moments of sadness about Nidhi's condition, and these moments she shares only with her sister, mostly in joking terms such as "oh you will become a nani, whereas I will never be one." She feels bad that people around her are collecting jewelry and saris for their respective daughter's marriages, whereas in her case there is really no need to do this because Nidhi will never wear saris and because of shaky hand movements she will never be able to wear heavy jewelry. The mother is also forcibly denying herself and Nidhi the little pleasures of life. For instance the mother will not go to a place which is inaccessible for Nidhi, saying that she (the mother) doesn't feel like going there. However over time Nidhi has understood this is the mother's way of not letting Nidhi feel bad about not going. But the family always ensures that Nidhi goes everywhere that they go.

Although the mother appeared composed and mentioned that she rarely reveals her feelings except to her sister, she actually had tears in her eyes while conveying her anxiety about her daughter's future and who would look after her. The one thing the mother emphasized throughout the conversation was that the 'saving grace' of Nidhi's condition is that although she is 'mentally slow' she is at least not retarded. Hence the stigma attached with a typical disabled child as 'mad' is not there in this case.

The mother said that she was not particularly anxious about the future in terms of finances for Nidhi, because they have made provisions for that situation. And the mother is hopeful that Nidhi will be able to hold a job, not for the money it will bring but for Nidhi to be kept occupied, interact with other people and feel independent about her life. The mother envisages a life of loneliness for Nidhi if she doesn't have a job for how long can she continue in SSNI? Hence in Nidhi's case there is no financial problem nor is Nidhi's condition so severe that she is bedridden, yet it is a personal tragedy that the mother is still trying to resolve. The mother ends our session by saying that till she is there she will look after Nidhi, and in Nidhi's happiness is her happiness.

NARRATIVES 7 & 8: **"Time Seems Endless"**

In one of central Delhi's most crowded areas lives Ramesh with her husband and two sons. Both the sons have been diagnosed with having CP. The older son, Sumit is 21 years old. He is all of three feet, has profound CP and mental retardation, is bedridden, makes no eye contact, has no body control and is completely dependent on someone else for everything. The younger son, Dheeraj is 14 years old. He has also been diagnosed with CP, but he can walk unstably, eat foods like a chapati or carrot given in his hand, and is toilet trained but does not speak; someone constantly has to keep watch on him because he just gets up and wanders off whenever he likes.

The family lives in a room about 10 by 20 feet in dimension, there is no window or any other source of natural light or ventilation. There is a single box bed; nearby is a concrete ledge with a stove and few utensils and *dabbas* with provisions. There is a radio blaring with some raucous film music to keep Sumit company though he did not seem to respond in protest when it was switched off. The main source of income for the family is their little tailoring shop, which is in the front portion of the room. Ramesh does the bulk of the work while her husband does some of the embroidery work. They manage to make about 2000 rupees a month, out of which about 500 rupees goes in the medication of the older one.

While narrating the story of Sumit's birth, the mother stated that he was a Full Term baby and she had no problems during her pregnancy. Ramesh emphasized the fact that it was family problems, which affected her psychological condition. While Sumit's disability may have been a medical problem, the lack of family support, along with financial problems, not enough to eat, problems of physical space led Ramesh to feel that the whole situation is socially constructed. Though her family was supportive, she got no help of any kind from her husband's family. In the initial years the tense and strained family relations and the discovery that her child was disabled left Ramesh in a state of complete helplessness, hopelessness and despair and she would just keep crying. There was no one to give her a shoulder for support.

Ramesh was very young when she had Sumit and did not know much about babies or child rearing and there were no elders to guide her. When he was about 6 - 7 months old, the mother realized that the baby was not responding to things, was not making sounds did not smile or recognize even her. They took him to the doctor who just told the parents to play music for him and then he'd be fine. The mother was disgusted with the doctor's response because there were other problems such as his stunted growth, low weight, getting fits, apart from the lack of social responses that had not been attended to. After this experience the mother did not go to any other doctor.

However in the case of the other son, Dheeraj, at 8 months he started sitting. His growth till 2 years was good. But after that there wasn't much progress mentally. Regretfully the mother said that on their part too they couldn't do much - as they already had a handicapped child who needed their full attention. Apart from looking after the two sons, the mother also had to manage the house. She feels that if at that time she had got some help from the family, or an organization, or from the government, probably the younger one could have been a little more able to do things on his own. Financially also they fell on bad times and had to somehow earn their living. That is when they started this little tailoring shop.

The parents got to know about SSNI from a fellow passenger in the bus to a religious place. Ramesh is extremely grateful and thankful especially to the emotional support that SSNI gave them. Apart from the crucial emotional support, which she desperately needed, they taught her how to manage Sumit and Dheeraj. Though Sumit never became independent in his eating, dressing, and toilet activities, the SSNI training did help in managing Dheeraj. The counseling sessions also really helped especially Ramesh. The essence of what she was told during those sessions was that what had to happen has happened and cannot be undone; we must try to handle these children and work on whatever strengths they have; these are statements which have remained with her and it is that which has really helped her in coping with the situation to this date. The SSNI also asked her to do many things from exercises to other skill training but she was never really able to do them due to various constraints and they know it for she never lied about having done it committedly.

When Sumit was 6 years old, the little one was 6 months old, on one instance the helplessness and hopelessness of her situation hit Ramesh in such a way that she just cried; the Big Madam at SSNI told her "cry as much as you want today. Look your younger one is better than your older one, but what if he was worse, would you have thrown him away? Thank God for what you have and live as happily as you can with them." That statement made Ramesh look forward in life and take a grip over her situation.

Apart from the counseling sessions there were *bhajans* in the school, which calmed her and gave a lot of solace and some kind of inner strength to deal with the situation. Her husband is very supportive. But he never worked with the children because he felt that it did not make a difference. At times even she used to feel similarly but she'd overcome that feeling by saying to herself "it is our duty to do what we have been told to do".

Ramesh got no support from her husband's family. It was only her mother who could not contribute much financially but offered to take the younger boy to the village. However the mother was already aged, and as Dheeraj grew older his hyperactivity also increased. After a few years it became difficult for the grandmother to look after Dheeraj and she brought him back to Delhi. The grandmother used to often come to Delhi to help the daughter look after the children but due to the lack of space she could not really stay for very long. The grandmother's way of dealing with the trauma, and the irreconcilable fact that there is no cure for them is to see the children as God's avatars, especially the older one who makes humming sounds. Hence her reasoning is that one can only help look after them to the extent of making them comfortable - the rest is in God's hands.

Today reflecting back on her life Ramesh said "one has come a long way, there have been changes in our thinking and understanding of the situation." She talked of the energy and courage she once had when she was younger. Now she is finding that it is no longer there with the same vigor. The ability and will to bear harshness is flagging. She said, "now we ourselves are growing older, we are getting all sorts of aches and pains. One is no longer physically fit to deal with the situation and this results in anxiety about the future." The levels of anxiety had reached such an extent that a local doctor told her forcefully that it was imperative that she get out of the house for at least half an hour a day to retain her sanity and 'mental balance'. This statement of the doctor was taken seriously by Ramesh and with a determined effort she fights the guilt of leaving her children and family unattended for half an hour as she goes to visit a neighbour, or to do some shopping. One month of trying this new routine has brought renewed energy in her life, and she no longer has the same intense feelings of claustrophobia, of being boxed into an existence where there seems to be no life of her own outside of her two disabled children and a financially troublesome existence.

Ramesh is very articulate in expressing her feelings and state of mind: through tears and smiles she narrated the ups and downs of her life. In the beginning she used to feel this is not the life she had dreamt of, she had doubts about "were they bad people that such mishappenings should befall them" and "now God was testing them". However today she has gotten over all those fears and in a more rational frame of mind she has come to the conclusion that her consanguineous marriage, along with tense family relations and poor economic conditions have brought about this situation. She still dreams of a normal family, normal in terms of children, finances, and every day living. And this dream she nurtures in the form of still having a child who is 'normal' and at some level feels that then it will be that child who'd perhaps help look after the two disabled children; that child would also be someone with whom she can just have a normal reciprocal interaction. Sometimes she feels resentful of her situation, she feels if only she was more educationally qualified to get a proper job, if only she was more educated to argue with her parents not to be married into the same family, and if only she could shift out of this cramped space back to her village where the feeling of claustrophobia would not be there. But she stops herself abruptly from saying anything further for, as she puts it she has lots to do and doesn't have the time or the energy to be remorseful. Also she thinks aloud, for how long can she be remorseful. Time seems endless and is taken over by new fears and anxieties at each point. Looming large at present is the anxiety not about how they as parents will cope but what the future holds for the two children and what will happen to them once the parents are no more. Resignedly but not without determination she ends by saying that just as we have lived life till now, some thing will come up to look after the children when we are no more. There was no expectation from the government or the organization in terms of providing support but it wasn't as if any support would not be welcome even now. The only thing that came to her mind regarding government provisions was that in the initial years, at the time she was bringing up her two disabled children and facing tremendous financial problems, if the government had some scheme by which parents could hire services it would have helped enormously. Even if the services were not provided free of cost, the mental and physical difficulties they went through may have been reduced and they could have better provided for their children.

NARRATIVE 9: **" A Lifelong Condition"**

Shweta belongs to an upper middle class government service family. Both the parents are educated; however the mother never worked outside the home. Shweta is 26 years old and is diagnosed with a case of moderate CP. She was born prematurely at 7 months. During her pregnancy the mother had severe bleeding in the 4th - 5th month. It was only when they noticed that Shweta's milestones were delayed did a doctor tell them that Shweta was spastic. At that time they never knew that it was going to be a lifelong condition. All that they were told was that she would be slow in doing things. When Shweta was around 4 years old they took her to AIIMS where they put her on a 3 months exercise schedule. On one occasion, as they were taking her for the exercises, they had seen the SSNI vehicle and noted the address and decided to take her there and she got admission.

From the time that Shweta was a baby the parents have done everything for her. They were fortunate that very early on they got to know from a family contact the meaning of spastic, and the importance of exercises in ensuring some amount of bodily movement. Neither parent's family commented upon Shweta's condition as a misfortune nor in fact did anyone else; everyone was very helpful and went out of their way to get more information about the condition. Further, since the father was in a transferable job, the family was a nuclear unit, hence all decisions taken were their own rather than the extended family getting involved. All the relations are good to them and especially to Shweta. Shweta accompanies them and is invited to all family and other social occasions. Initially they used to live in a rented accommodation, but they had no problem regarding Shweta in such accommodation. They never felt embarrassed or ashamed about Shweta's condition. But this statement seemed strange because throughout the interview or, even at the time of my leaving they never offered to introduce me to her and when I asked them to meet her, they hedged a bit. And I never met Shweta.

The mother acknowledged that she still goes through periods of depression, not so much about 'why did we have such a child', but about 'what will her future be' and she feels sorry for the kind of life that Shweta will have to live. The parents had believed fervently in God and took her to all possible places told to them by well wishes around. The mother kept all sorts of fasts and made all sorts of offerings. But after a while they thought that if medical science cannot find a cure how will these things help and they stopped doing all these 'tamashas'. However they still have trust in God, and although they know that she will never become completely okay all they now pray for is that her mind should be peaceful and calm. Shweta's father has never expressed moments of depression regarding Shweta's condition but he is anxious about her future. He also helps a lot in looking after her, from helping to give her a bath to feeding her and other such ways of looking after her. Recently Shweta underwent a hysterectomy, a decision taken in consultation with Shweta, her parents and the school. They took this decision because it was getting difficult to lift her and Shweta herself was finding it difficult to manage. Thus in Shweta's case she is well provided for in every way, the family includes her in all the activities and decision-making. For instance it was Shweta who finally decided the bride for the elder brother.

Now she no longer goes to the SSNI as the authorities said that other more 'able' students should also get an opportunity. This decision has upset Shweta considerably and she has become a very embittered person ever since she left Spastics Society 5 years ago. This anger of hers is something that the family is finding very difficult to deal with. For instance Shweta gets very angry at the mere mention of the SSNI. The parents also are angered by the fact that Shweta is no longer going to SSNI and they feel that the attitude adopted by the SSNI that since everything has been taught to the parents they might as well look after her, and the SSNI is not able to give anymore does not recognize the harm that is experienced by Shweta. The parents feel that all the support and comfort the SSNI provided in the years when Shweta was there has been withdrawn without the realization that such children once had a routine, had friends and peers in the school, and going to SSNI was also an outing for them. All this is causing the child such mental agony that it is difficult to cope with it; she cries, she is frustrated, is angry, and above all feels helpless because of her condition. The parents in turn feel that if only the SSNI is willing to give them physical space to organize activities for such persons who have been withdrawn from the formal programmes of the SSNI it may help their children cope psychologically with their situation. The parents feel that already the disabled are discriminated against and if an organization that is sensitive to the needs of the disabled, and has provided so much physical and emotional support, then why this discrimination when the children grow up and are not considered 'worthy' of training anymore and someone more able-bodied is given preference over them. The parents have no objection to the fact that other disabled children, who are capable of doing much more should not be given a chance but they feel that children who are not so able should not be left out too.

The parents are very troubled regarding Shweta's future. In their present state of mind they feel helpless about what to do. However parents of children in a similar situation have decided to get together and organize a gathering of the children every month so that there is at least some social interaction. Even so it is getting difficult to keep Shweta occupied. She feels cooped up at home the whole day. Shweta is very bulky and this has affected her mobility: hence taking her somewhere is also a major problem especially since the parents are getting on in age and the brother is not always available to help. The parents have also not been able to engage a reliable person to help them. They know about the 'benefits ' for the disabled in terms of the government provisions such as rail concessions and income tax rebates. The parents felt that there was nothing much that the government was doing for the ordinary 'normal' citizens so they were quite sceptical of how it could be expected to do anything for the disabled.

NARRATIVE 10: "Allah ki Azmaish: Becoming a Lawyer for the Disabled"

In the course of my talking two young professionals at Vidyasagar, a school for persons with Cerebral Palsy in Chennai, and a reference was made to a young woman called Umul. The context of the reference was how much, they as professionals, had learnt about the needs of the disabled in reality from Umul than just through books. Expressing my wish to meet Umul, the next day I was led to the room where Umul and another girl, a slow learner were busy studying for their Open School exams. She very graciously agreed to have a little chat with me and was quite flattered to do so, as she later shyly revealed to me. Umul used to live in Bangalore with her parents and brother. At present she is in Vidyasagar doing her tenth standard from the Open School and is learning to cope with living independently.

Umul is 25 years old, small made, with a lovely smile and is a very chirpy and enthusiastic young woman. Her mind is full of ideas about things she has to do. She narrated her life story so to say interspersed with confessions of details she didn't know too well. She narrated the hardships her parents have gone through. And of how now she feels responsible for helping them out so that at least the rest of their life they can lead peacefully and happily. In a very lively manner told she me about the big circle of friends that she has made, her life in Chennai, how she has overcome her fears and is learning to cope by herself. One of the biggest fears she had was traveling to Bangalore all by herself in a train. Although she was nervous, the people at Vidyasagar instilled enough confidence in her to undertake the 6-7 hours journey all alone. This first trip brought a new confidence in her so that she is capable of managing herself beyond the daily living skills of eating and dressing. This experience along with other things she has picked up to build her confidence, has made Umul sensitive to the rights of the disabled. This understanding has led to Umul's ambition to become a lawyer for the disabled. She elaborated on the reason for choosing the profession of a lawyer not only to fight for the rights of the disabled but also because a lawyer gets paid well and she would be able to support her family too. As soon as she told me about her ambition in life, she abruptly ended the conversation by saying, "okay, now I have to go and study." And I wheeled her back to her study room.

When I went to Bangalore I met Umul's family. Umul's parents and younger brother live in a tiny one-room apartment in Bangalore. Her father is about 75 years old and the mother about 50 years. Neither of the parents works any more, except that the father takes up small tailoring jobs to be able to purchase the daily necessities. Narrating the story of Umul's birth the parents said that after she was born she did not make any sound. She never lifted her neck or head. When she was about 1 year old they took her to a Unani doctor who prescribed some herbs and hot fomentation of the neck area. Although she started holding her head her hands, legs and body still didn't move. But from the beginning her mind was absolutely alert, she followed what was said to her and tried to respond. When she started talking she would ask the mother to move her hand for her or turn her over. However for a long time no one really knew what was this condition was called. All her milestones were delayed. Everyday the mother used to take her to the hospital for exercises. But once the mother started working, she could not manage to take her for exercises. The father used to go off for work and the mother used to lock up Umul in the house from 9 to 5 since there was no one to care for her. This resulted in Umul's legs getting locked. When they next took her to the Unani hospital, the doctor there said sternly to the mother "do you want your daughter or your job?" the mother replied "my daughter", to which he said "then leave your job and do these exercises with her." It was a very tough decision to take because the financial situation was very bad and they were in debt. In the anxiety of repaying the debt Umul's father had a massive heart attack and lost his job. Ever since then he has no longer been able to do any job which requires strenuous work. The mother still had her job as a schoolteacher but was very low paid. In the hope of a better job and to avoid problems such as being dependent on his family for a livelihood the father decided to shift to Bangalore from Madras. They had no savings, no money for daily expenditure and somehow they managed to procure

Umul's medicines, which were necessary. Juggling the shift to the new place and managing two small children, and an invalid husband, the mother some how tried to retain her job in Madras. She used to commute from Bangalore to Madras by train, carrying Umul who was 8 years old, every where on her hip because she couldn't walk and they did not have a wheel chair. On one occasion they came across spastics' society in Madras and admitted Umul there. The mother stayed on in Madras but this was only for 1 or 2 years because the expenditure of running two establishments was too much. Finally the mother left the job without managing to complete the term to get a pension and returned to Bangalore. Even today the mother regrets that she left the job and if only they could have borne the hardship a little while longer then at least now they would have been living on a pension.

Umul was born 9 years after their marriage and thus was very precious to both parents and hence they were not disappointed or sad about her condition. Also since Umul was mentally very alert from infancy she had won her parents hearts. The father reflecting back said that if they had been disappointed then how would they have been able to support her emotionally today. She has been their pillar of strength through all ups and downs.

Once they were in Bangalore they put her in the Spastics Society with the aim that she would learn to walk. But the Spastics Society only focussed on teaching her vocational skills of stitching. Although she is good at it and it was a useful skill she didn't like it at all. Then they put her in another school which also did not help much and Umul felt frustrated as she wanted to do something more than just stitching and embroidery. This frustration to do something and be of use is the starting point of Umul's story of determination. Once they went to Madras for someone's marriage. There Umul contacted the director of the then Madras Spastics Society, Poonam Natarajan through great determination, hardship and persistence. Umul talked to the Director at length about wanting to do something and to become someone and be independent. Finally Poonam asked the parents to leave Umul for three months so that they could train her in independent living skills. Realizing that Umul also has the aptitude for academics they admitted her into the Open School. Not knowing what to say the parents just said, "she is your child - do as you like but make her someone worthy. We don't have the resources to do that for her". It is since that day that Umul has been living in Spastics Society's premises, pursuing her Open School studies, to become a lawyer and fight for the rights of the Disabled.

At the time of Umul's birth and in the subsequent years the extended family had a lot to say and transferred their anxieties upon the parents about how would they bring up not only a disabled child but also a girl on top of that. Listening to all these things the mother used to go into depression and anxiety. However Umul's father, although he went through bad times and is still in the same situation, has extreme faith in Allah. He believes that Allah sent them to earth and now He will also look after them. At the moment they are going through a bad period but a day will come when things will look up. He says all this Allah's Azmaish.

Soon after Umul went to Madras to study, the mother had spells of blackouts, or she would for no reason start laughing or crying. They took her to the NIMHANS and discovered that she had a swelling in the brain and had to be immediately operated upon. Somehow, by taking loans, they managed to get the brain surgery done. As a result of this expense now there isn't money to have the father's cataract surgery done. Despite all these hardships the parents have not lost their spirit for living life, they have never hidden Umul or her condition, and she has participated in every event of their life-- happy or sad. Today she turns to the parents and supports them emotionally and helps them to deal with their anxiety for her. The parents are wonderstruck at Umul's capacity to be perceptive, understanding and sensitive to her parents' conditions. They have pinned all hopes of a better future on both their children. On her part Umul is very optimistic that a day will definitely come when they will all live happily ever after.

EMBEDDING THE INDIVIDUAL BIOGRAPHY

> *Case studies of individuals reveal suffering, they tell us what*
> *happens to one or many people; but to explain suffering,*
> *one must embed individual biography in the larger*
> *matrix of culture, history, and political economy.*
> *- Paul Farmer*

The Professionals:

The ten narratives of disabled persons and their families presented in the last chapter reveal certain patterns and a number of points emerge for discussion. To begin with, it is apparent that left to their own devices in a hostile social environment, parents have had to find their own mechanisms of handling their children's disabilities. The accounts of the almost all parents suggests the very basic nature of medical knowledge prevalent about Cerebral Palsy (CP) twenty or more years ago, which meant that the parents did not really get to know what was wrong with their child's development. Additionally, the manner in which the disability was handled by the medical profession at that time left a lot unstated. In the absence of precise medical information the parents could only attribute the cause of the disability to the 'lack of oxygen at the time of the birth of the child', or to a fever suffered during infancy. At no point did the medical profession reveal to the parents what the *specific* condition of the child was, or what the future would entail for the child concerned, or for its parents. The routine 'solution' offered by the profession was to ensure that 'exercises' were done regularly so that the child would become capable of some level of independence. The birth of a child with a disability remains for parents a situation which they feel is totally beyond their control, something they are completely unprepared for, as Ghai recounts on the basis of work with parents of the impaired for many years. Ghai writes eloquently about the emotions that parents are engulfed by when they 'discover' that their child is disabled:

> The ordeal begins with the very act of diagnosis. Doctors and allied professionals tend to avoid breaking the news, typically offering a cause for disability after the child's birth, giving the news abruptly or failing to give the parents the a true picture of the disability. Presumably this is done to reduce the stress of the situation, although each measure may serve only to increase parental feelings of futility and hopelessness.[1] .

Not much change seems to have occurred in the last twenty years in the attitude of the medical professionals in the handling of a disabled child. It is not unusual, even now, to refuse to help out a child who may have something as simple as a cold, because it is feared that something 'will go wrong' almost as if a disabled child is subject to a different medical pattern than the 'normal' child is. In the case of Dolly, the senior doctors of a government hospital refused to handle the case when she broke her jaw, dismissing it as too risky. It was only the courage of a junior doctor, who went against the orders of his senior and performed the requisite surgery under local anesthesia, that restored Dolly's ability to eat, speak and give that lovely smile which is so characteristic of her.

Another aspect, which emerges from the narratives, is that despite the small number of organizations in existence 20-25 years ago the services offered in terms of emotional support is perceived to have been 'tremendous' in the case of those children and parents who could access the organization. However over the years it seems that though the number of organizations have grown the range of services offered has not really diversified. The new organizations coming up still seem to be providing the same basic services-- that of early training of the disabled-- just as the SSNI and other such organizations had done twenty years ago when they had started the programme. Even organizations, such as SSNI, which by now has children in the age group of 20 to 25 years, and can see the changing and growing needs of the disabled children-- now young adults, have not, for various reasons, been able to further the catering of services to this age group of children. Such organizations have realized the need to change their orientation in terms of the educational and, to an extent, vocational, emotional and social needs of the disabled persons, and even more so that of the parents, in order to deal with the needs of the later stages of the lives of the disabled. Yet there is nothing that they have been able to actually do to service these needs. This is evident from the oft-repeated refrain of the parents that children with special needs require social interaction and need to be kept occupied. The parents are caught in a dilemma: they realize that younger children, and children with slightly less severe degrees of disability, will benefit far more from educational and vocational training than their children might, as well as the fact that the institutions are constrained by resources and space. But the parents also realize, and want organizations also to recognize, that it is beyond the capacities of the parents to be able to organize social and emotional interaction for their children. This is because not only do they lack the resources for organizing these sessions but also because they have run out of the energy that requires to sustain them on an ongoing basis. Their energy is required not only for the physical caring of the child, but also in trying to ensure a secure future for the child once the parents are no more. Another aspect related to the expectation of support from institutions in dealing with the disabled at different stages of their lives is the fact that since such organizations had come to the aid of so many parents in the initial difficult and troubled years of bringing up a disabled child, the parents have high expectations from the organization later on too. In the absence of any other support structure, medical or social, the organization has come to function as a crutch for them; the feeling of betrayal comes across poignantly in the lament of the parents that 'the organization is not doing much for the children now'.

Need for Space

From the discussion above it is apparent that there is a desperate need for social and psychological spaces in which parents as well as the child can express themselves. While parents are now seeking ways by which it becomes possible for the growing disabled child to be in touch with other people, the organizations are not adequately prepared to cater to such needs due to several constraints mentioned earlier. At the same time the family's social interactions have come to be severely restricted due to a number of reasons such as the difficulties of sustaining a social network in the face of a hostile and stigmatizing society. In most cases interaction remains confined to the extended family. In the course of recounting their lives one rarely came across the parents talking of taking their child to their friends' place or of friends coming over to spend time with the parents, or drop in on an occasional social visit. The situation is one of a bind wherein the social and the familial relations are amongst the same people - the island of parents, siblings and the disabled person since the public typically cannot understand the child's situation. The need for social and psychological space, particularly in the case of the disabled persons, is evident in Natarajan's account of a plan for a summer camp that was designed for a group of mild to moderate CP adolescents. When they discovered that their parents wanted to accompany them they rebelled at the idea-- the whole point of the summer camp for them was that they would be away from home--and that included their parents! The students went up to her and told her quite forthrightly that they did not want their parents in the summer camp with them. Natarajan sees this situation as the parents being over-protective and sheltering their children too much, so that the children had no life outside of their parents.

However, another way of looking at parental over-protectiveness is that although it may be excessive, the social support network is so negligent that the parents in their attempt to ensure some entertainment for the children have themselves become their primary 'entertainers' as this need is not recognized by anyone else as a need. Natarajan's example also highlights the different levels at which the parents have to take responsibility for their disabled children by displaying their active participation in every aspect of the child's life, not just in physical caring. But it is necessary to recognize that the parents too need psychological and social spaces for themselves --which they perhaps cannot articulate to the world outside, and maybe not even to themselves, caught up as they are in the stereotype of the *seva bhav* that is expected of them. Thus

Ramesh, the mother of two disabled children/ adolescents, who has absolutely no time to herself and is worn out with work has had to be medically advised by her doctor to go out of her house for a while everyday as a way of switching off from her duties as a mother caring for her disabled sons. The need for social and psychological space is also articulated by Ramesh who talks of the need for 'space' more in physical terms, expressed in the desire to go back to the village, a more open space where life would be 'easier'. However the revelations of the study of 41 villages of Andhra Pradesh indicate that the need for 'space' is very much a psychological need, emanating from a feeling of being trapped in a situation rather than merely in a physical space. The romantic notion of life being easier "there" is dispelled in the case of a mother with two children with disabilities, one aged 3 and the other 5, who lives in a village: "the mother wept and said that she had not been able to leave her home even once in the past five years because of the unrelenting need to take care of the children."[2]

This leads us to examine the issue of whether institutions actually cater, or can cater, to the "felt needs" of not only an educational and vocational nature but also to the emotional and social needs of the disabled persons and their parents. Given the meagre facilities that are available to the disabled and their families it appears that there is a long way to go as far as meeting the felt needs of disabled is concerned.

Institutions, as a provision for long term care, especially for the profoundly and severely disabled persons, have not been seriously regarded as a support service in the Indian context. As a result the only types of services provided by institutions is for prevention, detection and early training of the disabled persons. The western model of the institution as a "modern" institution, which can take over the caring function otherwise performed by families, has not been considered. However the case of Erwadi[3] and the rural study of 41 villages in Andhra Pradesh[4] reveal that there is a need for institutional support of a kind, redesigned perhaps as caring support for long term care needs, especially for the profoundly and severely disabled persons. The report on Andhra Pradesh describes how the disabled are left without food and care for long periods as families go out to labour. Erwadi brings out the indigenous variant of the institutional solution to care linking it to faith and traditional healing beliefs, a system existing outside of the state structure. This leads us to think about locating the issues of the rights of the disabled, and of care and caregiving, in a broader political economy and cultural context. Neither from the narratives of disabled nor from the secondary writing on disability, do we get a picture of either the state or alternative traditional structures actually providing any significantly feasible, humane and acceptable ways of caregiving to those who need it from the point of the disabled and their families.

Role of NGOs

At this juncture it would be useful to examine, from the viewpoint of the parents, the origins and the entry of the NGOs into the field of disability. Since there was almost nothing being done by the government for the disabled, about two decades ago, the parents of the disabled children and other concerned citizens in the urban areas found it imperative to take it upon themselves to provide at least some of the necessary services. A few parents and parents associations have come up since then to cater not only to the early training of disabled children but also to form a parent support network for the future of their children. Their lobbying for some services, which can address the future of the disabled children, has resulted in the setting up recently of the National Trust for persons with Cerebral Palsy, Mental Retardation, Autism and Multiple Handicaps.

One of the services offered by organizations, which has received universal praise, is the counselling provided by them. The parents were unanimous about the tremendous help they got from the organizations in the initial years of their coming to terms with their child's disability through counselling sessions, or therapy, through organizing satsangs or bhajan sessions. Such services do cater at one level to the 'felt needs' of the parents; the activities also mark out the capacity for innovativeness on the part of NGOs rather than restricting themselves to merely providing services in terms of early training of the disabled child.

A crucial lacunae that comes to light in many of the cases is the absence of support services for the physical day to day caring of the child, the caretaking and caregiving has taken a tremendous toll on the parents, both in physical and psychological terms. The physical toll can be seen in the form of getting severe backache, which was mentioned explicitly in the case of Surinder's father, a consequence of lifting the child all his/her life. The responsibility of physically lifting the child begins in infancy and continues through adolescence to the present when the child is a young man or woman-- well into their twenties--and the parents have to lift the young adult many times a day. The psychological, as distinct from the physical, toll can be seen in the case of Dolly's father who cannot walk because of the psychosomatic condition brought on by the anxiety about a daughter's future. Apart from 'routinized' ill health of the parents resulting from looking after the children, other cases of ill health such as the instance of the parent who had cancer, there were no support services outside the family on which the mother could rely throughout the period of her treatment. The NGOs cannot address such problems and at the most they can provide a sympathetic ear. It is to deal with these kinds of situations, as well as many others, that the state can help as it alone has the resources to initiate a wide network of services to help the individual families which are otherwise trapped in their own individual struggles of trying to cope with their existential realities. For example Ramesh drew attention to the need for a subsidy from the state which would enable her to employ domestic help to help look after her two disabled sons; without such a subsidy she cannot afford to hire any help.

Caring and Caregiving

In the context of the responsibilities falling upon parents there is a need to understand the issue of caregiving and caregivers in the larger context of society. Both the state and society need to have a holistic understanding of the role of the caregiver, who would need a range of supports which extend beyond the family, to the community, to health care, to educational and vocational supports. Three dimensions of caregiving in the context of the provision of care for AIDS patients have been identified: the relationship between the caregiver and ill partner, changing conditions of caregiving, and the development of caregiving skills over time. This would apply to the care required by the disabled too.

While disability is one condition which requires long term care there are others such as diabetes, epilepsy, mental illness and AIDS which also require different types of care. It is with the international concern for AIDS that the area of caregiving is receiving a lot of attention nowadays. Whatever the reason for recognizing caregiving as a long-term requirement of certain conditions the 'burden' of caring still falls on the family and within the family more specifically on the wife/mother/ or any other woman. The continuous responsibility of caregiving by the family in the absence of any support networks results in the suppression of feelings such as not wanting 'to do it anymore', which can happen at some point in time. For instance in the case of Ramesh who has two CP children, the father though supportive, doesn't actually do any of the exercises for the children because he feels that there "is no point", since in his view it doesn't make a difference in terms of improvement. While Ramesh also has similar feelings, she still goes ahead with doing the exercises by reasoning that 'it is our duty to do them'; as a woman and a mother the option of not doing so does not arise. Similarly Manav's mother left her aspirations to work as a teacher because she felt it would result in neglecting the care of her child and 'seva' is what the child needs. The need to cope with the situation as well as rationalize her stance of 'seva' has been internalized to such an extent by Manav's mother that she is even willing to look after 10 'such' children she says, highlighting the fact that in the course of looking after Manav she has developed one of the essential caregiving skills, that is patience.

Stigma

A painful feature that emerges very clearly from almost all the narratives is the fact that the stigma attached to having a disabled person in the family does not really ever go away. The family may be psychologically 'tough' and may come to accept their disabled child and there could even be certain situations for which the family prepares itself to deal with; for instance while renting a house it is expected that the family may be discriminated against for having a disabled child. However there are also situations for which the family is never really ready: for instance the stigma the parents have faced when they try to get something as basic as medical attention for a cold their child had. The local doctor's blunt refusal to even see the child, and telling the parents to take the child to the government hospital instead, is something no parent could ever be prepared for.

Another form of stigma faced by the family is that experienced by the mother of the child: not only is the child stigmatized for being disabled but the mother is also stigmatized for bearing ‘such’ a child. In these situations while the parents may learn to handle people's comments about their disabled child, the mother is never able to handle the stigma attached to her for having borne 'such' a child, particularly when the husband himself believes that the mother is the 'cause' for the child’s disability. Ghai describes the mother of a mentally handicapped daughter recounting to her with horror how her sister-in-law told her that it was her own '*shrap*' or curse that was instrumental in giving the parents such a child.[5] Apart from the unequal power within households, in which the daughter-in -law remains the most vulnerable member, what emerges from these instances is the sheer cruelty of society as distinct from the negative and discriminative attitudes towards disability people have been socialized to uphold.

'Social' Support

A noticeable feature of the narratives, which comes prominently to the fore, is the role of the extended family in terms of the various kinds of support they provide to the parents of the disabled. In most cases it is mainly the woman's side that provides the family support in terms of financial, physical and emotional sustenance. It is the mother's 'burden', which draws her natal family to come into the picture in terms of sharing her labour, or trying to give her some physical relief. From the narratives it is clear that where the extended family support is present it has been of tremendous help to the immediate family of the disabled child in tiding over difficult moments. Again, what is interesting is that it is the mother's mother, or the mother's sister, who get involved in the physical looking after of the child. It appears that it is women who substitute for each other's labour out of affection and concern for the mother, who is the primary caregiver of the disabled child. On the other hand the lack of family support can have devastating effects as in the case of the mother with an alcoholic husband who had no support from the in-laws, and whose parents could only support her in a limited way due to constraints of resources. In such cases the mother was very fortunate in finally finding an institution to support her, thus highlighting the importance, role and need for support services outside the family. The model of family support, or family-like caring is an aspect of societies and states, which have few institutional facilities. As Dalley writes, 'societies, which do not have formal segregated care systems, the principle structure of kinship has to provide the basis for caring'. In India institutional care is almost totally absent, so clearly where the responsibility for providing care falls on 'society', the form of care adopted is either modelled closely on the familial model or falls upon the family directly.

The discussion on care highlights the fact that in the absence of support services, the hardship the family has to undergo is enormous. It is also evident from the narratives that in most cases the families were not in a position to hire the services of another person to help in looking after the disabled person for various reasons: first because the families concerned cannot afford it; second because even though it is specialized work it is not paid very well so only a few will be willing to work in such a capacity and, finally, it is not considered dignified work. For instance Manav's mother, in expressing her anxiety about who would look after Manav after the parents are no more, said that it would be better if they all die together because no one would look after Manav with the same care and affection as the parents since looking after 'such' persons is considered "*ganda kaam*". Even in families where they can afford to hire services, as in Surinder's case, the service is not very reliable and the turnover is very high. In any case the inability to hire services is mainly due to lack of finances to buy the requisite services. This brings out the existential fact of the 'burden" on parents in terms of care giving and raises the issue of poverty, stable and remunerative employment and social support. For instance in Umul's mother's case the family needed the finances for just the daily running of the household expenses; the mother *had* to go out to work and she could only do this by locking up Umul for about 6-7 hours everyday. This had an adverse effect upon Umul whose legs then started getting locked, neutralizing the mother's efforts of exercising Umul's legs before going to work. This 'no choice' situation was followed by the blunt statement of the doctor, 'do you want your daughter or your job?' An even tougher decision followed for the mother, straddling on one side the emotional guilt of being uncaring and on the other the financial imperatives of the family.

The situation of Ramesh who has to look after not one but two disabled children is even more desperate: while both parents are struggling to cope with the physical needs of their children, and require help to look after them, they have to also make ends meet. They have to balance the doubled burden of care giving with earning a living. Their only support, Ramesh's mother, can offer her services only for a limited period because she herself is aged and is in need of support. The limited availability of family support to the primary caregivers is also tilted in the direction of the maternal family. Thus in almost all the cases, cutting across classes, it is the maternal family that comes to the assistance of the mother as Ramesh's mother, though aged did. She took the younger child of Ramesh and her husband to the village when he was small and still comes whenever possible to help her daughter look after the children. Similarly in Anjana's case it is the maternal grandmother who provided the financial support in the initial years of the mother's widowhood. Even in the case of the better off family of Nidhi it was the maternal family, specifically the maternal uncle, who insisted that his sister shifts to Delhi from a small town after the death of the husband so that Nidhi could go to a special school. Perhaps the mother's family is involved because they are close to the daughter and understand her difficult situation, but perhaps they are drawn in because of the way the mother gets stigmatized for bearing a disabled child and therefore the husband's family simply abandons them to their 'fate'.

From working with families with disabled members, Naidu has also found that the disabled child's mother has stronger alliances with her maternal family. Thus her mother or sister helps out with the disabled child. In most cases the husband's family rarely provides any support because they think "all the problem has come from the mother's side." Over a period of time Naidu has found that what happens with all the different programmes of the organization is that they end up giving a lot of information to the mother. This results in the mother's transformation: for example she learns to come to the institution by bus, learns to handle people's responses. Through all this learning process her world expands. But one does not find the same thing happening with the fathers. The fathers are busy with their own work. They have their own feelings of anger and grief, which considering the way men are socialized, they often do not find ways to express or to give vent to their anger and grief. Therefore, as the woman is becoming more capable of handling her life she is really becoming independent: mothers thus become leaders in their own right at the 'knowledge' level. They become free of all other trappings of what is considered being a 'good wife' and mother because they have to deal with this challenge on a day to day basis. They are good problem solvers as well as good demystifiers of disability according to Naidu. The mothers are able to handle different kinds of challenges. What has to be facilitated is the husband-wife relation given the traditional role of the two in India. So while the mother is becoming more empowered, the question is will she be educating the husband? And in that case then what about the responsibility of the programme itself? Naidu feels that over time both parents need to restructure the way they look at disability, which sometimes on a daily basis, given the situation, is very hard.

Gender and Caregiving

The gendered nature of caregiving is also implicit in the narratives of the disabled. Although from many of the parent's responses it appears that both the parents are equally involved in the looking after the child, it is not actually so. In most of the cases the mother is at home, or has 'sacrificed' her desire to work in order to look after the child, or in some instances the mother has to take time off from her office to cater to some need of the child whether the child is ill or needs to be taken for exercises. From observations during the course of the interviews it could be seen that the mother was the one who was more actively involved in the actual physical caring of the child. This is an important facet and a facet, which has been much written and researched about as we indicated in Chapter One. It has been subjected to criticism by feminists in order to encourage a change in the attitude of society and to draw attention to the need to recognize that caring is not the 'duty' or the 'prerogative' just of women. While this is a valid argument and has been exhaustively discussed in Chapter One an interesting dimension to the gendered nature of caring was provided by a father of a Downs Syndrome young adult who in a conversation with me presented the flip side of the father's peripheral role in caring for the child. In his interaction with parents of the disabled he had observed that through the 'process of daily routine care giving the mothers were able to give vent, or release, to their emotional distress and emerged more resilient to crisis situations.' This was a contrast to the fathers who were bound by the stereotype that men are not involved in routinized care giving and did not participate in the physical looking after of the child. As a result my informant found many fathers suffering from depression and loss of will because they had no cathartic release or outlet for their bottled up anxiety for the child. This can be seen in the narratives presented here: the psychosomatic or real 'chronic' ailments were associated with the fathers more than the mothers.

We can see then that caregiving as well as the running of the organizations for the disabled have a very gendered orientation. All the narratives of the families of the disabled and discussions with professionals show that it is women, extending possibly the role of the woman as the primary caregiver, who mostly staff the services. What is interesting is that when the question about the gendered nature of the staffing pattern was put to the professionals, most responded by acknowledging the fact. However, they did not critique it as an issue-- there appears to be an unstated assumption that no other options are available and so there is not much point in dwelling too much on the biases in a situation that is perceived as almost inevitable. Dalley's explanation of the gendered nature of the services is borne out by all the interviews with professionals which is that in the public sphere, the same forces are at work as in families and societies: women go into the caring occupations because their natures and their intertwined capacities for "caring for" and "caring about" are thought to suit them well for those types of jobs (see Chapter One).

Women and Disability

An important aspect of the narratives, especially in the case of the girls, is related to their sexuality although it is not explicitly dwelt upon. In Anjana's case the girl faced sexual harassment twice over and both times the family did not really believe Anjana, or even try to listen to what she was saying. The latent assumption seems to be that being 'disabled' and 'crippled' Anjana and others like her will not be subject of abuse, as they cannot be regarded as attractive as women. This kind of attitude also suggests that the persons around Anjana almost consider her to be 'a non-person'; during the interview the mother expressed surprise about how Anjana could realize what was a 'wrong touch' when no one had talked to her about such matters. It is notable that on the one hand the parents routinely say that 'the child is very sensitive' and is 'just like any other 'normal' person in expressing themselves or having feelings,' but in matters of sexuality thinking about 'normal' feelings seems to be difficult. The attitude of surprise on the part of the mother about knowing something without being specifically told about it raises the question that just because a person is disabled does it mean that the intuitive capacity to learn or understand is lost. This way of reasoning is to undermine the sensibilities of the disabled person.

The other extreme of the anxiety is precisely the fear of this sexuality and its abuse. In expressing his anxiety about the future of his daughter Dolly's father referred to the possibility of Dolly's marriage, but only obliquely, by pointing out that 'they do not want to sell their daughter to the highest bidder.' Even Shweta's hysterectomy is of course a way to ease the handling of the sexuality of their daughter; even as the rationale the mother gave was the difficulty of handling the menstrual cycle of Shweta she simultaneously expressed a sigh of relief that the daughter's future was now safe as a consequence of the hysterectomy. According to Ghai, this kind of reasoning was cited in the case of forced sterilization of mentally handicapped girls in an institution in Maharashtra, which stated that 'now the girls would be safe'. Ghai says that by just performing the hysterectomy the notion that the disabled girl is safe is very wrong because hysterectomy only 'protects' the girl from getting pregnant but not from being sexually abused. In a recent study on disability in the rural areas the project found that young disabled women who suffer from routine sexual abuse experience the highest level of vulnerability.[6] It is the latter which has to be taken up as an issue by both the disability and women's' movement.

In many of the interactions with women professionals and disabled women, one often came across references to the women's movement. Parallels were drawn between the two movements in terms of the issues raised by the respective movements. However, equally, Anita Ghai also expressed a sense of betrayal by the women's movement for not taking up the cause of disability and in particular not addressing the issue of women with disability. She believes that 'the women's movement has marginalized disabled women totally.' Ghai asks, 'if the women's movement could take up issues like the dalit question then why was disability left out? One reason could be that existential concerns have not come through to them such that the women in the movement may have reacted.' But, she counters 'how could it come at all if the members of a women's group have a meeting on the third floor and there is no lift? Or if the material of communication is for the sighted and with hearing only?' Ghai recognizes that the sense of having been betrayed by the women's movement has arisen because there is a belief that the women's movement fights for all kinds of oppressions and so it must support the disability movement too.

Elaborating on the theme of women and disability Ghai argues that the focus has to be on a kind of understanding that even disabled women are under pressure. 'As a disabled woman you are marginalized on several counts - one because you are a woman; two because you are disabled; then there can be three you are a poor disabled woman; four because you are a poor dalit disabled woman, etc.' Thus what emerges is that there are different levels of marginalizations. And when the different levels multiply with each other, the effect is very alarming and cannot be easily ignored, she says.

The whole feminist spirit was to go in for autonomy and independence. Ghai argues; yet nowhere was there an understanding that in the 'Indian cultural scenario of embeddedness, in which we, disabled women, too are embedded in relationships, in families; embeddedness would mean something completely different for us,' she points out. The women's movement has not thought of what autonomy can mean for someone whose life is virtually at stake without some help or assistance--daily assistance. Ghai asks 'how is a feminist discourse going to reconcile with this kind of reality?'

Ghai raises another concern, an issue which has received very little scholarly attention but is much portrayed and emphasized, especially in the media--that of beauty and perfection. 'And you are saying this to people who are not perfect in any case - but who also get these messages strongly,' whether it is meant for them or not she says. Feminists would need to build this also into their understanding of what the media does to disabled women too apart from other women who would not fit the stereotype of the 'perfect' woman.

Ghai also went on to discuss questions of health: 'Even in the area of public health no one, not even the feminists talk of access of medical care for the disabled. Nowadays there is so much happening on the issue of reproductive health but no group talks of the reproductive health problems of disabled women,' she says. Although Ghai sees herself as part of the women's movement, she articulates a strong sense of betrayal and a sense of being let down by the women's movement; Ghai's perceptions need to be discussed seriously by the women's movement.

Grief and Anxiety

A feature of the narratives of the disabled is the implicit and explicit discussion around the theme of dealing with the realization on the part of the parents that their child is disabled and coming to terms with it. Although the mother, in particular, may be going through a certain cathartic release in the course of her routine looking after of the child the family does go through some kind of a 'grief cycle' when they first discover that the child is disabled. The cycle is probably once again gone through when the child reaches the age of 20 or more years when a different kind of anxiety takes over the parents. The parent's age, their own ill health, their death anxiety along with the fact that the future of the child has to be made secure, consumes them. The tendency of the parents, when the child was younger, was to deal with the situation by responding to the needs of a dependent helpless person-- a stage that is not vastly different from that of the parents of 'normal' children though it involves a great deal more of care. But there is a point where the needs of the disabled child become very distinctive. Once this distinction is established, or hits the parents, the different stages of the grief cycle begin to be experienced by the parents of the disabled.

Grief is a process not easily acknowledged in our society, in particular the grief associated with experiences other than death. Yet grief is an integral part of most life changes and experiences. Some of the emotional responses to grief are shock, anger, guilt, fear, exhaustion, depression, confusion and bargaining. Rando defines grief as "the process of psychological, social and somatic reactions to the perceptions of loss".[7] The grief cycle or the different stages of grief identified are denial and isolation, anger, depression, bargaining, and acceptance.

It is fairly obvious from the narratives that all the parents went through a grief cycle when they 'discovered' that their child was disabled. For instance, when asked about their immediate reaction to the discovery that their child would be disabled, Surinder's father replied that they were not very depressed initially for they didn't realize it would be a 'lifelong condition'. This reaction of the father does indicate an underlying facet of grief -- the discovery did mark a sense of loss, at whatever stage the realization dawned on the parents that the disability was a lifelong condition, and the early reaction was a kind of cover up, or a putting off of the recognition of the disability, in order to deal with the situation. Another instance of one of the consequences of grief is the example of Dolly's father, whose psychosomatic ailments and narratives continuously showed the anxiety and the cycles or periods of grief he went through in thinking about his daughter's situation as it is at present, and especially about what it would be in the future.

Thus the experience of grief wears many faces at different times in the life cycle for families whose lives are challenged by change, turmoil, illness, death and/or loss of hopes and dreams. Studies, as well as field experience, corroborate the fact that families with a disabled member do go through what is called the grief cycle. For example both Renu Singh and Anuradha Naidu talked about the fact that families go through a such a process of experiencing grief which may be repeated many times in the lives of the parents of the disabled. In discussing the way families experience the disability of a member Renu Singh, while rejecting the term suffering as an aspect of the experience, replaced it with grief cycle, and said: 'I wouldn't call it suffering. What parents experience is a grief cycle. Having a disabled child is like a loss. One may go around the cycle and then come back to it at a later stage.' Singh believes that there are different points in life when the grief cycle starts again because issues keep changing as the disabled person grows older and so do the parents. According to Naidu having a special child changes the relationship in the family equations till the family finds the balance again. It does disturb the equilibrium of the family. People perceive that the same social stigma that was attached to disability is now working within the microcosm of the family. Everybody has different reactions to a child who is different. Hence a new cycle starts every time there is a new stress in the lives of the family or of the disabled person. Kleinman views this way of suffering as a mode of social experience. The point is not to minimise the seriousness of problems faced by the individual patients but rather to appreciate the importance that they and their families attribute to the 'interpersonal, relational locus of hardship among the family members. Appreciating the implications eventually requires that we understand suffering as a different way of living illness in the social world'.[8] Kleinman points out that even within the family the social experience of suffering is not homogeneous and it may even be divided.

On the subject of grief Poonam Natarajan, a professional as well as a parent, and Director, Vidyasagar, talked about how she went through two cycles of grief in quick succession. One was when she discovered that her child was spastic and the second, about two years later, when she realized that their child was also mentally retarded. The latter discovery was a feature that had never occurred to her as a possibility and was not a condition she was familiar with. According to Natarajan, the experience of grief is also exacerbated by the fact that there is not enough information available about various disabilities and especially about multiple handicaps. This was because the image of the model CP person portrayed until the eighties was that of an intelligent child trapped in a crippled body and most of the CP persons she had interacted with were of average to very high intelligence. She was also not quite sure whether she had ever really overcome the grief of discovering that her child was disabled; in the initial years every new discovery such as the realization that 'the child will not walk or will not go to school,' was an extremely painful process and it is only very gradually that one learns to come to grips with the implications of disability.

Similarly Ghai described parents recounting to her the whole range of emotions they went through before coming to terms with their child's disability. Among the emotions were feelings of powerlessness, helplessness, vulnerability, anger, despair and grief. 'The experience impacts upon every aspect of their lives. All of them pass through a series of emotional states before accepting the shock. Very broadly these stages reflect a cycle of initial shock, denial, anger/sadness, adaptation and re-adaptation. How the sequence of these reactions is coped, depends on the kind of interpretation parents attach to the child's disability. If fate is seen as causing the problem, the chances of parents providing the opportunities for rehabilitation become less. However, if the challenge is accepted, then the endeavour is to put their hearts and soul into the child's welfare,' says Ghai. It is the challenge factor that has spearheaded mothers into setting up facilities for the disabled not only to help their own children but other children who have similar disabilities, as Poonam Natarajan herself did.

However, a point that was not articulated and may have needed more probing was that as the child grows up, the feelings of grief may change to resentment, anger and frustration, which the parents could not easily articulate to me because they were meeting me for the first time. For instance Naidu gave examples of how in the course of her field experience she had come across parents who referred to their disabled child as a 'headache' or used a term which meant 'waste of food' and denied food to the disabled child. But it is also possible that in the case of CP children, since there is a visible physical condition rendering the person incapable of doing any 'productive earning' work, a sense of pity seems to rationalize many of the parents feelings of anger or frustration about the child's condition. Either way the wish and hope that the child is able to do something in the future in terms of earning a living and being independent is very strong in all the parents. Initially all the parents had believed that 'this' was not going to be a lifelong condition and all their effort were directed towards making the child independent, and capable of some work or other. Over the years as the realization had grown about the child's limitations what parents wanted, more than anything else, was that the child should at least be able to be independent in terms of their routine self help skills. The oft-repeated statement of the parents that they did not initially think that their child's disability was to be a 'lifelong condition' also emanates from the fact that in normal circumstances it is expected that when children are young they will be cared for by their parents but when the parents grow old they will be cared for by their children. As Dalley put it 'in the case of the disabled, the caring seems unending and as parents grow older, their caring of the child itself becomes increasingly difficult... Love, in this context, often becomes fractured, or distorted, by feelings of obligation, burden, and frustration. But the prevailing ethos of family-based care suggests that 'normal' tasks are being performed, that roles enacted are straightforward, expected and unproblematic but in reality obligation and willingness are highly relational and context specific. As long as a handicapped daughter or son is a child, caring even though arduous falls within the normal parameters. However once the child becomes an adult, tensions in the caring relationship may develop - love, obligation, guilt, dislike - may all then be intermingled' (See Chapter One).

The anxiety of lifelong caring for the disabled persons takes different forms: the death of the disabled child is an imminent consideration; even well meaning people like neighbours and doctors can speak of the death of a disabled person in double edged ways. Anjana's neighbour bemoaned the death of her father, whose life was valued, and spoke casually about how it should have been Anjana and not her father who should have died. Another mother of a child with cerebral palsy referred to the shock of learning that her child was spastic but being traumatized by the doctor's passing suggestion that if she were to stop feeding the child, the child would just wither away[9].

But another and more common form of the way the imminence of death comes into the lives of the disabled is in terms of the parents' anxiety about their child outliving them: who would then care for the child? In some of the informal conversations with parents of disabled persons, they spoke almost guiltily of their wish that their child should die before them. It is almost as if the parents feel they would be uncaringly 'abandoning' the child, now a young adult, into a cruel and uncaring world if they were to die before the child. At another level the societal pressures of having a disabled child in terms of stigma, social exclusion, and non-accessible services underlie the 'burden' of a disabled child causing great anxiety. While in the urban sector a handful of parents may be able to come together to set up some network for the future caring of their children this does not seem to be possible for a majority of the parents especially in the rural areas. The study of disability in Andhra Pradesh revealed that rural families with members who are disabled carry a variety of burdens: social, economic and psychological. There is a pervasive sense of stigma, shame and social isolation. 'Many caregivers spoke of their sense of deep despair and suicide was not infrequently mentioned as a serious option.'[10] Two case examples show the level of despair - one is the case of the mother who has two young children with congenital disabilities. Her husband is an agricultural labourer, the sole family member to bring in money and food. Both parents were desperate and spoke of suicide. Harsh Mander writes that he had rarely met anyone else 'so decisively exiled from hope as that young woman.' The other is the case of a young mentally challenged woman who was being cared for by her elderly grandmother. 'The girl's parents had committed suicide as they found the burden of the disabled child too hard to bear amidst their poverty', states the author. Thereafter their old mother has fought many years to keep both bodies alive.[11]

While grief and the 'burden' of care are among the most common problems encountered by parents, Renu Singh states that professionals may not have been able to respond to their feelings: 'we haven't created anything to sustain them', she said. Anxiety about the future of the disabled, which is an enduring aspect of the unarticulated grief of the parents, too is yet to be addressed in a way that could reassure the parents. The continuing grief is also linked to the understanding that the disabled are permanent dependents. While the development of independent living skills is stressed in the west, Singh feels that 'we aren't even working towards it. It will only come about when the movement starts to take it up, when persons with disabilities come together and decide what their future should be rather than us (professionals) trying to decide for them'. In a sense both parents and professionals have tended to regard the disabled as incapable of thinking and acting for themselves-- as having no agency, but as Dalley says 'their dependency is not intrinsic to their physical or chronological condition; instead they have been 'socially constructed' as dependent because they are arbitrarily ruled out from being party to the bargain or contract which non-dependent individuals are able, or obliged to enter into with society' (See Chapter One).

Coping with Disability

The coping strategies used by the parents to deal with their child's disability vary according to circumstances but Singh considers that the biggest strength for the parents is family support. Parents also seek the support of institutions but whether the institutions really manage to cater to their demands remains questionable as parents are placed in an unequal relation of power with the institution, which provides services to their child. Singh feels that the parents are really not in a position to 'demand' anything from institutions, as they are too vulnerable. Singh cited a parallel instance to highlight the vulnerability of the parents: ' when even we as parents whose children are not disabled cannot speak their minds out [in making demands] then where is the question of parents with disabled children demanding anything'. What was being suggested is that the families of the disabled have no bargaining power and are not in a position to make demands.

According to Naidu, field experience as well as research has indicated that in upper middle class families what has been found very difficult to accept is mental disability. This is because there is so much significance attached to 'intellectual' capabilities. So children with motor disability, if they excel academically, are accepted and included into the family relatively more easily than a person with mental disability is. In contrast, in working class homes a child with a physical disability is more difficult to manage and is considered a 'burden'. This is because it has been found that children with mental disability are involved a lot in domestic chores and help the mother especially in cleaning the house, washing, and collecting firewood. So by their participation in the labour of the household they make a tremendous contribution to the domestic economy of the family whereas children with physical disability are not able to contribute that much in a situation where survival is the issue. A child with mental disability can be taken to the field whereas a child with severe and profound physical disability cannot be carried all that way. As a result there may be no alternative but to lock up the disabled child at home till their parents come back. Naidu emphatically points out that it is not as if their parents don't love them. They love them very much. Parental love for the disabled child is one thing that has been found across the social classes, Naidu says.

On the issue of whether the disabled child is considered a 'burden', Naidu has found that the reference to the child as a burden per se is not present but sometimes indirect expressions are used, such as 'he or she is a headache'; in the south she has come across a particular term which means 'it's a waste feeding him/her' which Naidu feels is one of the most cruel expressions she has heard. There have also been instances when their staff has had to intervene to save the child from dying due to hunger. According to Naidu the purpose of such an intervention is not a question of standing on moral judgement over the family because it is a fact that they do not have enough food to go around the family and one has to understand the situation: this is also not to say one condones their act. But such a situation brings up forcefully the question of survival for everyone in that family.

According to Anita Ghai, the coping strategies developed by the family are highly individualized. The strategies depend on the infrastructure the family has. Elaborating the point Ghai states that any crisis has the potentiality for developing a coping strategy. Thus what is required is the presence of an existential framework; whenever there is a void of any kind it also has the potential for growth. 'Whether we grow or not is of course another thing' she points out.

Ghai is convinced that constructions of disability have to change. At the same time they cannot change unless 'you change and are empowered' that is the disabled can be empowered and thus can change. But for empowerment one would have to create the basic conditions such that empowerment can actually take place. And she says it is 'feminists who have to create the conditions for empowerment', as Ghai greatly invests hope in the women's movement.

In the context of family strategies in coping with disability Poonam Natarajan finds that today parents don't respond in the same way to disability as they did 20 years ago. She attributes this changed scenario to the fact that probably there is more awareness about disability nowadays. The parents probably know that more services are available. And also the fact that there are more services in terms of choice. She also implied that therefore there is less suffering for the parents than before. An aspect to coping that Natarajan has found important is the manner in which the parents themselves handle the child's disability: 'How we as parents respond to the child will influence how others respond to the child,' she says. She has however found that it is only over time, and step by step, that parents learn to cope with the situation of their child's disability.

Faith as Succour

In the absence of institutional support in coping with disability, whether on a daily basis or on a long-term basis, and in the attempt to alleviate suffering, a recourse to faith has been an important dimension of the lives of the parents. Thus, watching the suffering of the disabled, and the suffering experienced by the parents on their own account, has led most parents to invoke God or the Almighty as an anchor in their lives who will 'surely find ways' to look after their disabled children, once they are gone. The most common form of dealing with suffering is through belief or faith, and is thus expressed in spiritual terms. This leads us to the understanding that although counseling, rationality, and active involvement in the cause of the disabled may support the parents it is the underlying faith in God, and in 'seva,' that ultimately helps the family tide over not only the daily coping but also in dealing with the future anxiety for the child. Faith is also important in cases where the disability of the child, per se, is not perceived as the real issue hampering their lives but rather other factors such as financial or economic problems, or even problems such as a husband's alcoholism.

One reason for the sense of being overwhelmed by the circumstances that the family with a severely disabled member, who requires lifelong care and often turns to faith as a succour, is placed in, is that the state did not seem to exist as a support for the disabled. All the narratives reflect this understanding. In almost all the cases the parents did not seriously or systematically think of the government as an agent or resource which should be involved in the welfare of the disabled. There is general scepticism about the government's role and the common argument made is that 'the government does not do enough for the 'normal' people what is it going to do, or how can it be expected to do anything, for the disabled'. The only context in which the state or the government appears in the narratives is as an agent of legislative changes; thus only the parents and organizations which are 'aware' consider that the government can be approached for help like reservations, tax concessions, or the grant of land for the long term rehabilitation needs of the disabled, and it is this group of parents who have managed to mobilize themselves into a pressure group and demanded services from the government. The possibility that the state should be responsible for the provision of basic medical services for the disabled did not exist in the perception of the parents of the disabled.

Summing up

The attempt in this study has been to not leave the narratives merely as qualitative insights but to argue that while they are derived from a small sample, the urban middle and lower middle class, a range of issues emerge that point in the direction of the problems faced by lower income groups. The issue would be multiplied several folds in the light of the quantum and variety of disabilities that are evident from the NSS data. This data shows the characteristics, distribution and health seeking behaviour of the people. The narratives reveal a thin layer of the scenario prevalent in the urban lower to middle class section which leads one to visualize what the condition would be in the rural, semi-rural areas, semiurban and urban slums. In these areas there are various categories of populations such as agricultural workers, daily wagers, manual labourers, domestic workers and migrant population who would not have even the most basic facilities for diagnosis and information about disability. These difficulties have been highlighted in the study of disability in Andhra Pradesh cited earlier.[12]

Studies have shown the relationship between poverty and disability and the narratives too indicate that the intensity of suffering increases as one goes down the class gradient. In a study by Sen, the relationship between poverty (economic disability), 'weakness' (social disability) and the incidence of medicalized disability has been studied.[13] Sen has found that 'simultaneous deprivation' is further compounded by a syndrome composed of ideological reinforcement, punitive experience and psychological extinction. This syndrome sets up barriers against participation of all types of disabled people, especially the mentally disabled and girls in social development. Similarly another study a census of three villages in northern Tamil Nadu working with people's own definition of chronically sick and disabled household members showed a positive association between disability and poverty.[14]

There is also the argument of an inverse relation between income-poverty and the prevalence of disability on grounds that mortality from disability is greatest among the poor. There is evidence for a disability transition during which disabilities due to malnutrition and infectious/contagious disease are eradicated, but more than offset by reduced mortality rates, survival of paraplegics and quadriplegics and increases in disabilities due to trauma and old age, such that the total incidence of disability increases.[15] There is also international evidence for the inverse relationship.[16] According to Barbara Harriss-White this latter evidence of the inverse relationship even in developed countries, however is no excuse for non-interventionism in the lives of the disabled poor in India because raised levels of mortality clearly result from the economic incapacity of poor families to sustain the lives of disabled members.[17]

Another aspect of the relationship between poverty and disability is revealed by the NSS data which shows that especially in the rural areas the major reason for 'not taking treatment' is that the treatment is too expensive. It is only a small percentage of persons who were not aware of the availability of treatment and therefore did not access treatment. The issue of the treatment being too expensive is not just in terms of the expense involved in acquiring the aids or the appliances but is about the issue of incidental costs. For instance in a study regarding the rehabilitation of the disabled in a rural and urban area, it was found that although specialist services in government hospitals was given free of cost, incidental expenses such as transport, boarding, and lodging, and loss of daily wages takes a toll on family income and therefore hampers accessing medical treatment. Hence studies do suggest a relation between poverty and disability.

Another factor revealed by the narratives is that the experience of disability is not merely an individual's experience. If one were to take the disability problem as the suffering of an individual person or a single family, then the related issues and consequent suffering can be alleviated with the help of social work and psychology, the two disciplines which have been associated with disability for a long time. It is at this level that psychological and emotional support, along with inputs in training the family to handle the disabled person, that the NGOs response to help the disabled individual and the family members comes in. However, if one takes cognizance of the fact that suffering is real from a population perspective and that it is exacerbated by the lack of services, and support to the life-long caring that is required in the case of the disabled then data shows the need for looking at agencies which can deal with disability at the level of the wider population and this is where the state needs to come in.

One of the important ways through which the state can reach out to the disabled and their families is the Health service. Rehabilitation is one of the aims as well as services of primary health care along with prevention, cure and promotion of health. Hence the basic services pertaining to diagnosis and information regarding disability should be provided at the primary level rather than at the secondary or tertiary level. In a study by Burrett the lack of referral services for the disabled at the district level resulted in over 50% of the cases dropping out from the treatment process because of the problems of time, distance and money involved to go to the city hospital.[18] The poor socio-economic conditions proved to be yet another constraint, especially in the case of families who were daily wage earners. Extending the case further the daily wage earners not only lose one day's wages but many days because they would have to make repeated trips to the hospital since the assessment, providing of aids or appliances and continued monitoring of the aids will not be done in one day. In such families a disabled child is not a priority in the light of more pressing burdens.[19] Hence the services at the district level should be provided at the primary level to provide access and reach out to the felt needs of the people. These studies reveal the substantive issues in the health seeking behaviour of the persons interviewed which is contrary to the commonly held belief that people do not seek treatment for the disabled because they resort to beliefs such as karma or kismet.

However it is important to note that arguing for providing services at the primary level is not to make a case for a medicalized model of disability, but is to make a demand for a more accessible system for all sections of society since it is known that the access to requisite services are related, at the moment, to the class to which the disabled person belongs. The areas where the state can intervene at the primary level are: providing the basic technology for diagnosis, for information, and for prognosis; formulating a treatment plan not only a medical plan but including providing the requisite aids and appliances; and establishing a referral system similar to the one for communicable diseases.

Caring is an important component of any health service system and is not just a need of the person or family. In the course of the shifts in public health, viewing the body in mechanical terms has under emphasized the role or aspects of the medical tasks other than just curing. The caring, or palliative aspect, tends to get lost as the body is split into different body systems that need specialists to deal with each of them. As a consequence 'caring' is accorded a low to negligible priority in terms of time and resources. It is only recently that with the discovery of AIDS, a similarly stigmatized condition that the strong input of personnel, both medical and paramedical, in the area of caring has been realized. However all stigmatized conditions not only AIDS, but TB, leprosy and disability also require this orientation. It is at this level that the NGOs can have collaborative role with the state in terms of expertise and skills. Therefore it is important to have health services.

Thus Public Health has a role to play in the area of disability as in case of any communicable disease, as the NSS data provides epidemiological evidence for. The health seeking behaviour of the people can be assessed too. The fact that there are different needs involved is to be recognized. Since public health has a holistic perspective for human life it has to provide the services right from the primary level onwards. Thus while the psychological and social support may not be necessarily provided by the system it should at least ensure that all the other aspects of disability are addressed in a tangible way.

Apart from the medical, psychological and social needs of the disabled person and family, the educational, vocational, and employment needs are equally important. Although the narratives are mainly restricted to coping with disability in the absence of any kind of support measures from the state, they do bring out the hopelessness of the situation. This situation would apply in differential degrees across regions, urban and rural, and across class. One other major area where the state can intervene is in terms of providing insurance or public security. This would be of significant help because such a measure will go a long way in not just helping the disabled person but the family too. Therefore while planning for a meaningful intervention it is important to recognize various needs - emotional, psychological, social and medical needs along with an educational, vocational and employment component. But far from formulating measures to respond to the needs of disabled Renu Singh says that the various ministries involved in dealing with issues such as health, education, or employment for the disabled are adopting a fragmented approach to framing policies and this is the "most important barrier operating in the field of disability." A holistic approach would be able to address all the needs of the disabled outlined above: instead the segregation model, which is really the charity model still prevails according to Renu Singh (see Chapter Four).

The argument made here is not just for a statist intervention because certain functions, perhaps, require the NGO's skills and expertise or can provide the personalized touch. But it is more than clear that the NGO cannot supplant the state. The frustration experienced and expressed by the persons in the narratives directed towards the NGOs is partly because the state has abdicated its responsibilities of providing an integrated perspective operating in the larger system as the protector of people's rights. As Javed Abidi said it was unfortunate that although India had certainly adopted the welfare state framework disability had not found a place in the welfare frame (see Chapter Four). At the same time the demand for public intervention does not wipe out the possibilities of or the spaces for private response in many areas. In order to join social and health policy, narratives as well as numbers, social services along with health services and social theory together with health science perspectives, must have a place in policy formulation.[20]

The way issues have begun to be posed in the era of liberalization however is State versus NGO's, and a medicalized institution model, which is somehow linked to the state, versus a community based model. Given the dire need for care, for services, resources, and the right to equal opportunities there is need for creative and sympathetic interaction and action on the part of both the state and of society, not an artificial dichotomization of the two arenas.

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[1] A. Ghai, 'Refocusing on the child with disability', www.leeds.ac.uk/disability-studies

[2] H. Mander, "At the Precipice of Despair," *Frontline*, August 2, 2002, p. 112.

[3] S. Wadhwa, 'Edge of Town', *Outlook*, August 10, 2001, pp. 52-54.

[4] Ibid. p. 110.

[5] A. Ghai, see n. 1.

[6] H. Mander, see n. 2.

[7] T. Rando, cited in Richard A. Pessagno, 'Grief, Loss and Bereavement', www.nursingceu.com

[8] A. Kleinman et al., 'The Social Course of Epilepsy: Chronic Illness as Social Experience in Interior China', *Social Science and Medicine*, Vol. 40, No. 10, p. 1329.

[9] A. Ghai, see n. 1.

[10] H. Mander, see n. 2.

[11] H. Mander, see n. 2.

[12] Ibid.

[13] A. Sen, cited in B. Harriss-White, 'On to a Loser: Disability in India' in *Illfare in India: Essays on India's Social Sector in Honour of S. Guhan*, B. Harriss-White & S. Subramanian ed., Sage, New Delhi, 1999, p. 140.

[14] Madras Institute of Development Studies Field Survey, cited in B. Harris-White, see n. 9, p.141.

[15] D. Mohan, cited in B. Harriss-White, see n. 9, p. 142.

[16] E. Helander, cited in B. Harriss-White, see n. 9, p. 142.

[17] B. Harriss-White, see n. 9, p. 142.

[18] G. Burrett, cited in Rama V. Baru, 'Rehabilitation of Disabled Children: Lessons from Two Community Projects', *Indian Journal of Social Work*, 1989.

[19] Ibid.

[20] A. Kleinman et al. see n. 8.

BEYOND INDIVIDUAL SUFFERING

> *Society has to acknowledge that until there is*
> *a coordination of efforts between a range of medical,*
> *allied health, and developmental services,*
> *families will go on facing recurrent stress and pain.*
> *- Anita Ghai*

The literature on disability, and the narratives of parents, professionals and disabled activists, which form the basis of this study suggest that suffering is actually prevalent in the lives of the disabled and those close to them. The accounts of frustration, anger and anguish experienced by young adoloscent disabled persons whose helplessness has been invisibized by society, along with discussions about issues of faith, the importance of family support and the adverse effects of the lack of state support are all indicators of social suffering undergone by the disabled person as well as the families at various stages in their lives.

While disability is a medical condition it is also a condition that requires caring and both conditions are lifelong which is an aspect of suffering. Although people would have to deal with disability at an individual level, the suffering is not only an individual experience but has a strong social component to it. The lack of medical knowledge, the difficulties of accessing services, acquiring the aids and appliances, developing the skills for training-- that is the basic facilities that would help in reducing the disability factor and enhance the self help skills which are just not available-- all affect the quality of life of the disabled. Apart from the fact that the social, psychological, educational and employment potentials of the disabled individual are not enhanced, which the disabled have a right to, these deprivations and the need for 'care' in the widest sense of the term create enormous suffering for those affected by disability.

Disability is socially constructed. However what is important to note is that even the acknowledgement that disability is socially constructed has not led to the recognition that the 'social' construction is tilted in a certain direction, wherein it is still seen primarily as an issue that is an 'individual' rather than a 'social' concern. This limited way of seeing the social construction of disability is a discourse shared by the policy makers, professionals, those advocating CBR and almost all the disabled rights activists. This way of thinking about the 'social' construction of disability may be attributed to the fact that stigma and charity are still strong underlying reasons which creep into the way disability continues to be constructed even today. But stigma is not the only cause of suffering as has been revealed by the studies and the narratives examined in this work. The political economy is a crucial aspect of the way suffering is experienced by those affected by disability. As the study on disability in rural Andhra Pradesh cited earlier shows despair is a dominant motif in the lives of the disabled poor and their families as they struggle to care for the disabled without facilities of any kind and struggle too to earn enough to fulfil their subsistence needs.

For even those who are better off the wider political economy determines the way disability is perceived. Inclusion is necessary in every aspect of society be it in education, employment or just in neighbourhood activities. The need is to sensitize society towards the inclusion of the disabled and the possibility of disability in their own lives. For example, when a person becomes disabled in old age, especially a man, his family or others around do not undervalue him because he is judged by the fact that at one time he was a productive individual. From this we can see that the value of labour potential, or its absence, is a structural factor in the current view of the disabled: the fact that an old man who is disabled is not marginalized, as a disabled child would be from the beginning of its life, tells us something about the need to rethink the relationship between the individual and the social and between disability and society, and also between disability and the state both of which reflect the political economy.

As of now disability continues to be seen as a 'burden', which must be borne by the family with fortitude and patience; disability is still constructed as a situation where 'suffering' is inevitable. As Ghai noted families are told by counselors that the way to deal with adversity or pain is to 'tough it out', that if you can avoid showing the pain, then you have been stoic and dealt with the problem 'competently'. Such ways of dealing with pain and suffering prevail since all those who are involved with disability in India, as parents, as disabled, as professionals, and as disability activists, are still trying to formulate their understanding on the wider context in which disability needs to be located. The relationship between the state, society, and family in the context of disability is also yet to be formulated. As Marta Russell put it in a sharp piece of writing reflecting the understanding of a disabled woman herself 'The Political Economy Affects Us All'--perhaps we can add 'whether we recognize it or not.' And until then:

> *Across our countryside, shrouded from our collective view*
> *and conscience people with disability and their care-givers*
> *somehow are living out their lives, surviving, but only just,*
> *most often on the precipice of dark despair. It is probably only*
> *when they organize into a social and political collective voice*
> *and assertion that an uncaring state and society*
> *will finally be forced to act. (Harsh Mander)*

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