

OCCASIONAL PAPER

34

**Disabled Definitions, Impaired Policies:
Reflections on Limits of Dominant
Concepts of Disability**

Nandini Ghosh

May 2012



INSTITUTE OF DEVELOPMENT STUDIES KOLKATA

DD-27/D Salt Lake City, Sector - 1

Kolkata - 700 064

Phone : +91 (33) 23213120/21 Fax : +91 (33) 23213119

e-mail : idsk1@vsnl.net, Website : www.idsk.edu.in

Disabled Definitions, Impaired Policies: Reflections on Limits of Dominant Concepts of Disability

*Nandini Ghosh**

Disability is a complex category as it is understood and interpreted in very different ways. While disability has been defined primarily in terms of medical deficit, socio-cultural constructions give meaning to impairments and influence the experiences and interactions of disabled people in different socio-historical contexts. The different models of disability help to illuminate the multi-faceted definitions of disability, through debates that have described it either as a medical 'problem' or as socio-cultural constructions reflecting the power relationships between disabled and non-disabled people. Although disability is projected as a departure from an un-stated physical and functional norm, it becomes a highly relative concept, with people placed at varying degrees of able-bodiedness or disability within differing socio-cultural contexts. In India, historical evolution of social policy towards disabled people, from a charity perspective to one of welfare and recently to equal participation, has been a difficult and lengthy process. Disability policy in India reflects the cultural assumptions, changing definitions and social perceptions of disability and the power relations that shape it. In response to international developments advocating the rights of disabled people, the Persons with Disabilities Act was enacted in 1995 and the National Policy for Persons with Disabilities was framed in 2006. However, these landmark policy documents still operate within limited medical definitions of disability, which determine special provisions and programmes for disabled people and reflect the lack of political will of the State to promote inclusion. This paper divided basically into two sections analyses the impact of the different models of disability in shaping policy in India. The first section attempts to engage with the debates within disability theory in order to offer a nuanced conceptualization of disability from a socio-cultural perspective. The second section looks at disability policies in India and tries to assess the extent to which these policies promote inclusion of disabled people.

* Associate Professor of Sociology Institute of Development Studies Kolkata (IDSK), Salt Lake, Kolkata

"Thus in consequence of a remnant of (the guilt of former) crimes, are born idiots, dumb, blind, deaf, and deformed men, who are (all) despised by the virtuous." ManuSamhitaChap.11 (53) 1st Century BC translated by George Buhler 1886.

"World Health Organisation's International Classification of Impairments, Disabilities and Handicaps (1980) define disability as follows:

Impairment: any temporary or permanent loss or abnormality of body structure or function, whether physiological or psychological.

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 a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual."

"Disability is the disadvantage or restriction of activity caused by contemporary social organisation which takes little or no account of people who have impairments and thus excludes them from participation in the mainstream of social activities. Disability is a particular form of social oppression." Union of Physically Impaired Against Segregation, *Fundamental Principles of Disability*, United Kingdom, 1975.

"From this viewpoint, society is at fault, that is a disabling society that is geared to, built for and by, and controlled by non-disabled people - a society that excludes disabled people. This exclusion is created and constructed in every aspect of living, including ways of thinking, language, the built environment, power structures, information, values, rules and regulations. Whether you are disabled or not, you are living in a disabling society." John Swain, Sally French & Colin Cameron, *Controversial Issues in a Disabling Society* 2003.

INTRODUCTION

Disability is a complex category as it has been and still is understood and interpreted by different people in very different ways. In almost all societies, individuals with physical or intellectual anomalies have been assumed to be, by the very nature of their condition, inferior. As the term disability carries with it the connotation of a lack or deficiency, whether mental, physical or sensory, it has been defined primarily in terms of medical deficit. However, it has

to be acknowledged that the word disability is itself not a homogeneous category, subsuming under it different kinds of bodily variations, physical impairments, sensory deficits and mental or learning inadequacies, which may be either congenital or acquired. Disability has been recognised as a human rights issue in the international arena, with the United Nations Declaration on the Rights of the Disabled Persons focussing attention on the needs of disabled people globally.

Disability activists in United Kingdom, other European countries and in the United States questioned the medical definitions of disability forwarded by the World Health Organisation and UNO. Although these definitions conceptually distinguished between impairment and disability, they assumed a uniformity in the treatment meted out to disabled people by an able-bodied society. Yet in all societies, the experience of disability is mediated by socio-cultural constructions that give meaning to impairments and influence the experiences and interactions of disabled people in different socio-historical contexts. The social interpretation and experience of such varied types of physical and mental impairments also vary depending on the socio-cultural contexts. These contexts influence the definitions and interpretations of various kinds of physical and mental inadequacies as well as the resources available to facilitate the inclusion of disabled people within the community. The definitions of disability are multi-faceted and various, and highly contested by disability activists and academicians.

The social valuation of people considered to be disabled is socio-culturally and historically variable (Garland 1997). These social constructions of disability and disabled people have an equally profound effect on people with disabilities as their physical or mental deficits impinge on their daily lived realities. While acknowledging the presence of physical or mental differences among individuals, disability scholars and activists have reframed the concept of disability in terms of power relationships between the disabled and the non-disabled based on the social and cultural interpretations of different impairments which lead to the marginalisation and stigmatisation of people with disabilities. Such redefinitions of the concept of disability have had a strong impact on the way in which states have designed policies and

programmes for persons with disabilities globally and specifically in India.

This paper attempts to locate the discourse on disability with special focus on construction of disability in India, through the exploration of western and Indian literature on disability. Academicians and activists in the western countries have attempted to trace the historical changes in the ways in which disability has been viewed in different socio-economic formations through models of disability. The different models represent the socio-cultural assumptions made about disabled people and hence about disability at various stages of development of knowledge, and the ways in which disabled people have been subjected to various kinds of discrimination and stigmatisation. The first section of this paper therefore explores the debates about the different models that have tried to explain and define disability, its causes and its implications for both disabled and non-disabled people. These debates both within the disability movement and in academic circles have looked at disability from many different viewpoints: religious, administrative, welfare - all characterising disability as a personal tragedy, medical aspects and societal perspectives. The section finally attempts to reconcile the newer perspectives on disability that lay stress on embodied socio-cultural experiences of disabled people within socially engineered environments with the existing dominant modes of thinking regarding disability and disabled people.

The next section locates the Indian discourse on disability, which has been greatly influenced by the different models posited in the West. According to the Census 2001, there are 21.9 million disabled people in India. The data reveals that of the 5 types of disabilities on which data has been collected, people with visual impairments (10.63 million) comprise the bulk of the population, followed by people with mobility related impairments (6.10 million). People with speech and hearing impairments (2.9 million) and mental disabilities (2.26 million) constitute the rest of the disabled population. In India, the issues facing disabled people have only recently been recognised by the State, but the definitions of disability are strongly influenced by historical, economic, political and social constraints that arise from legal, medical, political and literary discourses of exclusion of people with real and perceived physical and mental deficits. The historical evolution of policy

towards disabled people in India from a charity perspective to one of welfare and recently to equal participation has been shaped by processes that are influenced by cultural assumptions, power equations and international developments. Social policy towards the disabled in India still retains a strong welfare orientation, and has a tendency to medicalise the impairment of disabled people. Thus this paper critically reviews historical development of state policy concerning disabled people in India, with a view to understanding changing definitions of disability and social perceptions, which influence the socio-legal provisions especially in the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 and the National Policy for Persons with Disabilities 2006.

MODELS OF DISABILITY

Disability activists and scholars in the western countries have been using the different models of disability to try to explain the changing social perceptions about disability and disabled people. The development of these models took place primarily in the developed countries of the West, that is, in United Kingdom, United States of America and certain European countries, where disabled people themselves took the lead in demanding equal rights for themselves. According to Oliver (1996), initially there were just two models: the individual model, which looked at disability as a personal tragedy and of which medicalisation was an important component, and the social model. However, as the domination of the medical professionals was seen as oppression, there was an increasing acceptance of the operation of a medical model of disability, which was then critiqued by disabled people themselves by advocating an adherence to the social model of disability. While different scholars have used different terminology to point to administrative and welfare models, these may be classified under the individual model of disability. While these models have been conceptually distinguished from one another, they coexist and interact in most communities, impinging considerably on the lives and experiences of disabled people.

INDIVIDUAL MODELS OF DISABILITY

These models include a range of views about disability ranging from the religious/moral ideas about causes of disability, to considering disability as a personal tragedy, to the administrative

or welfare orientation to disability. The reason for putting such varied ideas together is because they all consider disability from the perspective of the individual. The individual model of disability primarily locates the 'problem' of disability within the individual, stemming from the functional limitations or psychological losses which are assumed to arise from disability (Campling 1983, Oliver 1990, Silvers, Wasserman & Mahowald 1998). However, the reasons for and impact of the disability may be explained by the socio-culturally and historically variable constructions about disabled people.

Religious Model of Disability

From a religious/moral perspective, disability has been regarded as the divine retribution or punishment for sins or misdeeds committed by disabled people or their kin members. In the moral model of disability, disadvantage is the deserved consequence of impairment as impairment is itself likely to have been earned, if not by the individual who suffered it, then by some ancestor who failed to be sufficiently solicitous of his descendant's welfare (Garland 1997). The moral model of disability has directed attention to the question of responsibility of the individual for acquiring the particular disability. Thus Aristotle believed that blindness, when caused by factors beyond a person's control properly evokes pity but is shameful when caused by condemnable conduct like drinking. For the Greeks, disability was seen as the retribution for the flawed individuals. Garland (1997) has observed that in antiquity, impairment was associated with lack of self-discipline and abandonment of other-regarding values. Thus the compensatory powers conferred by impairment could be as dangerous as others as repudiation by others to individuals with disabilities.

From a religious perspective, disability has been regarded as a punishment inflicted upon an individual or family by external force. In Indian and other Asian societies, the concept of karma governs basic assumptions about disability, where disability is seen as the result of sins committed in previous births (Ghai 2001, Karna 2001). The triad relationship of sin, punishment and disability convey a strong message that disability is a consequence of personally committed evil acts or ancestral wrongdoings. Thus disabled people, whether dumb, blind, deaf and deformed, were feared or despised by the 'virtuous'. People with visible deformities

are portrayed as villains, devils and witches causing harm to 'normal' able-bodied persons. Mythological characters like Manthara and Shakuni in Indian epics, Ramayana and Mahabharata, reinforce the images of evil (Miles 1995, Ghai 2001). However there are two examples of disabled characters portrayed positively in Indian mythology - Sage Astavakra, named for having eight deformities was known to be a wise man while blind Surdas, friend of Krishna, was well known for his singing abilities.

However the religious/moral model has been criticised for foreclosing a view of strong, positive persons with disabilities, evidence of which may be found in some of the eastern societies, where disabled people played an active part in the activities of the community. Emperor Ashoka used to use dwarves and crippled people to act as spies for him during war (Miles 1995). Disability theorists in the western countries have acknowledged that all disabled people may not have been subject to a universal socio-religious antipathy in pre-modern societies as religious and ethical mores were socially concretised for disabled persons. As in most capitalist societies impaired people are projected to be in need of service and welfare, disabled people's relatively recent experience of service dependency and marginalisation is considered to have been present in all past social formations. The view of all disabled persons as beggars thus identifies impairment with social dependency (Hahn 1988; Gleeson 1997).

Disability as personal tragedy

Disability as a personal tragedy, considers that individuals diagnosed to be 'suffering' from a particular condition or impairment, are 'helpless, dependants, incapable of mastering the elementary skills essential for engaging in productive social and economic activities' (Thomas 1982, Lonsdale 1990). Thus disability also carries with it the connotation of functional limitation and inability, as against familiar ways of functioning, magnifying "normal" bodily and intellectual performances into standards that render disabled people incompetent and incapacitated. This model of disability primarily locates the 'problem' within the individual and considers the causes of this problem as stemming from the functional limitations or psychological losses which are assumed to arise from disability (Campling 1983, Oliver 1990, Silvers, Wasserman and Mahowald 1998). Disability is seen as an individual condition and the way

to deal with it is through professional interventions designed to deal with either the medical complications or the functional limitations of impaired individuals.

Whatever their personal accomplishments, people who are impaired bear the burden of membership in what traditionally has been viewed as a 'weak class', one defined as requiring heightened protection because its members are feeble or incompetent. Insofar as they have been defined as being helpless, they have been exempted from contributing to, but also pre-empted from profiting from the collective good. Being disabled thus entails a reduction in the opportunities for people with disabilities and also in their obligations (Silvers, Wasserman & Mahowald 1998). Disability, by virtue of the functional limitations it represents, is seen to alter people profoundly rendering them naturally unequal, and in need of protection and welfare (Silvers, Wasserman & Mahowald 1998). The welfare model, also known as the administrative model, therefore defines disabled people as those who are in need of help and aid, whether financial, medical or other.

Medical Model of Disability

The advance of the modern medical sciences in the western developed countries led to a growing body of knowledge about the human body and its functioning. The definitions of disability also changed radically, with a range of physical, sensory and mental conditions coming to be labelled as abnormal or disabling. Disability came to be seen as a negative variation from the physical norm that impaired the functional capacities of the physically disabled person. The medical model explains physical, sensory or cognitive disabilities in terms of biological or physiological deficits that denoted the influence of a medical aetiology, and stressed the causal relationship of the origins and outcomes of various types of disabilities. Thus physical explanations are now used to account for the effects of a person's impairment or for his/her disablement and the responsibility for such people with physically impaired bodies is handed over to the medical and paramedical specialists (Lonsdale 1990). The main focus of the medical model is the disability as it relates to certain parts of the body, like the eyes, ears, legs, joints etc. and not the individual with an impairment.

Diagnostic labels are attached to people with different disabilities, and disabled people come to be seen as that group of people whose bodies do not work, or look different, or act differently, or who cannot do productive work (Shakespeare 1996). The responsibility for such people is then handed over to medical and paramedical specialists for interventions designed to correct either the medical complications or the functional limitations of impaired individuals (Hahn 1985, Lonsdale 1990). There is a power play between the doctor and the disabled person or the patient, who is ascribed a clinical label and sought to be normalised through preventive or curative medical technology. Such clinical definitions of disability also become administrative tags for controlling disabled people's access to financial and other assistance as well as attaching a stigma to the labelled person by suggesting a physical imperfection or deviance from the norm. Defining disability and providing facilities for the disabled people are the main supports of the medical model of disability, which aggravates the dependence of the disabled person on the 'professional' caregivers. The medical model aims at reducing the numbers of people with disabilities by preventive or curative medical technology. Despite the scientific associations, the medical model resembles the moral model in its assignment of responsibility because impaired individual's deficits are often attributed either to his/her own inadequate health practices or to his/her bad genes (Silvers 1998).

The medical approach raises the question of normality, both in the sense of performing and conforming to a certain standard from which disabled people deviate. Normalisation has been described as the use of culturally valued means in order to enable, establish and/or maintain valued social roles for people. Medical interventions aim at restoring the disabled person to normality, as reduction of the ability to perform in the 'normal' modes and at 'normal' levels needs to be remedied. The identification of physical, sensory or cognitive deficit with anomalous modes of performance, and the subsequent equation of anomaly with dysfunction and diminished quality of life, takes on the character of determinism within the context of the medical model. The importance attached to culturally valued means to improve the social position of disabled people effectively negates the possibility of challenging both the established norms of society and the embedded material conditions

which generated them. Normality as the set of culturally valued social roles is both naturalised and reified by this principle.

Normalisation is played out in both medical and educational programmes that intervene to repair or restore or revise members of the non-dominant groups. Thus, to normalise a person refers to refashioning the groups with which an impaired individual socialises rather than restoring the individual to a naturally desirable standard. Normalising programmes are imposed to adjust anomalous individuals to environments not suited to them but to the dominant social class. Normalising equalises opportunity only to the extent to which people can be maintained in or restored to the image of the dominant group. It should be recognised that the dominant group's fashions of functioning are not the product of any biological mandate or evolutionary triumph, nor are they naturally endowed to be optimally effective and efficient. Rather members of this group impose on others a social or communal situation that best suits them, regardless of whether it is the most productive option for everyone (Silvers, Wasserman & Mahowald 1998).

The medical model has been very powerful in influencing the international definitions of disability, even in the face of strong protests by the disability activists in the western countries who advocated for a social model that posited a conceptual distinction between disability and impairment. Under mounting pressure from the disability movement in the developed societies of Europe and America, the World Health Organization (WHO) developed the International Classification of Impairments, Disabilities, and Handicaps (ICIDH), defining disability and impairment as primarily physical, resulting from disease or accidents, that lead to different handicaps for people living within a particular socio-cultural set-up. The three-fold distinction between impairment, disability and handicap, has been defined as follows: 'An impairment is any loss or abnormality of psychological, physiological or anatomical structure or function; a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being; a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that prevents the fulfilment of a role that is considered normal (depending on age, sex and social and

cultural factors) for that individual' (WHO 1980). The strong medical orientation of these definitions has however acknowledged the role of socio-cultural ideologies in influencing the experience of disability in different parts of the world.

The influence of medical ideas on disability is reflected further in the later international documents like the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1991) and the World Health Organisation's International Classification of Functioning, Disability and Health (2001). While the UN declaration views disability in terms of physical, intellectual or sensory impairment, medical conditions or mental illness, which may be permanent or transitory in nature, the WHO classification reframes impairment as pertaining to biological systems rather than to organs, but it retains the reference to supposed biological norms as the standard against which individuals are judged to be impaired. A third term, handicap, has been used to refer to social aspects of disability, that emphasizes and focuses on the barriers in the environment and in many organized activities in society, like communication and education, which prevent persons with disabilities from participating on equal terms.

The medical model was subjected to criticism by disabled people themselves because of its biologically deterministic stress on physical or sensory deficits and ignoring the lived experiences of disabled people. As the medical gaze constitutes the patient as a docile and passive body, the application of clinical labels to individuals obscures the different dimensions that impairment or disability assumes for different people. Medicine 'has a tendency to ignore, minimize the importance of or deny outright any bodily experience that it cannot explain' (Wendell 1996). Thus the medical model ignores or denies the subjective social experiences that unite disabled people, and focuses only on the medical dimensions of difference (Shakespeare 1996). The application of a clinical label obscures the ubiquity of physical disability i.e. the experience of stigma, exclusion, discrimination and dependency - all of which deprive people with disabilities from having control over their own lives (Lonsdale 1990, Marks 1999). The medical gaze thus constitutes the patient as a docile and passive body, rather than a reflexive subject. By monopolising 'cognitive authority', medicine often subjects disabled

people 'to possible private and public invalidation by others. It has a tendency to ignore, minimize the importance of or deny outright any bodily experience that it cannot explain' (Wendell, 1996). There is a denial of common social experiences, which unite disabled people and the focus is only on the medical dimensions of difference (Shakespeare 1996).

The medical model completely ignores the crucial role of obstructive environments in creating dysfunctionality by treating the built and arranged environment as an invariable and hence disabled persons must adapt and adjust to their surroundings. From the standpoint of persons mobilising in wheelchairs, disablement is experienced not as the absence of walking but as the absence of access to public facilities. Often the functional deficits customarily associated with disability are neither more or less than alterable cultural artefact (Hahn 1985; Silvers et. al. 1998). There is a denial of common social experiences, which unite disabled people and the focus is only on the medical dimensions of difference (Shakespeare 1996). Hence disabled people become categorised into 'blind', 'deaf', etc. thereby highlighting their differences of experience rather than the commonality of the discrimination they experience.

Disabled people have been critical of the normalising medical programmes that aim to refashion bodies of individuals to conform to 'naturally' desirable standards. Abberley (1991 cited in Gleeson 1997) rejects normalising philosophies that fail to locate abnormality in the society and assume abnormality to reside within the individual. Normalising programmes imposed to force anomalous individuals to adjust to environments suited to dominant social classes totally ignore the role of obstructive environments in creating 'dysfunctionality'. Moreover, as disability is contextual and variable over time and circumstance, any individual can become impaired at any point of time. Impairment is simply a bodily state, characterised by absence or altered physiology, which defines the physicality of people. However if disabled people are defined by their physicality, it means that non-disabled people have denied their own physicality. If everyone is impaired then one must look at the way in which a specific group of people, the non-disabled, ignore their experience of impairment and physical limitation (Shakespeare 1994, 1996).

SOCIAL MODEL OF DISABILITY

The social model of disability developed out of the disabled people's movement both in Europe and in the United States of America in the 1970s and 1980s. The social model's categorization of impairment and disability highlighted the fact that bodily impairments or deficits are compounded by the disadvantage or restriction of activity caused by contemporary social organization which takes no or little account of people who have physical impairments and excludes them from the mainstream of social activities. The social model recognises that disability is not the outcome of bodily pathology but is socially produced by systematic patterns of exclusion that are built into the social fabric (Shakespeare 1994, Hughes & Paterson 1997). The social model questions the assumptions of the medical model that attributes the physiological body as the proximate cause of disability and the ultimate cause of handicap, and tries to understand the processes whereby disability is created within oppressive societal structures.

Disability activists and scholars have criticized the WHO for confusing the distinction between the terms 'disability' and 'impairment'. For them, impairment refers to physical or cognitive limitations that an individual may have, such as the inability to walk or speak. In contrast, disability refers to socially imposed restrictions, that is, the system of social constraints that are imposed on those with impairments by the discriminatory practices of society. Thus, the Union of the Physically Impaired Against Segregation (UPIAS 1976) clarified the definitions of impairment and disability in the following manner: An 'impairment is lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body'. 'Disability is the disadvantage or restriction of activity caused by contemporary organization which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities'. WHO has subsequently revised the earlier classification, specifying functioning at both the level of body/body part, whole person, and whole person in social context. The revision which is outlined in the International Classification of Functioning, Disability and Health (2001), reframes impairment as pertaining to biological systems

rather than to organs, but it retains the reference to supposed biological norms as the standard against which individuals are judged to be impaired.

In the initial stages, there were three strands of the social model, the Nordic social model, the strong social model developed in the United Kingdom and the minority group model propounded in the USA.

The Nordic social model propounded by the disability movement in the Scandinavian countries in the early 1970s, emphasised equality and citizenship rights for people with disabilities along with the welfare provisions and advocated for independent living for disabled people. The thrust of the Nordic model was on integration of people with disabilities in the mainstream of society by removing specialised institutions, modifying the social environment and changing cultural perceptions about disabilities. The main assumptions of the Nordic model were that disability is caused by a mismatch in the relationship between a person and the environment, and that disability is situational/contextual and relative.

The social model developed in the UK by disability activists was a result of the increasing awareness about the needs of the people affected by various physical impairments. The Union of the Physically Impaired Against Segregation (1976 cited in Oliver 1996) defined disability not as an impairment (a deficit of body or brain), but as a relationship between people with impairment/s and a discriminatory society (Shakespeare 2004). Disability therefore becomes a stigma, or labelling of atypical people, that devalues and excludes disabled people from mainstream society by constructing different acts/people as deviant, which reflects the power differentials in any particular society (Abberly 1991 cited in Gleeson 1997). Disability confers stigmatised status on all disabled people, as the physical characteristic becomes a master trait swamping personal differences. Thus disability is socially imposed on physically impaired people through restrictions, ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements. Further, the consequences of such restrictions do not simply and randomly

fall on individuals but systemically upon disabled people as a group who experience it as discrimination institutionalised throughout society (Oliver 1990).

In the USA, the minority group model has equated disability with minority identity, as able-bodied people, whether individually or collectively, oppress through the manifestation of hostile social attitudes and the enactment of social policies. Physical disability is therefore a form of social oppression through the prototyping of people with physical, cognitive or sensory impairments as limited and deficient (Bogdan & Taylor 1987, Silvers, Wasserman & Mahowald 1998). The social model of disability transforms the notion of 'handicapping condition' from a position of a minority group of people which disadvantages them in society, to a state of society which disadvantages the minority community. Disabled people have been isolated and have had little opportunity to portray their own experiences within the general non-disabled culture because of the interaction between people with disabilities, and stigmatising social values and debilitating social arrangements (Hahn 1988, Morris 1992).

The concept of difference has been applied to the study of disabled people as non-disabled people turn to prototypical portrayals of disability for legitimising the social exclusion of the disabled people (Bogdan & Taylor, 1994). This prototyping of people with physical, cognitive or sensory impairments and presenting them as limited and deficient has led to their marginalization. Silvers (1998) argues that the inequality visited upon persons with disabilities is rooted in social practices that bar them from demonstrating their competence. Normalising society posits disability as the product of profound natural inequalities in corporeal and intellectual functioning, as the disabled are rated primarily in terms of their deficits and the receipt of welfare allocations. Social deprivation collectivises the disabled as a weak class, and practices are fashioned in such a way that disability disqualifies people from access to civic and commercial goods. (Silvers 1998)

The social model of disability has served as an effective tool for remedying the injustices faced by disabled people and relocating efforts of service providers from individual solutions to removal of

barriers to participation in the mainstream activities. While the social model recognised the importance of appropriate individually based interventions in the lives of disabled people, it chose to focus on their limitations in terms of furthering their inclusion and empowerment within a society constructed by non-disabled people for non-disabled people (Barnes 2003). The social model was able to bring about structural changes in the developed countries in which it had been developed by insisting on citizenship rights and anti-discrimination legislation. At the same time the social model argued for a strong minority identity and demanded better services and facilities for the disabled, like higher benefits, more provisions for education and employment and increased access to all public facilities.

As the original social model had overlooked certain aspects of the category of disability, it has been modified and refined by later theorists, who have explored the economic and cultural implications of disability. One strand of the social constructionist paradigm suggests that society creates a negative social identity for people with disabilities, which is characterised as deviant or abnormal (Asch & Fine 1988). Disability is equated with helplessness, dependency and incompetence at all social interactions, and disabled people are subjected to isolation, lack of social support and social networks, low social esteem and a concomitant feeling of powerlessness. The able-bodied community uses prototypical portrayals of disability for legitimising the social exclusion of the disabled people. The disabled identity exists as mutually exclusive identity from all other identities because the cultural and media discourses on disability are influenced by the personal tragedy principle or by images of the super-cripple or the emotionally stunted disabled stereotypes. The complete absence of disabled role models has added to inequalities and injustice experienced by disabled people. The existing impaired role models are mainly heroes, heroines, victims and villains like Beethoven, Julius Caesar and Richard III, with which most disabled people cannot identify (Oliver 1990).

Another strand of the social constructionist paradigm posits disability as both a socially and historically relative social relation that is conditioned by political-economic dynamics (Finkelstein 1980 cited in Oliver 1990). Attitudes, discourses and symbolic

representations are critical to the reproduction of disablement, but are themselves the product of the social practices which society undertakes in order to meet its basic material needs (Oliver 1996, Gleeson 1997). The material conditions that produce the attitudes and meaning systems about disability have a great influence on the concrete experience of, and attitude towards impairment, which may vary between different modes of production. The social construction of physically impaired people as disabled people arises, in the first instance, from the specific ways in which society organises its basic material activities.

In western societies, as individuals gain recognition through their productive activities, people with disabilities find themselves enmeshed in a culture that forestalls their engaging in daily routine activities by equating impairment with weakness. Physically impaired people are excluded from mainstream socio-economic activities, as disability is seen as the product of natural inequalities in corporeal and intellectual functioning, and the disabled are rated in terms of their deficits and as recipients of extra allocations of resources. Non-disabled people have an interest in promoting those productive practices in which they can participate effectively and therefore advocate a segregated system responsive to the "special needs" of people, who cannot see, hear, move, think or perform other activities (Albrecht 1992 cited in Barnes 1998). Exclusion is thus linked to both economic independence and participation in social activities as specifically oppressive practices debar them from productive social roles (Oliver 1990, Erelles 1996, Silvers, Wasserman & Mahowald 1998).

Society produces the category of disability within capitalist social formation in a particular form with a particular worldview. Within this worldview, the production of disability is similar to the production of material goods through a set of activities specifically geared towards producing a good - the category disability, supported by a range of political actions, which create the conditions to allow these productive activities to take place and underpinned by a discourse which gives legitimacy to the whole enterprise (Oliver 1996; Erelles 1996). The hegemonic understanding of disability as it is produced by capitalist society - stems from the ontological assumptions it makes about the pathological and problem oriented nature of disability. Thus capitalist

society is increasingly concerned mainly with the causes of disability in individuals with a view to eradication, prevention cure and treatment. Treatment and cure are the appropriate societal responses to pathologies and problems. These assumptions and concerns exert a considerable influence on the way in which disability is experienced by both able-bodied and the disabled people alike - to have a disability is to have a problem (Erelles 1996).

The ideology of disability has been used to justify and regulate the asymmetric allocation of resources within capitalist societies by invoking biological difference as the natural cause of all inequality, thereby successfully justifying the social and economic inequality that maintains social hierarchies. Disabled people are relegated to the bottom of the social hierarchy which is built on structural inequality. The hegemony of disability in capitalist society is concerned mainly with the causes of disability in individuals in order to eradicate, prevent, cure and treat it. Thus disability also represents relationships of power between the non-disabled community and disabled people like carers and medical professionals, educational and other institutions, the administrative/welfare set up, the material production process or in the daily interactions with the stigmatising attitudes of social groups in general.

However, even though the social model has shifted the focus from the disabled individual to societal structures, it has failed to take into account subjective and bodily experiences of people with disabilities (Morris 1991, Tregaskis 2002). This rejection of the lived experience of impairment in favour of the social barriers to disability, denies the pain of impairment, both physical and psychological. The social model of disability proposes an untenable separation between the body and culture, impairment and disability, and in spite of its critique of the medical model, actually concedes the body to medicine and understands impairment in terms of medical discourse. The impaired and dysfunctional body is seen as devoid of meaning and history, a fixed, material entity subject to the empirical rules of biological science, existing prior to the mutability and flux of cultural change and diversity and characterised by unchangeable inner necessities (Csordas 1994, Shakespeare 1994). As a consequence, the body disappeared

from disability discourse (Hughes and Patterson 1997, Asch 2001, Shakespeare 2004).

QUESTIONS OF DEFINING: DISABILITY OR IMPAIRMENT

Disability theorists however differ with regard to the appropriate terminology to describe the life experiences of an individual with disability/impairment. British scholars (Oliver 1990, Barnes 1996, Priestley 1998, Abberly 1987) have stressed using the term disabled people to denote that while impairment refers to the biological condition, disability is the society's failure to address the needs of people with perceived physical impairments. Disability theorists in UK favour a two-tiered distinction/ construct where impairment refers to physical conditions as well as sensory and intellectual impairments, which is recognition of the fact that all physical conditions have psychological implications and all intellectual impairments have physiological consequences. As walking, seeing, and hearing are performances crucial to the major life activities, impairments that substantially limit them are usually considered disabilities. However it should be recognised that every impairment does not impose disablement. On the other hand, disablement can occur even without impairment, sometimes merely being regarded as impaired can disable a person. The 'disabled' names the class of individuals whose apparently anomalous physical, sensory or cognitive performances are the occasion of diminished functionality.

Thus British scholars define disability as the disadvantage or restriction of activity caused by a society that takes little account of people who have impairments and thus excludes them from mainstream activity. Therefore disability is like racism and sexism, resulting in discrimination and social oppression (Finkelstein 1980, Oliver 1990, Abberley 1991, Shakespeare 1996). Impairment is a characteristic, feature or attribute within an individual which is long term and may or may not be the result of disease, injury and may affect the individual's appearance in a way which is not acceptable by society and /or affect the functioning of that individual's mind and body either because of or regardless of society. Disabled people are those people with impairments who have been disabled by society (Morris 1991). The term disability thus means the disabling barriers that determine the life chances of the disabled person. Disability does not only mean impairment

but also denotes the disabling barriers of prejudice, discrimination and social exclusion. These labels were also seen as socially imposed rather than chosen and are politically and socially divisive.

On the other hand, scholars in the USA use the term people with disabilities, thereby implying that the term disabled indicates that a person's disability is synonymous with the person himself /herself rather than just one of many personal characteristics. The implication is greatly advocated by people who know that they are much more than a missing limb or faculty (Oskamp 1988). Having a disability does not mean that the individual is fully disabled but possesses an impairment that may or may not lead to disability. Thus in American studies, people with disabilities are defined in terms of their impairments, i.e. disability here means impairment or what the bodies of specific individuals cannot do. There is a distinction perceived between those who have "objective departures" from species typicality, and those who are inaccurately perceived as impaired (Asch 2001)

However Barnes (1998) has criticised American scholars for being impairment specific, limiting their discussions to "people with physical disabilities" or the body. Here disability is seen both as a biological condition as well as a social construct. The bifurcation of impairment and disability is analogous to the traditional feminist bifurcation between sex and gender, which was seen as a way of focussing attention on the social nature of women's inferiority. The tendency to view both impairment and disability in terms of simplistic, collective accounts of ontologically diverse experiences are founded on the dualisms between mind and body (Corker 2001).

Given the complexity of the conceptual relationship between impairment and disablement, the term people with disabilities refers to the collections of individuals who have a condition considered to be a physical, sensory or cognitive impairment; 'disabled people' refers to the collections of individuals subjected to the social process of disablement; the 'disabled' signals an assertion about the class of people with disabilities (Silvers, Wasserman & Mahowald 1998). The terms 'disabled people' and 'people with disabilities' are sometimes used interchangeably, which reveal issues about causality, the roles of language, its

normalising tendencies and the politicisation of the process of definition. While the British disability scholars emphasize disablement as a social process preventing individuals with certain characteristics from being respected and rewarded as other ordinary persons, American activists stress that disablement does not reduce the essential inner person, however much it oppresses the contingent social person.

The re-conceptualisation of disability thus takes into account the historical, economic, political and social constraints, and questions the concept of the normal body in order to critique stigmatisation (Erevelles 1996). Disabled bodies can become 'extraordinary', as disability is defined not as a set of observable, predictable traits - like racialised or gendered features - but as a departure from an unstated physical and functional norm (Garland-Thomson 1997). The normate is the constructed identity of those, who because of certain bodily configurations and cultural capital that they assume, can step into a position of authority and wield the power that it grants them. Thus different forms of corporeal diversity underlying a hierarchy of bodily traits acquire cultural meanings through complex processes that determine the distribution of privilege, status and power. Disability operates within culture through legal, medical, political and literary discourses of exclusion, that create the physically disabled body as an embodiment of corporeal insufficiency and a repository of social anxieties about control and identity. Disability is interlinked with complex social power relations, which implies that an individual's impairment will always be part of an embodied identity (Meekosha 1998). Therefore embodiment has to be looked upon as a constantly shifting experience of physicality with an inextricable element of lack, disease, degeneration and suffering, that can affect any individual to varying extents and at different times (Shakespeare 2004).

DISABILITY DISCOURSE IN INDIA

In India, the state has always assumed responsibility for providing the welfare of disabled citizens. Thus in historical texts, there are references to residential institutions and hospitals for the physically disabled (that included the blind, crippled and deaf people) and the infirm (Mani 1988). In the colonial period, institutions for disabled people were started mainly in towns

with religious shrines (like Benares and Lucknow), where there was a preponderance of disabled people, living off the charity of visiting pilgrims. These schools and residential institutions founded by 19th century reformers aimed at providing education and vocational training to disabled people, mainly the visually and orthopaedically impaired. There were also sporadic efforts to set up hospitals and charitable institutions by individual philanthropists, especially after World War II. But the problems of disabled people were not addressed in a comprehensive manner (Mani 1988). However, an important step for providing accurate information towards guiding policy for the disabled was taken at the initiative of the colonial rulers: from the first census in India in 1872 to 1931, data about different categories of disabled people (physically and intellectually disabled and leprosy affected) was collected.

While there was no clear-cut policy during colonial rule and even after Independence, the general attitude towards the disabled has been one of charity and welfare. After Independence, the state in India accepted social welfare as a state responsibility, seeking to promote the welfare of the weaker sections of society, defined as groups of individuals in need of special considerations like children, women, people from certain scheduled castes and tribes and disabled people. Thus welfare activities that had been the responsibility of voluntary or religious organisations now became state responsibility (Billimoria 1985). The Constitution of India has guaranteed through the Directive Principles of State Policy and Fundamental Rights, equality before the law and equal protection of law for all its citizens, and prohibited discrimination on the grounds of 'religion, race, caste, sex, place of birth'. However the orientation towards people with disabilities has been that of welfare, as is evident from Article 41 which stipulates, 'The state shall, within the limits of its economic capacity and development make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement' (Advani 1997).

The reluctance of the government in formulating and implementing a coherent disability policy reflects the socio-cultural assumptions about the disabled in India, where a religio-moral-medical model

of disability is still prevailing. Thus socio-religious conceptualisation of disability is that impairment is divine retribution for past or present sins, and disabled people were looked upon as objects of pity. While the welfare approach towards other disadvantaged sections of the population like women, children and the Scheduled Castes/Tribes led to comprehensive State initiated policies and programmes, the attitude towards disabled people was of token inclusion and general neglect and apathy for their concerns. The Planning Commission, entrusted with the responsibility for allocating funds and planning programmes for different sections of the populace, sought to define during the first Plan period the physically disabled as those lacking in one or more physical senses like blindness, deafness, those suffering from movement difficulties, mainly orthopaedic, and lepers and epileptics (Mehta 1983). This definition of disability, with its strong medical bias, has since then influenced the state's attitude and orientation towards disabled people and their concerns. In India, given the competing claims of other policy sectors, the concerns of the disabled population are often accorded low priority (Mani 1988). Thus in the first three plan periods separate allocations for the welfare of the physically handicapped were negligible, one of the reasons being that there was no data available on the extent of disability in India. The allocation of funds for the disabled followed an arbitrary and skewed pattern, with the medical rehabilitation of the disabled receiving top priority, as the state had by then, adopted the medical model of disability as the key paradigm for service delivery.

Therefore, a large part of the financial allocation for welfare and rehabilitation of disabled people was channelized into providing facilities for medical treatment and management of people with different orthopaedic and sensory disabilities, like restorative surgery, provision for assistive aids and appliances and different therapeutic interventions (Mohit&Rungta 2000). Aids and appliances for people with different disabilities provided by the Grant-in-Aid scheme and routed through local non-government organisations were able to cover only a fraction of the population due to limited funds. The setting up of the National Institutes, one each for visual impairment, orthopaedic impairments, hearing handicaps and mental retardation in the late 1970s and early

1980s, to provide medical and para-medical support services to the disabled all over India, further reinforced the medical model of disability. However the major responsibility for providing medical and support services to the disabled still remained with the local Non-Governmental Organizations (NGOs), who were catering mostly to the needs of the disabled in the urban areas.

The state's commitment towards education of disabled people, mainly with visual, hearing and orthopaedic impairments has been strong, as is evident from the scholarship schemes and aid provided to special schools and institutions for the disabled under the aegis of the Ministry of Education. In 1966, however, there was a policy shift with all responsibility for the disabled people being entrusted to the Ministry of Social Welfare. While the Ministry of Education aimed to cater to the needs of 'normal' children only (Ramanujam 2000), education of disabled people was seen as the responsibility of special schools that would be monitored and funded by the Ministry of Social Welfare. The National Policy on Education 1986 advocated Integrated Education in general schools for the orthopaedically impaired and mildly disabled children and Special Education for the severely handicapped children (Zachariah 2001). Thus the state efforts were concentrated on providing services for the education of disabled children with physical disabilities, mainly through scholarships and establishment, funding and monitoring of special schools.

The welfare state in India with its charity outlook and emphasis on medical aspects of rehabilitation lacked the political will to encourage the empowerment of disabled people. There was little direct commitment towards bringing about changes at the social or political levels. Therefore even though the first Special Employment Exchange for the Physically Handicapped was set up in Bombay in 1959, and 3% of 'identified jobs' in C and D categories in the government and the public sector were reserved for the disabled, very few people have benefited from it (Advani 1997). The individualistic orientation of the programmes towards the disabled people is also evident from the fact that other important concerns like integration, social attitudes, access etc. received little attention as the aim was to secure the welfare of the disabled individual, without intervening at the level of community practices.

POLICY DIRECTIVES FOR PERSON WITH DISABILITIES IN INDIA

The apathy of the State in developing a comprehensive policy for persons with disabilities becomes apparent from its sporadic efforts, initially in 1970-71 and then in 1980, to draft a suitable law for the disabled. These half-hearted strategies however were initiated only due to the pressure from international developments, like the United Nations General Assembly's Declaration on the Rights of the Disabled Persons in 1975, and the declaration of 1981 as the International Year for Disabled Persons. In response to international pressure and disability activists in India, the state incorporated disability as a category of data collection in the Census of 1981, which would reveal the magnitude and then help in framing adequate and equitable policies. However, the biased terminology used in the census operations (totally crippled, totally blind and totally dumb) rendered the data inadequate, as only 0.16 % of the total Indian population was found to be disabled, leaving out two major categories, people with hearing impairments and mental disabilities. At the same time a draft legislation known as Disabled Persons (Security and Rehabilitation) Bill 1981 was prepared and then shelved (Abidi 1996, Advani 1997).

In the international sphere, disability came to be recognised as a human rights issue, and in 1985 the Universal Declaration of Human Rights was specifically extended to include disabled people (Priestley 2001). The International Decade of Disabled Persons (1983-92) culminated in the development of United Nations' Rules on the Equalization of Opportunities for Disabled Persons in 1993. In Asia also, the Economic and Social Commission of Asia and the Pacific (ESCAP) declared 1993-2002 as the Asia and the Pacific Decade of Disabled Persons to give impetus to the implementation of the World Programme of Action in the ESCAP region. In response to such international developments and increasing pressure from disability activists in India, the Government of India enacted the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act in 1995. However the law came into force only in February 1996 (Mohit 2000).

The hurried passage of the Persons' with Disabilities Act in India in 1995 in response to international pressure, forestalled the

drafting of a comprehensive policy which would include a broader set of initiatives, decisions, priorities or guidelines that address a goal and a plan for its achievement. A National Policy on Persons with Disabilities, stating the government's clear stance towards the issue of disability would thereby outline the state's attitude towards disabled persons and would then lead to the passage of necessary laws for fulfilling the directives mentioned in the policy. The People with Disabilities Act 1995 thus became the first policy statement in India, which recognised the rights of people with various impairments to equal opportunity to participate fully in social, cultural, economic and educational programmes of the country. The National Policy for Persons with Disabilities in India which came into effect in 2006, is a more forward looking document because of the influence of the United Nations' Convention on the Rights of Persons with Disabilities, which was passed in 2007 and became an international law in 2008. The National Policy for Persons with Disability 2006, attempts to clarify the framework under which the state, civil society and private sector must operate in order to ensure a dignified life for persons with disability and support for their caregivers. The policy recognises the need to replace the earlier emphasis on medical rehabilitation with an emphasis on social rehabilitation. Community Based Rehabilitation (CBR) is seen as an effective means of rehabilitation, and the policy states that CBR will be encouraged.

Although the National Policy "recognizes that Persons with Disabilities are valuable human resource for the country and seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in society," it limits itself to only reiterating the provisions enlisted in the different laws for persons with disabilities in India. The PWD Act has defined disability in strictly medical terms, proceeding from the medical model of disability that ignores the social perceptions about disability (Mohit&Rungta 2000). Thus the categories of disability: blindness and low vision, leprosy cured, hearing impairment, locomotor disability, mental retardation and mental illness are all dependent on certification by medical professionals. This highlights and legitimises the control of the medical professionals over the diagnosis, management and interventions for the disabled. Moreover, many disabilities are conditions that

may not need medical interventions or management, but a more inclusive attitude towards the disabled person and his/her needs. The Act has however left out some groups - like people with epilepsy, older people with disabilities and certain genetic conditions, as well as learning disabilities and attention disorders - which can be very disabling in different social setups.

The main thrust of the Act has been to spell out the State's responsibility towards prevention of impairments and protection of disabled people's rights in health, education, training, employment and rehabilitation. The Act treats disability as a civil right, and lays down provisions for creating a barrier-free environment for disabled people as well as removing discrimination and abuse against people with disabilities. There are extensive strategies laid down for development of comprehensive programmes and services for equalisation of opportunities for disabled people and provisions for the integration of disabled people into mainstream society. The Act also emphasized the need for supporting institutions for persons with disabilities as well as social security provisions for the disabled (Advani 1997, Mohit & Rungta 2000).

The law has given equal importance to

- a) Prevention and early detection of disabilities by promoting various measures to prevent disabilities and pre-natal, peri-natal and post natal care at the Primary Health Centres, as well as running mass awareness campaigns to disseminate knowledge about causes and preventive measures.
- b) Education of disabled people that ranges from free schooling to integration into mainstream educational institutions to special schools with appropriate learning facilities. There is 3% reservation of seats in all government educational institutions as well as those receiving support from the government for persons with disabilities. The state also has the responsibility for providing adequate transport facilities to students with disabilities and accessible physical environments, as well as restructuring the curriculum, modifying the examination system, and providing scholarships for disabled students.
- c) Employment of disabled people by identifying and reserving

3% of jobs in different government departments for people with blindness/low vision, hearing impairment and locomotor disability/ cerebral palsy.

- d) Management of disability by providing aids and appliances to people with different disabilities.
- e) Promotion of non-discriminative attitudes by modifying physical environments for people with different disabilities, forbidding the denial or termination of service to persons with disabilities on the grounds of disability etc.
- f) Strengthening of institutions for disabled people and provision for social security.

In spite of focussing on different aspects of the lives of disabled people, the Act has sustained its inclination towards the medical model of disability, by projecting disability as an individual problem that can be remedied through different interventions and specialised services. The Act has ignored the definitions of disability advocated by the social model, which lay more stress on the disabling barriers faced by people with impairments and press for structural changes within society.

The availability of correct and latest data about the incidence, prevalence and spread of different disabilities all over India would help in further policy formulation, planning and implementation of programmes and resource allocation. The collection of statistics on disability in independent India was first initiated in 1981 when data was collected only on three categories of disability: movement, vision and hearing. However this data is highly unreliable as the questions posed were directed only at completely blind/completely deaf/ completely crippled, which led to collection of information about a small percentage of the disabled population. The category of disability was dropped from the 1991 census without any explanation, and then re-included in 2001 due the advocacy efforts of disability activists in India. However the 2001 census data has been criticised for collecting information for only 4 categories of disabilities, and not for all the 7 types of disabilities listed in the Act. The census operations have also been criticised for possible false categorisation of disability as the enumerators were not given proper orientation before the data collection.

The implementation of the policy programmes and various schemes for the disabled people both before and after the Persons with Disabilities Act 1995 have been characterised by ad hoc and sporadic efforts on part of the state. The disabled person has usually been treated as a compartmentalised being, with different aspects of his/her existence coming under the purview of different wings of the State apparatus, with little or no coordination among themselves. For example, while the prevention and early detection of disabilities is a programme of the Ministry of Health and Family Welfare, education and employment concerns are looked after by the Ministry of Welfare (now renamed as the Ministry of Social Justice and Empowerment). Even now the Ministry of Social Justice and Empowerment and the Ministry of Human Resource Development are running parallel systems resulting in a conceptual fragmentation of the core concerns (Alur 1997 cited in Ramanujam 2000). This kind of segregation and individual intervention is reminiscent of the medical model where the affected part of the body becomes the focus of attention and subjective experiences of the disabled person are negated. The primary focus of the rehabilitation services continues to stress the medical aspects of disability: prevention and early detection of disabilities as well as the management of disabilities through corrective surgery, supply and fitment of aids and appliances and assistive devices etc. State approach towards implementation of programmes has varied from benign neglect to complete dependence on non-government organisations for delivering different services in remote parts of the country, which has reached only 2% of the disabled population.

Both the State and most of the NGOs working in the field have tacitly adopted the medical model of disability as is evident from the latest Indian Human Development report that states 'physical disabilities are genetic, biological and even birth defects and future research must focus on the medical causes of such disabilities' (DPI Report 2004). As the recognition of a category of disability depends on its inclusion in the Act, people belonging to categories that have been overlooked are being sidelined and refused access to services. The stipulation that the disabled people will receive benefits according to the degree of their disability totally ignores the impact of social, psychological, or political factors on individual disability. As the provisions of the State depend on the medical

certificate indicating the percentage of impairment issued by State Medical Boards, there have been reports of gross discrepancies in the awarding of the disability certificates.

Programmes advocating education of disabled children like the Integrated Education of Disabled Children Scheme (IEDC) in 1974 and the Project Integrated Education for the Disabled (PIED) in 1987 met with limited success as exclusionary policies and practices prevalent all over India still deny admission to disabled children in regular schools. The lack of comprehensive planning and political will to achieve integration resulted in the poor implementation of the programme provisions like orientation and training of school teachers etc. Thus education of people with disabilities has remained confined mostly to special schools in urban areas. The Universal Primary Education (1997) programme that sought to integrate into general schools, children with visual, hearing, orthopaedic and learning impairments at the primary school level, has met with partial success. In recent years the District Primary Education Programme (DPEP) has had a powerful impact on integrating disabled children as it addressed core issues related to curriculum. However, the provision of only three resource teachers per block under the DPEP pattern has proved inadequate, as schools are spread over vast geographical stretches, limiting interactions between the teachers and students. Most schools have not been able to remove architectural barriers and hence still refuse admission to disabled children (Zachariah 2001).

According to Census 2001, there are around 14 million unemployed persons with disabilities. Although the government has established 47 Special Employment Exchanges and 41 Special Cells in the regular Employment Exchanges, the scheme has provided employment to only 49,000 disabled persons, most of whom had orthopaedic impairments (Centre for International Rehabilitation 2003). The special employment exchanges have achieved limited success even though most of those registered had received vocational training (NCPEDP-NAB 1999). The placement of disabled people in various private institutions has also been only partially successful. In a survey conducted by the National Centre for the Promotion of Employment of Disabled Persons (NCPEDP) and National Association of the Blind (NAB) in 1999, it was found that 50% of disabled people were self-employed as both public

and private sector companies were found to be employing very few disabled people. The reservation of jobs in identified government departments also has not been implemented properly and the posts filled are mostly in the lowest ranks. The concept of identified jobs is itself questionable as it may not take into account the actual capacities of people with disabilities (Rajalakshmi 2002). The National Handicapped Finance and Development Corporation (NHFDC), which finances a wide range of activities like self-employment ventures and loans for education to disabled people, has also met with limited success because of the lengthy and cumbersome procedures for accessing its services.

A serious lacuna in the Persons with Disabilities Act is that there are very few penal provisions for non-implementation of its measures. The Act stipulates that in most cases programmes would be initiated and implemented subject to the economic capacity and development of the state. There are no time bound programmes of action or obligations by the state for the initiation and implementation of the provisions of the Act. The enforcement of its provisions has been left to courts of law without specifying procedures to be followed in case of violations of the recommendations. This makes the enforcement of the provisions of the law very debatable and totally dependent on the magnanimity of the State (Advani 1997, Mohit 2000). Consequently, many state governments and local authorities have cited lack of funds as a reason for non-implementation of the provisions, especially those concerning access to public buildings and utilities. Campaigns for providing access to public buildings by disability organisations have been sporadic and limited to urban areas, yielding very little results. Although air travel has been made more accessible for people with disabilities following a Supreme Court directive, the more commonly used modes of public transport such as buses and trains, continue to be inaccessible to the disabled (Rajalakshmi 2002).

The complete lack of political will on part of the State and the tendency to sideline disability concerns has been reflected in the delay in the appointment of Coordination Committees and Disability Commissioners at state and central levels, who would ensure proper implementation of the provisions of the Act. As most states in India have appointed their Secretary of Social Welfare as the

State Disability Commissioner, in many instances the incumbent has little knowledge about the real concerns of disabled people. Disabled people also have been very inadequately represented in such implementing bodies (Abidi 1996, Rajalakshmi 2002).

The attitude of the government is reflected in the scanty measures provided for people with disabilities in other areas of public life. In the general Parliamentary elections in 2004, although the Supreme Court directed the Election Commission to make provision for disabled people to exercise their right to vote by providing extra facilities in the polling procedure like accessible polling booths, ballot papers and electronic voting machines, very few polling booths had special provisions like ramp access and facilities for reading poll instructions. The lobbying by different disability rights coalitions consisting of NGOS of and for disabled people however has helped in exposing the weaknesses of the Act.

CONCLUSION: EMBODYING DISABILITY FOR FRAMING POLICY IN INDIA

Western conceptualisations of disability have played a major role in influencing the ways in which the discourse on disability in India has developed, and which has been mediated by the socio-cultural and religious attitudes of society as well as of the policy makers. However, the disability activists and academics in the West have increasingly advocated a nuanced understanding of disability and impairment as impairment also is created, defined and understood within social contexts (Shakespeare 2004). Thus the relationship between impairment and disability becomes very complex as impairments are multiple and are seen to impinge differently upon disabled people at different points of time, depending on a host of psychological, social and environmental factors that are all external to the biomedical condition (Silvers, Wasserman & Mahowald 1998). Thus the ways in which bodies interact with socially engineered environments, which include the natural environment, the built environment, culture, the economic system, the political system, and psychological factors and conform to social expectations determine the varying degrees of able-bodiedness or disability (Garland-Thomson 1997).

Marks (1999) defines disability as 'the complex relationship

between the environment, body and psyche, which serves to exclude certain people from becoming full participants in interpersonal, social, cultural, economic and political affairs'. This definition of disability avoids the usual individual/social binary, and insists that disability does not reside within a particular body or environment, but rather is an embodied relationship. People with different forms of disability experience their bodies and negotiate their identities in different ways, as forms of resistance and the struggle for bodily control, independence and emancipation are embodied. Disability therefore becomes relative, its impact varying according to type and degree of impairment, socio-economic status, gender, social and geographical locations etc.

Disability as a cultural category that highlights human variations unites a highly heterogeneous group of people, who share only one common characteristic - that of being considered abnormal (Garland-Thomson 1997). Disability signals that the body cannot be universalised as it is shaped by history, defined by its particularity and may be at odds with the environment. Disability thus becomes the attribution of corporeal deviance - not as a property of bodies but as a product of cultural rules about what bodies should be or do (Shakespeare 1996). Disability is also experienced in, on and through the body, as impairment is interpreted in terms of personal and cultural narratives that help to constitute its meaning. Therefore disability is seen as culturally, spatially and historically variable, influenced by various social, economic and political determinants that affect the individual experiences of people with differing degrees of impairment. Recent attempts to theorise disability have however emphasized that any conceptualisation of disability must take into account other bases of identity like gender, race and class and the way in which these identities interact with the disabled status to exert simultaneous oppression over people with disabilities. As disability is a socially created category, its meaning varies according to other systems of power and inequality. Feminist disability scholars, in particular, have argued that the homogenisation of the experience of disability has projected the experiences of disabled men as representative of all disabled people, ignoring gendered societal standards that influence and construct cultural notions of masculinity and

femininity and shape the development of identities of men and women with disabilities.

In India, the welfare state has taken the responsibility for the care and protection of persons with disabilities through provision of social security measures that primarily include pension and scholarships. These welfare provisions, while of benefit to certain persons with disabilities, are actually oppressive for most as these reinforce the images of dependency, weakness and incapability. The state in India has retained a paternalistic attitude towards persons with disabilities, by seeking to provide for protection, welfare and medical rehabilitation. Socio-cultural and religious beliefs have blended with the rapid developments in the field of medicine in the minds of the policy makers in India, who have laid stress on normalisation of the disabled person, through support for medical treatment, aids and appliances, provision for special education and welfare pay-outs like pensions.

Despite the National Policy for Persons with Disabilities framed in 2006, claiming that disabled people 'are a valuable resource of the country', there has been little change in the actual treatment of disabled people by the state apparatus in India. Policy initiatives in India have remained confined within the dominant medical paradigm and has not only defined disability in medical terms but also handed over the power of certification of disability to the medical professionals operating within fixed infrastructural contexts. One major concern of the disability policy in India has been prevention of disability, which reinforces the medicalised interpretations of impairment, while the primary focus should have been on early identification and intervention. Disability policy cannot have the eradication of the very people for whom the policy is being framed as one of its objectives- prevention of disabilities can be part of the health and family welfare policies.

Most of the disabilities policies in India have assumed the uniformity of disability experience thereby denying the varied nature of the experience of disability depending not only on the type and degree of disability but also on other socio-cultural factors that include regional, geographical, class, caste, religion and gender identities. These expressions of power differentials and unequal relationships further influence the experiences of

disabled people, leading to different degrees of inclusion/exclusion within different social, cultural, economic, and religious contexts. The state, operating within, has failed to recognise the embodied experiences of people with disabilities. Thus disability policy has remained limited and inadequate as it is unable to envisage the lived realities and subjective embodied experiences of disabled people and the social and cultural constructions that represent disability as deficiency.

The implementation of disability policy by an administrative apparatus, impaired by the socio-religious and cultural ideas regarding disability prevalent in society, leads to the continued propagation of discriminatory attitudes and provisions at the grassroots level. Moreover, under the Constitution of India, primary responsibility for delivery of services and commitments to people with impairments rests at the state level, even though the policies are framed at the central level. This leads to problems of interpretation and coordination between the centre and state governments, and ultimately to the exclusion of persons with disabilities from the social fabric of the community. As the act specifies only some categories of disabled people, other categories of persons who have or might be considered to have a disability are left out of the provisions of the policies for their benefit. This exclusionary policy thereby recognises and legitimises certain conditions and impairments as disabilities while ignoring others, thereby creating a hierarchy among persons with different impairments with regard to opportunities and life chances. The policy also fails to state clearly the initiatives to be taken up by the state in the form of programmes and interventions to promote inclusion of disabled people in India. The policy acts merely as a recommendatory document, without proper time frames or penal provisions for non-compliance. As a result, the courts in India have become the medium through which disabled people have sought to access their rights. The judiciary in India has played a proactive role over the years in not only redressing wrongs done to persons with disabilities but also clarifying policy and promoting inclusion.

As the issues concerning person with disabilities cannot be divorced from the objective conditions - socio-economic and political realities - existing at any particular point of time, there

is need for greater realisation among disabled persons themselves about their rights. Globally, disability rights movements have brought about significant changes in the definitions of disability and the rights based policies being enacted for persons with disabilities, especially in the western countries. In India too, a range of national level disability related initiatives has been taken during the past two decades with the overt vision of ensuring equalisation of opportunities and full participation for persons with disabilities through specially enacted disability related legislations. However such policy documents contradict the overall espoused vision for greater inclusion of persons with disabilities in mainstream society, not only because they are mired in a medico-legal perspective but also because there is minimal participation of persons with disabilities themselves in the framing of these documents. Such documents in India are still being framed by medical and paramedical professionals and a whole range of people dedicated to the specialised services who do not promote inclusion as it threatens their own existence.

The need is therefore to stimulate and activate disability rights activists for achieving the goal of securing social justice, equalisation of opportunities and full participation in India. There is need for dialogue between disability activists and disabled people themselves regarding disabling barriers at the grassroots level, which will form the focus of any policies concerning disability in India. Networks of persons with different disabilities need to be developed locally as well as on a pan Indian basis to form a cohesive, powerful pressure group for demanding just public policies that envisage inclusion as a part of everyday process and not as a specialised agenda. There is need to educate every person with disability in India and the concerned families regarding mainstreaming disability issues within development debates and for actualising the goals of equalisation and full participation of persons with disabilities in nation-building.

REFERENCES

- Abidi, Javed. 1996. The advent of an advocacy age. *Dipsikha*. December.
- Advani, L. 1997. *Rights by Law*. Paper presented at the National Consultation Meet on Rights of Disabled Children.
- Asch, A. 2001. Critical Race theory, Feminism and Disability: *Reflections on Social Justice and Personal Identity*. Source: <http://moritzlaw.osu.edu/lawjournal> June 2003.
- Asch, Adrienne and Fine, Michelle. 1988. Introduction: Beyond Pedestals. In M. Fine and A. Asch (Eds) *Women with Disabilities: Essays in Psychology, Culture and Politics*. Philadelphia. Temple University Press.
- Barnes, C. 1998. The Social Model of Disability: A Sociological Phenomenon Ignored by Sociologists? In T. Shakespeare (Ed) *The Disability Studies Reader: Social Science Perspectives*. London. Cassell.
- Barnes, C. 2003. *Disability Studies: What's the point?* Notes for a verbal presentation at the Disability Studies: Theory, Policy and Practice Conference, University of Lancaster. Source: www.lans.ac.uk/fss/apsocsci/events/dsaconf2003/fullpapers. July 2004.
- Billimoria, R.B. 1985. *Educating the Mentally Retarded: A study of special schools in Bombay*. Ph.D. Thesis, Tata Institute of Social Sciences, Mumbai.
- Bogdan, R. and Taylor. S. 1987. Towards a Sociology of Acceptance: The Other Side of the Study of Deviance. *Social Policy* 18, 34-39.
- Campling, J. 1983. *Social Work with Disabled People*. Hong Kong. Macmillan.
- Census of India. 2001. *Tables on Disability*. Registrar General and Census Commissioner. New Delhi. Source: www.censusindia.net/disability/disabled.html September 2004.
- Centre for International Rehabilitation. 2003. India: Rights of Persons with Disabilities. *International Disability Rights Monitor*. Source: www.cirnnetwork.org/idrm/reports/compendium/india.cfm July 2004
- Corker, M. 2001. Sensing Disability. *Hypatia* 16(4), 34-52.
- Csordas, T. J. (Ed). 1994. *Embodiment and Experience: the existential ground of culture and self*. Cambridge. Cambridge University Press.
- Disabled People's International. 2004. *International Country Report on India*. New Delhi.
- Erevelles, N. 1996. Disability and the Dialectics of Difference. *Disability and Society* 11(4), 519-537.
- Garland-Thomson, R. 1997. *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York. Columbia University Press.
- Ghai, Anita. 2001. Marginalisation and Disability: experiences from the Third World. In M. Priestley (Ed) *Disability and the Life course: Global Perspectives*. Cambridge. Cambridge.
- Gleeson, B.J. 1997. Disability studies: a historical materialist view. *Disability and Society* 12(2), 179-202.
- Government of India. 1996. *The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995*.
- Hahn, H. 1985. Towards a Politics of Disability: Definitions, Disciplines, and Policies. *The Social Science Journal* 22 (4), 87-105.
- Hahn, H. 1988. Can Disability be beautiful? *Social Policy* 19, 26-31.
- Hughes, B. and Patterson, K. 1997. The Social Model of Disability and the Disappearing body: Towards a sociology of impairment. *Disability and Society* 12(3), 325-340.
- India: Ministry of Planning and Programme Implementation. 1981. *Sarvekshana Report, 36th round*. National Sample Survey Organization, Department of Statistics. New Delhi.
- India: Ministry of Planning and Programme Implementation. 1991. *Sarvekshana Report, 47th round*. National Sample Survey Organization, Department of Statistics. New Delhi.
- Karna, G.N. 2001. *Disability Studies in India*. New Delhi. Gyan Publishing House.
- Lonsdale, S. 1990. *Women and Disability*. London. Macmillan.
- Mani, D. Rama. 1988. *The Physically Handicapped in India: Policy and Programme*. New Delhi. Ashish Publishing House.
- Manu Samhita 1st Century BC translated by George Buhler. *Sacred Books of the East*, vol. 25.1886. Oxford. Source: <http://www.sacred-texts.com/hin/manu.htm> January 2012.
- Marks, D. 1999. Dimensions of oppression: theorizing the embodied society. *Disability and Society* 14(5), 611-626.
- Meekosha, H. 1998. Body Battles: Bodies, Gender and Disability. In T. Shakespeare (Ed) *The Disability Studies Reader: Social Science Perspectives*. London. Cassell.
- Mehta, D.S. 1983. *Handbook of the Disabled in India*. New Delhi. Allied.
- Miles, M. 1995. Disability in an Eastern Religious Context: historical perspectives. *Disability and Society* 10(1), 49-69.

- Mohit, Anuradha and Rungta S.K. 2000. Regional Experiences: Legal Protection for Persons with Disabilities in India. Source: www.interights.org/pubs/Bulletin May 2003.
- Mohit, Anuradha. 2000. Governance and legislation: initiatives of Government of India to advance Asia & Pacific Decade of Disabled Persons. *Disability World* 2, Apr-May.
- Morris, J. 1991. *Pride against Prejudice*. London. Women's Press.
- Morris, J. 1992. Personal and Political: a feminist perspective on researching physical disability. *Disability, Handicap and Society* 7(2), 157-166.
- National Centre for Promotion of Employment for Disabled People and National Association for the Blind. 1999. *The employment scenario in India with reference to People with Disabilities*. Report of study conducted by NCPEDP-NAB, India. Source: www.dpa.org.sg/DPA/publication/dpupub/fall99 August 2004
- Oliver, M. 1990. *The Politics of Disablement*. Houndmills. Macmillan.
- Oliver, M. 1996. *Understanding Disability: From theory to practice*. Basingstoke. Macmillan.
- Oskamp, Stuart. (1988). The Editor's Page. *Journal of Social Issues*, 44(1): 5.
- Priestley, M. 2001. Introduction: the global context of disability. In M. Priestley (Ed) *Disability and the Life course: Global Perspectives*. Cambridge. Cambridge.
- Rajalakshmi, T.K. 2002. A law on paper. *Frontline* April 12.
- Ramanujam, P.R. 2000. Social Policies on Disability in India. *International Journal of Disability Studies* 1(1), 3-15.
- Shakespeare, T. 1994. Cultural Representation of Disabled People: dustbins for disavowal? *Disability and Society* 9(3), 283-299.
- Shakespeare, T. 1996. Disability, Identity and Difference. In C. Barnes and G. Mercer (Ed) *Exploring the Divide*. Leeds. The Disability Press.
- Shakespeare, T. 2004. Social Models of Disability and other life strategies. *Scandinavian Journal of Disability Research*, Vol.6, Issue 1.8-21.
- Silvers, A., Wasserman, D. and Mahowald, M. 1998. *Disability, Difference, Discrimination: perspectives on Justice in Bioethics and Public Policy*. New York. Rowman & Littlefield.
- Swain, J., French, S. and Cameron, C. 2003. *Controversial Issues in a Disabling Society*. Buckingham. Open University Press.
- Thomas, D. 1982. *The experience of Handicap*. London. Methuen.
- Tregaskis, C. 2002. Social Model Theory: the story so far. *Disability and Society* 17(4), 457-470.
- Union of Physically Impaired Against Segregation, *Fundamental Principles of Disability*, United Kingdom, 1976. Source: <http://www.leeds.ac.uk/disability-studies/archiveuk/UPIAS/fundamental%20principles.pdf> January 2012.
- United Nations Organisation. 1991. United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities.
- Wendell, Susan. 1996. *The Rejected Body: feminist philosophical reflections on disability*. New York. Routledge.
- World Health Organisation. 1980. *International Classification of Impairments, Disabilities, and Handicaps*. Geneva. World Health Organisation.
- World Health Organisation. 2001. *International Classification of Functioning, Disability and Health*. Source: www3.who.int/onlinebrowser/icf.cfm February 2004.
- Zachariah, Job. 2001. *Universal light of Knowledge: Opening New Doors*. Source: www.un.org.in/JANSHALA/march2001/educdisb.htm June 2004