CHAPTER II

UNDERSTANDING DISABILITY

Disability is a complex term that includes multiple definitions, approaches and perspectives, each with its own distinct angle and purpose, ranging from the very narrow to very broad boundaries, and looks very differently from the point of view of various models- from the medical to the social and from the cultural to the local. There is no universally agreed way of defining and understanding disability. The definition of disability is continuously changing, and it varies greatly not only from country to country but also within each country. Disability is also seen and dealt with differently from the perspective of the various intellectuals, groups and organizations dealing with various kinds of disabilities. Defining disability is also difficult because there are several kinds of disabilities from the one intended to integrate in society to the one for exclusion and segregation. Hence there are bound to be differences in the understanding of an individual or group who looks at disability from the point of view of its integration and inclusion in the society and another who, for certain reasons, believes in its exclusion and elimination. There are differences of perception and approach within the disabled individuals and groups themselves which should not be surprising since there are so many different kinds and degrees of disabilities ranging from physical to mental and developmental levels, not excluding the various kinds of invisible disabilities, some of which are not even seen and recognized as disabilities. Notwithstanding all these differences and, in fact, duly taking into consideration the concerns of each of them, certain common parameters, definitions and integrated understanding would have to be reached for the purposes of analysis and discussion.

A general definition of disability, according to World Health Organization manual relates to “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” (Ramesh and Singh 37). A disability may be physical, cognitive, mental, sensory, emotional, and developmental or sometimes a combination of these. In the broadest sense of the term, people are labeled as disabled or handicapped because they look different from the rest of the society on account of their appearance or behaviour or capacity to learn and develop.

International Labour Organization (ILO) looks at a disabled person as an individual "whose prospects of securing, retaining and advancing in suitable employment are substantially reduced as a result of a duly recognized physical or mental impairment" (Ramesh and Singh 36). Taking physical appearance and behavioral factors into consideration, Rehabilitation Council of India, (1992), defines a disabled person as one "who in his/her society is regarded as disabled, because of a difference in appearances and/or behaviour, in combination with a functional limitation or an activity restriction" (Ramesh and Singh 34). It says that a functional limitation disability may be defined as "specific reductions in bodily functions that are described at the level of the person" (Barik 121). In the definition given by the Planning Commission of India, a disabled person means a person who is "blind, deaf, having orthopedic disability; or having neurological disorder, mentally retarded." The definition includes "any person who is unable to ensure himself/herself, wholly or partly, the necessities of a normal individual or social life including work, as a result of deficiency in his/her physical or mental capability" (Barik 121).

The Ministry of Social Justice and Empowerment, Government of India, prescribing a standard set of definitions along with standard tests for the purposes of certification of disability defines four major categories of disability. These include visually handicapped denoting total absence of sight; the locomotor handicapped as those having restriction in the activity of arms, limbs or other parts of the body on account of damage to the bones, muscles or nerves; hearing handicapped in whom the sense of hearing is nonfunctional for ordinary purposes in life and mental retardation which relates to sub average general intellectual functioning associated with maladaptive behaviour, occurring in the developmental period.

Definition of disability, according to Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, includes seven broad categories related to blindness, low vision, hearing impairment, mental retardation and mental illness and locomotor disability; whereas mental illness means any mental disorder other than mental retardation, mental retardation means a condition of arrested or incomplete development of the mind of a person, which is specially characterized by subnormality of intelligence. According to Disability Act, a person with a disability must suffer from not less than forty percent of any disability, to be certified for the same by a medical authority. A person with low vision means a person with impairment of visual functioning even after treatment or standard refractive correction but who uses or is potentially capable of using vision for the planning or execution of appropriate assistive device. A locomotor disability, according to the Act denotes disability of the bones, joints or muscles leading to substantial restriction of the movement of the limbs or any form of cerebral palsy.

Thus, the term ‘disability’ summarizes a great number of different functional limitations occurring in any population, in any country of the world related to the physical, intellectual or sensory impairment, medical conditions or mental illness. The disabled broadly are people with one or more physical, mental and sensory impairments which limit one or more of the basic life activities such as seeing, hearing, talking, walking, using hands, understanding, learning, communicating and inadequacies of a similar nature. The International Classification of Functioning, Disability and Health (ICF), produced by the World Health Organization, distinguishes between body functions and body structures such as physiological and psychological functions, for instance, vision and body structures. Impairment in bodily function or structure is defined as involving an anomaly, defect or loss or other significant deviation from certain generally accepted population standards, which may fluctuate over time. The ICF lists broad domains of functioning, which can be affected as, “Learning and applying knowledge; general tasks and demands; communication; mobility; self care; domestic life;

interpersonal interactions and relationships; major life areas; community, social and civic life, including employment and other major life areas" (Barik 2).

World Health Organization (WHO) rightly looks at disability as an:

> Umbrella term, covering impairments, activity limitations and participation restrictions. Impairment is a problem in body function or structure. An activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. (Disabilities)

The demography of disability is quite difficult as counting persons with disabilities is a challenging task. That is because disability is not just a condition, entirely contained within the individual; rather, it is an interaction between medical status and the environment. The World Health Organization in 2004 estimated a world population of 6.5 billion people of which 100 million people were estimated to be severely or partly disabled (Disabilities). There is also widespread agreement among experts that disability is more common in developing countries than in developed nations and that Afghanistan, with more than one million disabled people, "has one of the highest incidents of people with disabilities in the world" (Afghanistan).

Disability in India was included in the census for the first time in 2001, following a sustained campaign by the Indian disability movement. The census found that 2.2 per cent of the population was disabled. However, this figure is contested by organizations working in the field, which estimate India's total disabled population at approximately six per cent or 70 million – a figure larger than the entire population of the United Kingdom.

The theoretical roots concerning the debates on how disability should be defined reside in medical, structural and minority models. The medical model defines disability as a functional impairment; the minority model emphasizes upon the lack of equal rights for the disabled and the structural model defines environmental factors as the root cause of disability. The social world differs from the natural world in one important fundamental respect that human beings give meaning to objects in the social world and subsequently orient their behavior towards these objects in terms of the meaning given to them. Disability is seen and understood, to be primarily a social phenomenon. It is society that disables people who have impairments, by failing to recognize and accommodate difference, and through the attitudinal, environmental and institutional barriers that it erects against people with impairments. Disability thus arises from a complex interaction between health conditions and the context in which they exist. Thus, disability is a complex phenomenon that reflects an active association between biological features and physical and mental deformities of a person and the attitudes and characteristics of the society in which a person lives and functions.

Disability, more often, is seen as a tragedy and disabled people are treated as victims of fate, chance and discriminatory socio-cultural circumstances and opportunities. This treatment of being victimized not only seeps through everyday interactions, but also gets translated into social and economic policies, which try to compensate these victims for the tragedies that have befallen them. If disability is defined as a social operation, disabled people would be seen as collective victims of an uncaring or unknown society rather than as individual victims of circumstances. Such a view, when translated into social policies, would be geared towards alleviating oppression rather than compensating individuals. However, at present, the individual and tragic view of disability tends to dominate social view of disability, social interactions and related policies. The main focus has to be the people in the country. Disability from the social perspective is a socially created notion which does not mean that physical and functional limitations of living with impairments are not to be taken into account. It only means that society has to be restructured in its ways of looking at things and individuals with difference.

Many people in the world have a medical condition which could be considered an invisible disability in the sense that their disabilities are not ordinarily visible to the casual viewer. An individual with an invisible disability such as chronic or debilitating fatigue would not want to disclose their particular impairment since this chronic medical condition of one kind or another of nearly half of the population does not impair or hamper their normal activities. Hence, most of these people are not actually disabled. It is estimated that 96% of people with chronic medical conditions live with a disability that is invisible. Seemingly, these people look perfect as if, not affected by disability as they do not use any supportive device. At least one-fourth of the total population of people with invisible disabilities have some kind of activity limitation which can lead to chronic conditions later on. Those with invisible disabilities are protected by various national and local disability laws.

There are several ideologies pervasive in public culture, expressed in a multitude of ways, which play into how people with invisible disabilities are treated. The ideologies most crucial to understanding invisible and visible forms of disability are related to the medical and the social model of disability though other models like charity model, economic model, rights based model and various others operating at national, regional and local levels might also be significant in specific times and circumstances. These models serve as an important tool, to understand various aspects of disability and its manifestations at the individual, social and cultural level.

The medical model views disability as a ‘problem’ caused by disease and, therefore, needs to be cured medically. It perceives the disabled as ‘defective’ and ‘deformed’, and so a ‘cure’ is aimed at with the help of medical professionals. It can also guide the affected to make adjustments and to inculcate certain behavioural changes so as to be ‘normal’ and ‘cured’. The physician diagnoses the problem and prescribes treatment to reduce the ailment. It means that the person affected is not ‘normal’ and, therefore, should be ‘normalized’ with the help of medicine. However, as Mitchell and Sharon put it: “disability defies correction and tends to operate according to its own idiosyncratic rules” (Mitchell and Sharon 3). It means that medical intervention is not able to overcome many kinds of disabilities. Its objective is to normalize the person affected, and it keeps on trying to find solutions in the most difficult situations.

People with invisible disabilities are discriminated because they are ‘defective’, and people with invisible disabilities are usually accused of being attention seekers as they seemingly look normal. In other words, the medical model of disability can lead to misperceptions and misunderstandings that prompt some people to be “insensitive and less willing to accommodate the needs of people whose disabilities are not outwardly apparent" (Definitions of The Models of Disability).

Professional model tries to identify the impairments and its limitations and takes necessary steps to improve the position of the disabled person. It gives birth to a system in which service providers are over-active and provides facilities to a disabled. RCI has been contributing in creating a lobby of professionals who are trained to assist the disabled and their families. In India, this kind of facility is provided in extreme cases by the government.

The social model of disability was designed to discuss and defy discriminatory practices faced by people with disabilities. It supports the view that it is the mode of discrimination done in the field of public life, policy that disable individuals from full participation in social life. A person who has an invisible disability may indulge in conflict with the work ethics or social values if he goes for an interview. Social model emphasizes that social attitudes create barriers for a disabled. The conditions might change with shifts in perspective, and as Colin Barnes suggests that when society begins to value principles based on social necessity, obligation and interdependence, people with disabilities will be valued and included in employment opportunities (Barnes 445).

This model views the issue of ‘disability’ as a socially created problem and a matter of full integration of individuals into the society. In this model, disability is not an attribute of an individual but rather a complex set of conditions, many of which are created by the social environment. Surrounding society and environment are sometimes more limiting than the disability itself. So, the management of disability needs social help and social responsibility to make necessary changes in the environment so that full participation of the disabled is ensured.

Besides these two significant models which define and shape the attitudes towards disability and the disabled in a crucial way, there are few other models which play their own role in understanding disability and its various nuances and hence require brief discussion. The Spectrum model refers to the range of visibility, audibility and sensibility under which mankind functions. Human disability condition can well be classified into seven broad categories which comprise of mental retardation, emotional disturbance, hearing impairments, visually handicapped, physically/orthopedically handicapped, communication disabilities and learning disabilities. Spectrum model takes into account all kinds of disabilities and establishes the importance of variety of human existence due to its genetic and biological reason. And as human beings all are part of a ‘spectra’ of human variability, different spectrum of human existence have to be acknowledged and assimilated in the scene of human variation. As each disability affects human function in a different way, it has to be dealt with differently and needs different measures to exist in the society. In fact, disability only becomes a tragedy when the society is not able to provide different things needed by different people. Tragedy does not consist in using a wheel- chair, or in being blind or hearing impaired; what is tragic is that one does not find barrier free buildings everywhere and that the system, by and large, is insensitive to the needs of the disabled and often fails to provide appliances which could better the lives of those living with the impairments.

The Moral model refers to the attitude that people are morally responsible for their own disability. In the light of this model, disability may be seen as a result of evil actions of parents or people with disability if it is congenital or as a result of practicing witchcraft if it occurs after birth. This attitude may also be viewed as a religious fundamentalist offshoot of the original animal roots of human beings when humans killed babies that could not survive on their own in the world. Echoes of this can be seen in the doctrine of ‘karma’ in Indian religion.

The Charity Model depicts disabled people as victims of circumstances who deserve to be seen with pity as poor, helpless souls for their supposed tragedy or inadequacy. They are treated with ‘holier than thou’ attitude. People who help them tend to feel inflated because of their ‘generous’ acts of giving ‘charity’. This model, along with the medical one, is most often used by non-disabled people to define and explain disability.

As opined by Sandra Fredman:

> Persons with disabilities have always been considered as subjects for social welfare, charity and protection. The world over, until the last decade of the twentieth century, disability was thought to be at most an issue for assistance through social security or welfare and not as a rights or equality issue. In the field of employment laws, the only measures that existed were special protections for the disabled people. (Fredman qtd. in Kothari 1)

The Economic model defines disability as a person’s non-participation in work. It also provides us with data which tells us that impairment has different kinds of impacts on an individual’s productivity and has different consequences that affect the economic growth of the state or nation. This model is directly related to charity model in the sense that it propagates the theory of giving some sort of charity, concessions or special assistance to people with disabilities because they are restricted by their disability to participate in various kinds of productive works and earn like individuals with normal abilities. This model also resembles charity in the sense that it too, in a way, propagates seclusion of the disabled so that they do not demand economic independence and remain satisfied with ‘charities’ given to them by individuals, trusts or State and the Central Government.

As opposed to the Charity Model, the Empowering Model allows for the person with disability and the family to decide the course of their treatment. In this model, a professional acts as a service provider, to guide and help the disabled. Various services and treatment ‘empower’ the individual to achieve their goals without having a sense of guilt, burden or inadequacy.

Another model - the Market model of disability is a consumerist model that recognizes people with disabilities and their stakeholders as representing a large group of customers, consumers, employees and voters. And seems to empower people to carve out their own destiny by being economically empowered; but the fact is that, in this model, disabled people are nothing but consumers. According to this model, 1.2 billion people in the world consider themselves to have a disability. An additional 2 billion people are considered stakeholders in disability (family/friends/employers), and when combined to the number of people without disability, it represents 53% of the population, according to WHO statistics, which, indeed, is quite a substantial figure for the market to exploit in its own tempting ways.

Census 2001 estimates 2.19 Crore people with disabilities living in India constituting 2.13 percent of the total population, which includes persons with visual, hearing, speech, locomotor and mental disabilities. The census further describes seventy five percent disabled people living in rural areas, forty nine percent of the disabled population being literate and only thirty four percent being employed. Discrimination against such a vast population faced with disabilities has a long history of exclusion from active participation in society, segregation or restrictions on various grounds and denial of human rights in economic, social, cultural and political spheres related to education, employment, transport, cultural life and accessibility to various services. Though during the last few decades, the constant efforts of various groups, societies and organizations have led to an increasing recognition of the multiple capabilities of persons with disabilities and there is relatively more emphasis on mainstreaming them in the society based on their skills, abilities and intelligence.

A cursory look at the history of disability shows that in the feudal and medieval times, though disabled people were accepted as part of the family and were made to contribute in productive work yet they were looked upon as evil people possessed by black magic or sinners whose presence invited various disasters upon the society in the form of drought, floods, plague, pestilence, war and the like. Hence disabled people had to pay a heavy cost whenever there was any human or natural calamity. They were made to repent for their ‘sins’ in most inhuman ways like public flogging or self beating and other means of torture that were believed to ‘purify’ them and make them ‘holy’ enough to survive. In many cases, the deformed or disabled children were even killed or thrown away so as to escape any impending dangers or tragedies. Such practices were responsible for giving rise to the belief that while ‘good’ looked beautiful, any kind of imperfection and deformity was bound to be ‘bad’ and ‘evil’ in nature. The period of renaissance too, based on Classical Greek and Roman ideals, strengthened the idea of a perfect and ideal human forms and any kind of impairment was seen with resentment and suspicion.

The 19th century, due to Industrial revolution and mechanical modes of production, led to greater isolation of disabled people since they were thought to be ‘unfit’ for routine and uniform factory production. Hence the disabled had to face great discrimination due to commodification of work and modes of production, making them even more dependent on the medical profession for their treatment and cure.

The modern era, with an increasing emphasis on scientism and social Darwinism, resulted in a major shift in the roles of special institutions from agents of reform to agents of custody for social control and institutional segregation for those now described as sub-normal. Specialized Institutions became the instruments for the facilitation of social exclusion and elimination from the mainstream. Through a presumed scientific status, care for people with disability became depoliticised, technicalised and professionalised, nurtured on notions of tragedy, burden and helpless dependency. Since the 1970s, focus from individual care shifted to community based facilities and care. Medical perspective remained related to the productivity of an individual.

Due to the lack of resources, the disabled came to be considered helpless by the more privileged members of the society. They were thought to be objects of pity. In more recent times, concept of disability has come to have a socio-political construct as the rights-based model of disability has created space for it. People with a disability have, now, their own voice and are now politically motivated to fight for the rights of the disabled.

From the mid-1980s, some western countries have enacted legislation which addresses issues regarding social justice and discrimination. Disabled are no longer seen as inflicted by a ‘medical problem’ rather they are thought to be people with difference and are members of the community having access to employment, education, recreation and other social activities. The conceptual barrier of ‘normal’ and ‘abnormal’, which is a product of negative social attitudes, needs to be fought with as it cannot be legislated. One important thing that comes to the fore is that despite legislative changes, lives of the disabled have not changed much. Another model, which may be termed as Genetic model of disability, includes people with rare genetic disorders as part of the disabled population.

According to Canadian writer, Bickenbach, disability can actually be seen as a fluid and continuous condition which has no boundaries and which is, in fact, the essence of the human condition. In his article on ‘Disability and Equality’, Bickenbach observes that:

> Any anti-discrimination law should be grounded on a social conception of disability, in which disability is the outcome of an interaction between features of

> a person and the person's social, physical and attitudinal environment rather than a biomedical conception in which disability is an attitude of a person's body and mind. (Bickenbach 7)

As a condition which is experienced by all human beings at some stage of their lives, disability can actually be seen as something normal. This view is also supported by many Indian intellectuals who argue that bodily differences should not be allowed to mask one's essential humanity.

At the level of physical existence, diversity is a natural condition, and there is a need to welcome and embrace diversity outside of a hierarchical classification of difference. Yet, at another level, difference is simply a construction of ideology, not a state of reality. As all human beings are part of a bigger 'whole', the same life force that touches an 'able-bodied' does flow through a 'disabled' too. The challenge is to create a situation which is conducive to essential oneness and unity of all humans through obliterating various differences particularly related to various physical and mental impairments or inadequacies.

Disability Rights Movement that began in 1960s was, in fact, encouraged by African and American Civil Rights and Women's Rights movements. People with different disabilities came together to talk about common concerns. In 1960s only, the independent living concept came to be recognized through the consistent effort of Edward Roberts and other wheel-chaired individuals. The independent living moment talked of complete inclusion of the disabled regardless of diagnosis of any disease or disability.

Section 504 of the American Rehabilitation Act of 1973, which happened to be the first civil rights law guaranteeing equal opportunity for people with disabilities and which was enacted after huge protests for days together by people belonging to different kinds of disabilities, states that:

> No otherwise qualified handicapped individual in the United States, shall, solely by reason of his [sic] handicap, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance. (Section 504 of the Rehabilitation Act)

The Americans with Disabilities Act in 1990 provided comprehensive civil rights protection for people with disabilities. Closely modeled after the Civil Rights Act and Section 504, the law was the most sweeping disability rights legislation in American history. The local and state governments were directed to make 'reasonable accommodations' for their disabled workers and also dictated that no public place would discriminate on the basis of disability and if the public places are not accessible, they would be made so with desired modifications. Disability Discrimination Act 1995 made it unlawful to discriminate against people with disabilities. It was replaced by Equality Act 2010, which not only protected the disabled against discrimination but also talked about the financial services available to them including 'Incapacity Benefit' and 'Disability Allowance'.

In 1976, the United Nations launched its International Year for the Disabled Persons, later renamed as 'International Year of the Disabled Persons'. The UN decade of disabled persons featured a world program of action concerning disabled persons, which began with a single representative followed by representatives from many countries who are themselves individuals with disabilities. The 1980s was declared as 'UN Decade of Disabled Persons'. It was in 1987 that experts suggested that the UN General Assembly to draft an international convention to eliminate the discrimination against the persons with disabilities. But most of the nations thought that present provisions were enough. In 2000, 'Beijing Declaration' was issues and all governments were called on to support a convention.

It was a historic day when on December 13, 2006, the first human rights treaty sponsored by United Nations was formally agreed upon with an objective to protect and to enhance the rights and opportunities of the disabled people of the world. As of

September 2011, 149 have joined the convention. The nation who signed this treaty have to abide by new laws ensuring equal rights in every field for the persons with disabilities, be it education, employment or cultural life. It also ensures that they are not to be used as unwilling subjects in medical experimentation. There are eight guiding principles that underlie the convention which talk of ‘inherent dignity’, ‘individual autonomy’, ‘full and effective participation’, ‘respect for difference’, ‘respect for evolving capacities of the children with disabilities’, and so on.

The purpose of the convention is to promote, protect and ensure the full employment of all human rights and fundamental freedom for all persons with disabilities and to promote respect for their inherent dignity, to adopt immediate, effective and appropriate measure to raise awareness. It also aims to promote positive perceptions and greater social awareness towards people with disabilities, to promote recognition of their skills, merits and abilities and to foster an attitude of respect for their rights. It also proposes to encourage all organs of media to portray PWD in a manner consistent with the purpose of the convention and to promote awareness and training programs related to the rights of the disabled.

The main objectives of the convention relate to full and effective participation, and inclusion in society, subsequently enshrining the right of disabled to participate fully and equally in community, education, all aspect of political and public life, cultural life, leisure and sports. The Convention also promotes the concept of living independently and participating fully in the social and cultural life.

The Convention stresses that persons with disabilities should be able to live independently and participate fully in all aspects of life. And they should also have access to all kinds of facilities available to the public. The Convention stresses that persons with disabilities should be guaranteed the right to inclusive education at all levels, regardless of age, without discrimination and on the basis of equal opportunity and that every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others (Convention on the Rights of Persons with Disabilities).

A close look at the issue of disability in India reveals that, though there has been some positive shift in the individual, as well as societal attitudes towards disability, a lot more needs to be done for the disabled, to get equal opportunities in various spheres of life. In the introduction to the National Policy for persons with disabilities, it is stated that:

> The Constitution of India ensures equality, freedom, justice and dignity of all individuals and implicitly mandates an inclusive society for all including persons with disabilities. In the recent years … it has been realized that a majority of persons with disabilities can lead a better quality of life if they have equal opportunities and effective access to rehabilitation measures. (Ministry of Social Justice and Empowerment)

The government of India has enacted three significant legislations and is trying to develop the necessary infrastructure to provide equal access and a better quality of life to people with disabilities. The Persons with Disabilities Act, 1995 aims at ensuring 'Equal opportunities, protection of rights and full participation' to the disabled, while National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act, 1999 aims at enabling and empowering persons with a disability to live as independently and as fully as possible within and as close to the community to which they belong. It also gives facilities to support the persons with a disability to live in their own families and also provides with need-based services during time of crisis. The basic purpose is to facilitate the realization of equal opportunities, protection of rights and full participation of persons with disability. Another act, namely, Rehabilitation Council of India Act, 1992, aims at ensuring proper rehabilitation services. Besides, seven national Institutes are active in the direction of development of manpower in different areas of the country.

The National Policy for Persons with Disabilities recognizes that Persons with Disabilities are valuable human resource for the country and seeks to create an environment that provides them with equal opportunities, protection of their rights, and full participation in society. The focus of the policy lies on the prevention of disabilities and rehabilitation measures which include economic, physical and educational rehabilitation. It says that physical rehabilitation measures including counseling, strengthening capacities of persons with disabilities and their families, physiotherapy, occupational therapy, psychotherapy, surgical correction and intervention, vision assessment, vision stimulation, speech therapy, audiological rehabilitation and special education shall be extended to persons all over India including 75% of the disabled persons living in rural areas (Ministry of Social Justice and Empowerment)**.**

Education is the most effective vehicle of social and economic empowerment. In keeping with the spirit of the Article 21A of the Constitution guaranteeing education as a fundamental right and Section 26 of Persons with Disabilities Act, 1995, free and compulsory education has to be provided to all children with disabilities up to the minimum age of 18 years. However, as indicated by Census, 2001, a very large percentage, fifty-one percent persons with disabilities, are still illiterate. This shows that there is an urgent need for mainstreaming of persons with disabilities in the general education system through inclusive education. Sarva Shiksha Abhiyan (SSA) launched by the Government has the goal of eight years of elementary schooling for all children including children with disabilities in the age group of 6-14 years by 2010. Children with disabilities in the age group of 15-18 years are expected to be provided free education under Integrated Education for Disabled Children (IEDC) Scheme. Under SSA, a continuum of educational options, learning aids and tools, mobility assistance, support services and the like are being made available to students with disabilities but these schemes have failed to make any substantial impact on the overall situation related to illiteracy and other areas (Ministry of Social Justice and Empowerment).

The most significant development related to disability in India has perhaps come in the form of creation of a separate Department of Disability Affairs (DDA) in 2012 under the aegis of the Ministry of Social Justice and Empowerment to focus primarily on the ‘policy issues and problems’ related to disabled people. As announced by the union Minister of Social Justice and Empowerment, Mukul Wasnik: “There would be a separate budget for this department which would help in strengthening the existing schemes and also formulating new ones and also for technological innovations, which are very much required in this sector” (Wasnik). The creation of this separate department to deal with disability issues provides hope that, as Merry Barua, Director, Action for Autism, puts it, “perhaps disability issues will not play second fiddle any longer” (Iyer and Ojha 16). Disability in India needs to be understood in a holistic perspective in order to ensure proper and adequate implementation of various laws and schemes related to it. In an attempt to explain this holistic perspective, Merry Barua says:

> Disability is often represented as a homogenous construct whereas it is actually highly heterogeneous. For instance, for those with autistic spectrum disorders, whether children attend mainstream schools, special needs schools, or are at home, barring a few exceptions most have no access to educational supports that would help them achieve any kind of potential, and for students with autism, structural changes will not ensure access to an appropriate education. On the other hand, for those with mobility impairment, providing physical access can come close to ensuring an education that is as good or as bad as those available to others. So priorities would vary greatly across disabilities as also across areas. (Iyer and Ojha, 16)

So, any substantial action will have to be seen and executed beyond ‘traditional areas of focus’, and will have to take into consideration the effective use of latest means and techniques to empower people with disabilities, without losing focus on more severe challenges. Looking at the ‘huge gaps’ that presently exist in matters related to disability; there is an urgent need to bring systemic and holistic changes.

Significant initiatives have also been made at the level of media interventions, especially in the area of organizing separate film festivals related to the portrayal of the disabled and disability. An NGO working in this direction called BROTHERHOOD, in collaboration with the UN Information Center, New Delhi, has started ‘We Care Film Festival’ in 2009 on disability issues and has been organizing it very successfully since then to create an awareness about disability through the medium of films and to foster integration in society by spreading the message of abilities of People With Disabilities (PWD). It also aims at removing the myths, misconception, prejudices and stereotypes about disabled and disability among the society by using the medium of films. This film festival is organized first in Delhi and then travels to Mumbai, Pune and Kolkata. Films and documentaries received for the films festival are screened everywhere. This organization also organizes workshops on media and disability for various institutes of mass communication and journalism and film making Institutes. They are also planning to enhance their area to Uttar Pradesh, Haryana, Rajasthan, Himachal Pradesh and Punjab to sensitize students and society towards PWD and other related issues like the role of media, understanding disability, proper terminology and disability as human rights.

‘Ability Unlimited’ is a professional troupe of disabled people, which promotes employment opportunities and also taps the artistic capabilities of people with disabilities. Founded in 1989 in Bangalore, it later shifted to Delhi, where the group has performed to a large number of school children, for the common people and also performed abroad in Malaysia, Finland and USA. The troupe, with currently a pool of around 150 people from different socioeconomic backgrounds is, in fact, committed to changing the attitudes of negativity that surround education and employment and inclusion of person with disabilities in arts (Convention on the Rights of Persons with Disabilities).

With the onset of awareness about disability, a new discipline, called Disability Studies, has begun to flourish worldwide towards the end of the twentieth century, which is a new inter-disciplinary academic field which focuses on the roles of people with disabilities in history, literature, social policy, law, architecture and other disciplines. This multi-disciplinary field of ‘Disability Studies’ aims to challenge “the view of disability as an individual deficit or defect that can be remedied solely through medical intervention or rehabilitation by experts and other service providers" (Society for Disability Studies). It attempts to study and establish that medical research and intervention can be useful to interrogate the connections between medical practices and stigmatizing disability. It also plans to study the national and international context and perspectives, policies, literature, culture and history so as to place current ideas of disability within their broadcast possible context. Since attitudes towards disability have not been same across times and places, much can be gained by learning from other experiences. However, the actual scope of Disability Studies differs from country to country in spite of its common core. In the United Kingdom, the field of disability studies is primarily seen as belonging only to disabled people and disability activism. In the United States, there is a wide range of professions such as sociology and social work which involve both able-bodies and disabled people. Disability Studies are also facing criticism mainly because of its strict adherence to the social model, which now seems to have been outgrown. Another major area of contention is the frequent exclusion of the personal experience of impairment, cognitive disability and illness, which is most often left out of most of its discussions in the name of ‘focused’ academic discourse.

The problems related to disability tend to assume an altogether different nature and proportions when it comes to women since disabled women happen to be further marginalized amongst the already marginal component of society as women and surviving on the utter periphery, their lives and issues continue to remain almost completely invisible. In the total 2.1% of the population of persons with disabilities in the country, 12.6 million are men and 9.3 million are women, who constitute 42.46% of the total population with disabilities.

The Eleventh Five Year Plan of India for the period 2007-2012 observes that:

> Women with disabilities are considered a financial burden and social liability by their families; they are denied opportunities, movement outside the home and access to education; they are viewed as asexual, helpless and dependent … they are isolated and neglected with no hope for a normal life. (Gender and Disability)

Women with disabilities are very often faced with problems related to marriage and having children. In a society where marriage occupies a central place and where the role of a mother is seen as the primary one in defining womanhood, exclusion from marriage and having children, even if it is for medical reasons, leads to "social obscurity and annulment of feminity" (Ghai). Esther Boylan in her Book *Women and Disability* observes about marriage:

> As far as the marriage problem is concerned, the situation of disabled women in developing countries is much more difficult as most marriages are arranged. Stereotyped concepts, prejudices and negative attitudes about disability are so deeply rooted …Attitudes and ignorance are particularly virulent where blind women are concerned – no one would ask for her hand in marriage. Objects of pity and mindless charity, blind women are often relegated to the lowest status in the community – they are isolated from society and confined to a corner of the house, live in obscenity, silent misery and total social and economic dependency. (Boylan 3)

A study by Mohapatra and Mohanty in Orissa, in 2004, found that only 30.5 percent of the disabled women were married. Even when the marriage does take place, the able-bodied men leave disabled women for others, and this treachery leaves the disabled women dumbstruck forever; not wanting to enter into another relationship for the whole of her life. (Mohapatra and Mohanty qtd. In Policy Project of the Disability). As Binoy Acharya points out, “Many men also force their disabled wives to leave home so that they are able to live with other women. Women, on the other hand, continue looking after the needs of husbands and families even when their husbands are disabled and unable to earn a living” (Acharya 20). "Disabled women are denied their sexuality. They are seen as being incapable of bearing children or of looking after them, so their children are often put into the care of grandparents". The above study found that six per cent of physically disabled women and eight per cent of mentally challenged women had been forcibly sterilized (Thomas).

Further, women with disabilities are more prone to various forms of violence and insecurity, domestic and sexual abuse, and the situation is even worse for women with mental impairments who, in the majority of the cases, are taken to be devoid of all kind of sanity. Rape is one of the most heinous forms of torture inflicted upon them. According to the above study in Orissa by Mohapatra, 100 per cent of the disabled women surveyed were beaten at home, 25 percent of mentally challenged women and 13% with locomotor, visual and hearing disabilities had been raped (Mohapatra and Mohanty qtd. in Policy Project of the Disability). And, to add to the agony, many of them are not in a position to report the matter either to family members or to the police. In some of the cases, family members tend to ignore the brutal incidents of violence and rape deliberately for fear of shame and social disgrace.

There is no dearth of Acts and laws that could enable the disabled women to lead a socially and economically respectable life but the fault lies at the level of strict and effective implementation of these laws. Article 15 of the constitution of India states that there should be no discrimination on the basis of sex and article 16 prohibits discrimination on the basis of sex in matters of employment. The above articles do not prevent the State from making special provisions for disabled women. India has also ratified various international conventions and human rights groups committed to securing equal rights of women. One of the most important amongst them is the ratification of the convention of Elimination of All Forms of Discrimination Against Women (CEDAW) in 1993. *National Policy for the Empowerment of Women* designed in 2001, with the aim to mainstream gender perspective in the development process was particularly significant from the point of view of disability since it talked about the specially disadvantaged groups within the already marginalized and disadvantaged group called women. It included disabled widows. In 2005, the Government of India published a strategy paper prepared by the National Commission for Women entitled *Equality to Women with Disabilities in India*, and it enlisted major areas of concern regarding women with disabilities living in urban and rural India. It analyzed the status of women with disabilities and crucial aspects of their existence such as education, health, advocacy, employment and social exclusion. It suggested certain measures for improvement in the status of disabled women, which included ensuring full representation of women with disabilities; 50 percent reservation for girls with disabilities in schools and colleges (out of the existing quota), 50 percent of the job opportunities and 30-50% as per the PWD Act, 1995. It also suggested that district level Community based Rehabilitation (CBR) societies for persons with disabilities should work in accordance with special CBR societies for women with disabilities, and it recommended the formation of self-help groups(SHGs) for women with disabilities for their economic empowerment.

The National Policy for Persons with Disabilities, 2006 endorsed the need to support the doubly disadvantaged groups by creating a separate section on women with disabilities. The policy stressed upon the holistic growth for women with disabilities. It recommended for inclusion of disabled women as 25% beneficiaries in all rehabilitation projects. Some of the provisions and initiatives taken by the Central Government for the welfare of women with disabilities include special allowance of Rs. 1000/- per month for child care for women with disabilities, 1% rebate in the interest under the micro-credit scheme and a special rebate of 2% on interest in all the schemes of National Handicapped Finance and Development Corporation (NHFDC). There are certain grievance redressal mechanisms available to women with disabilities, and their political participation is also ensured to a limited extent by the fact that all central and state coordination committees, as well as central and state executive committees are mandated to have five persons with disabilities, one of them being a disabled woman, to represent non government organizations or associations which are concerned with disabilities. But these measures, though helpful, are not adequate enough to bring about economic and social empowerment of disabled women and inculcate enough confidence in them so as to lead a dignified life.

There is relatively increased recognition of the double disadvantage experienced by women with disabilities, but the steps for alleviation are primarily confined to fixing quota or allocation rather than implementing measures for radical change in the overall socioeconomic conditions. Further, the schemes and programs for women with disabilities are a subset of schemes for women and persons with disabilities and separate disaggregated data on women with disabilities has not yet been maintained. Initiatives should be taken to regulate the media which mainly focuses on the body and external beauty of women with the sole commercial objective of promoting the brands. Women with disabilities should be given extra space in media to promote popular brands so as to break the age-old myth of external beauty.

The general attitude of the society is critical in assessing both the intensity of disability and in chalking out effective means of intervention. The attitude of persons with disabilities and their families is equally crucial and, many a times, even more important than the societal attitudes. At the same time, the different set of attitudes clearly interact so that negative views about disabled people in the broader community are likely to be internalized in many cases by people with disabilities and their household members (World Bank Group). The notion of ‘disablement’ or disability is both socially and culturally constructed and defined. What is considered as a ‘disability’ in the West may not necessarily be the case in India. A person with dyslexia could find a job easily in

South India or in developed countries and be an earning member, but not in an agrarian society of the North India where he would be looked down upon for his disability. India is a land of diversity and has great variants as far as social, economic cultural, religious and political spheres are concerned. Hence it becomes challenging to understand the implications of being disabled in different contexts and circumstances.

Disability in India is still largely associated with religion and past wrongdoings. Much of the literature on disability in India has pointed to the importance of the concept of *karma* in deciding attitudes towards disability. Disability is perceived either as punishment for the misdeeds in the past lives of people with disabilities, or the wrongdoings of their parents. As two Indian authors, Ali Baquer and Anjali Sharma have put it, "At a profoundly serious and spiritual level, disability represents divine justice" (Baquer and Sharma 14). In a research conducted in Tamil Nadu and Andhra Pradesh in the year 2000, it was found that forty percent of the respondents agreed to disability being a punishment by God with visual & mental disabilities definitely being a curse of God while others like locomotor disability could be related to medical reasons. Most of these people were aged people with traditional mind-sets; with low or average income groups and little education.

At a more mundane level, people with disabilities are traditionally perceived as somehow inauspicious and are restricted from participation on festive and joyous occasions. Beliefs regarding disability vary from urban to rural areas. People who live in urban areas do have some vague knowledge about impairments, handicaps and limitations though this is not found to be adequate. The places where some sort of awareness through NGOS or networking of any kind is created, people are relatively more logical, caring and concerned, but that again, is far from satisfactory. Most of the people who live in rural background believe in or are guided by religious explanations. In villages, women who otherwise are never able to express themselves are often found to suffer from slight or serious mental problems and rather than being treated as patients, they are either believed to possess magical powers of Goddess (*devi*) or taken to be a devil who need to be liberated through *tantriks* and quacks. Their psychic problems are not taken into account, and they are rarely provided with proper care and treatment.

In India, the moral dimension attached to the presence of disability and the resultant cultural notions hamper with the effective development of community based actions. People are afraid to come in contact with the disabled people, feeling that it might be contagious or precipitate something evil. A study conducted in Uttar Pradesh and Tamil Nadu with 1400 households about their attitudes to participation of disabled in major social and economic activities revealed that three main activities related to education, employment and marriage/family life, are considered as critical to normal social participation of people with disabilities. The presence of the disabled on the occasion of marriage is considered undesirable and inauspicious. Disabled women participate very less in social activities, and those suffering from mental retardation are particularly unwelcome. This view is also supported by research studies in Gujarat. As far as voting or participation in politics is concerned, not much difference was found in disabled and non-disabled houses. However, with regard to employment opportunities, there are major variations in attitudes towards the disabled, guided both, by disability type and location. While generally it is believed that disabled could be successfully employed, there is found to be great resistance against employment of people with mental disabilities like mental illnesses and retardation.

It was also found that in general there is low-acceptance of children with special needs and disabilities attending regular schools. Though teachers and education administrators agree on the inclusion of the disabled to regular schooling, but they also point out towards the urgent need for the education system to find out ways to deal with the problems that subsequently arise. Despite PWD Act 1995, there is evidence to prove that many groups continue to have a negative approach towards inclusion of people with disabilities in services. In a study conducted by an NGO ‘Swabhimaan’ in 2005, it was found that Government officials and health workers had the highest rate of negative attitudes towards the disabled in Orissa. Workers in community places were found to have more positive views than the Government officials on the issue of the participation of the disabled in community activities and their inclusion in local and political groups. Only a minuscule (one percent) thought that they should not be allowed in any public dealing since it makes the whole thing cumbersome and their sight makes everybody uncomfortable.

Some intellectuals and research scholars have established that the social status of the family of people with disabilities also has an impact on their potential acceptance in society. Further, the acceptance level of disability inside the various families also varies to a great extent. There are many families, which are relatively much more sensitive and are caring about the disabled children, but a total acceptance of disability is still a rare phenomenon. Many parents feel hampered while taking disabled child with them in a public place because they cannot tolerate people commenting or making fun of their disability. Stares and comments of people devoid of sympathy and inhuman acts of keeping the ‘normal’ children away from the disabled child, are some of the reasons that force the parents to be confined within the four walls along with the disabled child, but there are parents who feel a sense of shame, remorse and guilt because of the physical, mental or cognitive disability of the child. In some of the extreme cases, parents even begin to lock up their children in rooms, bathrooms or send them away when somebody at home is expected. In spite of changes in social attitudes and awareness around the whole issue, the thought of public disgrace looms large on their minds and the parents are not able to go beyond it. People who care less about social status and reputation are generally more compassionate and human towards the kind of problem their child has to face. Community life can be very helpful for the disabled to link themselves to daily life.

Discrimination in public life is almost a ‘normal’ thing that the disabled have to cope up with in their daily lives. It ranges from small matters related to lack of various information and denial of help in their daily needs to environmental and attitudinal barriers. As one respondent in one of a group interview with disabled people by Sourbha during one of the community-based rehabilitation programme in April 1997, stated:

> Some people despise disabled people. But there are instances when people help a disabled person, for example, to get into a bus. However, by and large, the attitude is very negative ... People in the communities will try to avoid contact with a disabled person. But we have to accept both the positive and the negative sides and get on in life. Once we are trained and become economically independent, self-reliant people, people will respect us a little. We will have some status in society. (qtd. in Lang)

The communities, many a times, remain totally oblivious of their condition and economic needs. Their unsympathetic attitude even makes them think that it would be a waste of time and resources, to train hearing, speech and vision impaired people since they can not prove to be fully productive members of the society. Though India has signed many treaties and enacted various laws against all kinds of discrimination, the bleak world of the disabled is yet to see the bright morning of a barrier-free society.

Employment and marriage are two major concerns of the disabled people. Their dignity and self-esteem seems to be relying upon their obtaining an employment and becoming an earning member of the community. This should be valued high as most of time it is seen that disabled people either do petty jobs or indulge in begging. Most of the people who employ disabled people are not very sure about their guts and abilities and this perception impact negatively on the psyche of the disabled. Due to their constant underestimation and devaluation by others, they begin to doubt their own abilities and begin to perceive themselves as passive victims of fate and circumstances. Given to them, the disabled members are eager to contribute to the household income as far as possible. If they are unable to get a job for wages, they try to compensate by doing household chores such as child care and animal care. The importance of employment and marriage is as central to the life of the disabled as to any other being. It is perceived differently by males and females and is more or less structured by the stereotypical roles within the family. Many research studies have pointed out how women with disability face greater challenges in getting married and maintaining families. Even where marriages do occur, the rate of divorce and abandonment has been found to be too high, as the NSSO data on widowhood among disability clearly shows.

It is in certain ways a different world for men with disability. They are more confident about getting married though they too have to undergo certain difficulties. Many of the disabled men prefer able-bodied partners so as to be able to ease the problems that come with child-bearing and child-rearing. In one of the research studies, it was found that fifty percent of the households were found to have unconditional acceptance of a disabled man marrying an able-bodied woman, but there was resistance to a normal and able-bodied man marrying a disabled woman. Communities also indicated that if both belong to the same kind of disability, it becomes easier for them to pull on with life.

Disability is also closely related to poverty. Poor people with disabilities are caught in the vicious circle of poverty and disability, each being a cause and a consequence of the other. This is authenticated by the sector that deals with disability and development. While highlighting the direct and symbiotic relationship between poverty and disablement, Erb and Harris, assert:

> While disability causes poverty, in a country with much poverty; it is also possible that poverty causes disability. The mechanisms are malnutrition, exposure to disabling disease, inadequate access to inadequate preventive and enhanced risk of occupation-related accidents among the poor. The relationship between poverty and deprivation (economic disability) weakness and vulnerability (social disability) results in simultaneous deprivation." (qtd. in Lang)

According to World Health Organization (WHO), 50 percent of disabilities are directly linked to poverty and are preventable. In developing countries up to 70 percent of blindness in children is either preventable or treatable. The WHO also estimates that 50 percent of disabling hearing impairments is also preventable (Ramesh and Singh 59). Additional economic cost associated with a disability is a burden on the already poor family. Medical treatment, rehabilitation and transportation expenditure become important fronts on which one has to fight judiciously and compulsively. It restricts the economic activity. Sometimes there are hospitals and even specialized hospitals in close vicinity but a common man does not have the proposal money or even the margin money without which doctor would not treat disability.

There is, in fact, a great gap between the services that are currently provided and that are really needed by the disabled people. Many a times, not even the basic restorative needs of the disabled are met properly such as spectacles, hearing aids and orthopedic aids. Disabled people of low class are thought of as an economic burden. Poor families grow poorer as they have to share extra burden of taking care of a disabled child. People with low income are also susceptible to malnutrition, lack of sanitation, poor housing and related problems. People with disability and their carers are among the most disadvantaged groups in society. This can be seen through their social isolation, financial status, victimization, personal well-being and projection in media. This disadvantage is linked to a lack of support system and indifferent attitude of people. The degree of social exclusion varies enormously according to the individual's status and type of disability one is afflicted with. In the Orissa study quoted above, only 42.4 per cent of women with physical, hearing and visual impairments went out of homes regularly. This figure fell to 27.6 for mentally challenged women. The sexual abuse of women with disabilities who are confined to their homes is an increasing problem that has almost acquired epidemic proportions.

According to one of the major findings stated in the *Shut Out* Report by an Australian in 2009, 'exclusion and negative attitudes', were two critical issues regarding disability which discourage the disabled from moving outside their homes. The study states that people with activity limitation move ten times lesser than the general public. These activities may include visiting libraries, visiting museums, attending theater or concert, visiting zoo, going to hotel; visiting relatives and friends, and going to a stadium as a spectator. People who are deaf-blind are more isolated than others as they have to rely heavily on human support system such as interpreters, carers and communication devices to interact with the ‘outside’ world. Their social and economic participation is restricted by their being disabled in one way or the other. Even if some of them are able to get jobs through some sort of quota or reservation, the nature of their employment, in the majority of the cases, tends to be part time and lesser paid, whereas they have to bear with additional cost of living as compared to general people. Though there are people who despite their disability have risen to the top positions, but such cases are very few.

Disabled individuals receive less care as compared to other members of the family, whereas, in actuality, they need more than them. There are some more fortunate ones who get better attention and better opportunities, but they tend to lose their freedom to over-protective family environment. They are not allowed alone anywhere; someone or the other is found taking care of. The attitudes towards disabled people are complex and vary according to type of impairment and different social, community and family dynamics. People with mental health problem tend to suffer discrimination the most. Nevertheless, the dominant attitude towards disability is one of social welfare.

Susan Erb and Barbara Harriss, who conducted an anthropological study of disability in three rural villages in Tamil Nadu, in the year 1996, to examine what disabled people actually do and how they interact within an agrarian society in Tamil Nadu, arrived at a conclusion that disability was “self-defined by individuals and their family members” (qtd. in Lang). People who lived in the village had lesser disabilities as compared to those living in urban colonies. Many amongst the community showed a complete lack of understanding and awareness of the problems encountered by disabled people. She found that disabled people are not socially invited and even when they are invited, they invariably feel uncomfortable in attending a particular function due to a general lack of sensitivity and caring attitude towards them.

Disabled people not only encounter hostility and negative social attitudes from members of their local communities, but are also exploited by the Government officials and Government policies which have great flaws as far as execution is concerned. Many people with different disabilities have to pay bribes to get the disability certificates because the officials know that this certificate is crucial for the disabled to avail various benefits. Time-consuming, cumbersome and sometimes unfair government procedures and corruption that permeates Indian scene act as additional barriers that prevent disabled people from accessing various services. The Gujarat studies (Acharya), found that only 25 per cent of the disabled people were using aids and appliances provided by the government. The inefficiencies that stem from the system or the government policies, certainly need to be improved in order to ensure disabled people's right to full participation in social life.

According to a report by Action Aid India (2001) called 'Disabled Deserve Different Deals':

> 87% of the budget allocated for people with disabilities is spent on the salaries for the staff in the Disability Welfare Department and other administrative costs while a paltry 13% is spent for fulfilling their other basic needs related to health, education or for aids and appliances. (Swadhikaar Centre for Disabilities Information 13)

Apart from the above limitations, the physical and environmental barriers also adversely affect the accessibility of the disabled. There is the absence of proper ramps, lifts, sidewalks, sign boards or announcements at most of the places related to health, education or recreation facilities. Consequently, it becomes very difficult for them to access information related to their day to day needs and special legal provisions to which they are entitled. The roads, transport system, public buildings in India are not disabled-friendly and fall much short of meeting their mobility needs. For the disabled to be included in the mainstream, it is crucial to develop an environment that is empowering to them and sensitive to their needs.

However, while empirical insights do have a useful role to play in understanding the significant aspects related to disability, it is much more challenging to work on changing deeply entrenched and sometimes culturally grounded attitudes, which are far greater in the areas of mental disabilities. However, some NGOs like BROTHERHOOD, SWABHIMAAN, Ability Foundation, and VIKALP are actively involved towards attitudinal change on disability, in some cases with quantifiable impacts. Some NGOs work at a broader level, whereas others engage themselves with more localized work or tend to work, as service providers through different channels. There are many others who work with community figures and workers to change attitudes, and outcomes like Vikas Jyoti Trust (VJT) in Vadodara which has been working for the past 35 years in the slums of Vadodara on the rights and services available in the district for people with disabilities especially disabled women and children. These groups and organizations identify people with disabilities, link them with the service providers, establish personal contacts with people with disabilities and their families and enable them to work out individual plans. They try to involve the community to enhance acceptance of people with disabilities apart from orienting civil society to the rights and needs of people with disabilities. One area where they have concentrated their efforts is in getting children to schools. Using films, games, experience sharing and informal discussions, they try to facilitate interactions between children with disabilities and those who are non-disabled. This interaction has helped in highlighting the need of inclusion of children with disabilities, and resulted in the increased enrolment of children with disabilities in mainstream schools and special schools.

Changing societal attitudes, at times, present challenges, even among people with disabilities. They, sometimes, condemn traditional approaches as they seem to marginalize them further by being categorized as ‘special ’ or ‘different’ from the larger population. Governmental policies, attitudes and initiatives can play a significant role in changing attitudes to disability. Government can, at all levels, work to identify effective change agents in their communities, and allocate explicit funding to support their activities. They can also contribute to raising the profile of people with disabilities through various awards and other forms of recognition and appreciation such as the National Awards for Persons with Disabilities each year on International Day of the disabled persons.

There have been significant shifts in the attitudes towards disability from time to time. No other issue related to the development in India has seen so many shifts in focus, philosophy, approaches, and strategies as the issues concerning persons with disability. The increased awareness in understanding the issue of disability has turned many ideas and practices topsy-turvy, and has led to a society, which, by and large, is gradually becoming more tolerant and open in accommodating people with different capabilities. Different Acts, policies, conventions, rehabilitation measures and global policies to which India is a signatory; from Mental Act 1987, PWD Act 1995, UNCRPD 2006, UN Standard Rules to Biwako Millennium Framework to UN Millennium development goals, have resulted in significant changes that have taken place in India over the years related to attitudes and approaches towards disability. Various promotional or rehabilitation programmes that began in 1950s, and were exclusive in nature, began to be replaced in 80s with awareness programmes, which were more inclusive in approach, gradually paving the way for programmes and strategies based on the rights perspective in the latter part of the 1990s. Broadly, three types of approaches coexist in India related to Medical Model, Social Model and Rights Based Approach. Diversity being the core feature of India, one finds that various practices ranging from residential institutions to community based rehabilitation exist together to address the needs of persons with disabilities. One can broadly identify four major types of practices which are a result of revised understanding towards the issue of disability under the influence of global and national changes. These approaches include segregated care and institutionalization, special schools, institutions and health centres, integrated approaches and Community Based Rehabilitation, Rights based Advocacy movement and self-help groups. All these approaches co-exist and are not found in exclusively separate mode since diversity of disability in India does not leave scope for exclusive existence of any one kind of approach.

In Medical-based approach, where disability is seen as a specialized health problem, and the emphasis lies on clinical diagnosis, medical rehabilitation through isolated care and institutionalization comes to acquire utmost significance, which means helping the ‘dysfunctional’ or ‘abnormal’ person to lead a life as normally as possible. Modern medicine has led to the eradication of certain diseases. It has also prolonged life expectancy of many disabled people. But now in 21st century, the focus has shifted from ‘life expectancy’ to ‘quality of life.’

The focus in the social model tends to shift from the biological and medical impairments to the disabling social conditions and environment which includes discriminatory social attitudes and practices. So the centre of emphasis in the social model is not the normalization of the disabled, but on the removal of the barriers that prevent disabled people from exercising their right to participate in society. Social model, in fact, challenges the disabling world. The two models, emphasizing upon two totally different aspects, need to be updated in the light of WHO’s International Classification of Functioning, Disability and Health (2001), which asserts, “disability is a dynamic interaction between health conditions and environmental and personal factors” (Ahluwalia and Singh 48).

The Disability Rights Models with its focus on the ‘empowerment’ of the disabled through effective implementation of the laws began to develop as a result of the political activism seen in USA in 1960s. The main thrust of this model is to provide disabled people with resource, opportunities, knowledge and skills needed to increase their capacity to determine their own future and to participate in community life fully. Empowerment means enabling the person with disabilities to exercise their political rights. It is about making them influential enough to participate in decision making, and enforcing a political role. People with disabilities of different kinds are not visible as one group, and their exclusion from the mainstream has prevented them from participating fully on equal terms in mainstream society leading to a social handicap. So it is significant for the disabled to be ‘viewed', not as subjects in the developmental process but “as partners and owners of the development process and its production” (Wasserman). Community based Rehabilitation (CBR), in fact, is similar in nature to Gandhian philosophy that first emerged in India logically followed by the concept of inclusion and integration. Economic, social and legal empowerment through self-help groups, advocacy forums and social inclusion became an integral part of the rehabilitation scenario in the 80s.

The change in outlook is also reflected in the popularization of two approaches; one related to the Parent Empowerment Programmes*;* and the other associated with Family Centre Care. The Parents movement in India, which is mainly prevalent in South, got formalized in 1995 with the formation of an organization called PARIVAR which means family. It is a national federation – an umbrella organization of 130 parents associations, belonging to urban, semi-urban and rural areas with around 55000 self-help groups and over 4 lakh disabled persons being its members. Even mothers of the disabled children have formed self-help groups in Tamil Nadu. The support and strength they get from each other gives them confidence to overcome various problems.

Under the Family Centre Care Programme, National Trust trained 2000 people in 1990s who could conduct house based interventions, and they included professional physiotherapists, occupational therapists and trained professionals who set up aids and appliances. Home based interventions, by reducing the stress for the disabled and other family members intended to bring about attitudinal changes in the family. If a person is brought to the centre, he is individually treated, cured or trained; but at home, the whole family could be trained together.

Both the approaches with their emphasis upon the uniqueness of each individual, effectiveness of counseling and understanding the behavioural patterns of the disabled, have helped, to a certain extent, in the process of mainstreaming of the disabled. The concept of ‘person-centered’ and ‘Independent living’ approaches that originated in North America in late 1980s has also had its impact in India. It was based on the view that people with a disability should be recognized as active participants in the community needing support to achieve their lifetime goals based on their strengths, “The person-centered approach creates a team of people who know and care about the individual with a disability, who come together to develop and share a dream for the person’s future, and who work together and provide the supports necessary to make that dream a reality” (Garner and Deitz). With its main objective being to maximize the capacity of the disabled to take control of their lives, the person-centered approach too, has helped in providing necessary inputs for an independent and dignified existence of the disabled at the level of families and society.

There appears to be some confusion in India over the understanding of the terms ‘mainstreaming’ and ‘inclusion’. The confusion is largely semantic, resting on whether mainstreaming is the goal and inclusion the strategy, or vice versa. However, while the terminology may be contested, the meaning of the overall objective is clear, namely, the full realization of the rights of disabled people to full participation and equality of opportunity. Three key factors play critical roles in achieving this objective. These include the state, service providers, and disabled people’s organizations (DPOs). The roles and responsibilities of these three factors and the dynamics between them can be visualized as a three-legged stool; with each leg being equally strong to maintain the balance. This demands each of the three actors to work and engage with each other in a coordinated and mutually supportive manner.

Further, in India, the major obstacles in the way of improving the situation of the disabled appear to be more attitudinal rather than structural. The prime thing is that disability is still overwhelmingly viewed as a social welfare issue. As a result, disabled people are seen as passive victims requiring charitable assistance, and disability is considered a ‘special’ issue, isolated from mainstream development. This is a reflection of the broader understanding of one’s rights in the country. In India, rights are claimed less in terms of equality of access and more related to the notion that certain groups are under-privileged and require ‘special’ assistance. Secondly, many of India’s disability organizations (including organizations both for, and of, disabled people) neither effectively represent the needs of disabled people nor hold the state to account, and consequently many of them are either co-opted by the government or multinational agencies or get disengaged. The third important thing is that India’s disability rights movement is still divided along lines of impairment and infused with personal motives and rivalries, as is the case with the disability movement the world over. Many of the issues that have been raised by disability activists happen to be largely peripheral to the lives of the average disabled person. Most disabled people in India are unaware of their rights and entitlements, and they need their concerns to be appropriately represented. Currently, disability remains a ‘special’ issue, divorced from the mainstream. Though, a separate Department of Disability Affairs has been established within the Ministry of Social Justice and Empowerment, but looking at the huge gaps in matters related to disability, especially in the areas of health, education, livelihood and civil and political rights, the creation of a separate Ministry cannot be expected to act as a magic wand, to cure all that ails the disability sector.

The need for rehabilitation of people with a disability in most of the developing countries picked up after the United Nations Declaration of International Year of the Disabled in 1981. However the focus on rehabilitation of disabled people gained prominence after the International Conference on Human Resource Development in the Area of Disability Rehabilitation in April 2005. in the words of Major Ahluwalia, Chairman of the Rehabilitation Council of India (RCI):

> India has been following the shifts in international understanding in the field of special education and rehabilitation for the disabled. All over the world there are deep concerns, which have engaged the attention of scientists, doctors, rehabilitation professionals and society in general. Every nation is committed to

> ameliorating the suffering of persons with a disability to the best of its ability and resources. (Ahluwalia and Singh 4)

Rehabilitation of the disabled needs multi-dimensional intervention. The requirements of the rehabilitation depend on the needs and nature of disability, which in its turn depends on the profile of disability in the country. It depends not only on age, but also on the type and severity of the problem. Helping with appliances and devices is one way of intervention but dealing with mentally retarded patients needs skills more than devices. So training people in living skills is ensuring an independent and dignified life to persons with difficulties. Rehabilitation Council of India (RCI) was set up in 1992 to improve upon the quality of training programmes. Different models have been developed by the council with the expertise of National Institutes and other experts. By making persons with disability economically independent and socially secure and providing them with new opportunities to learn and cultivate and grow, it is possible to march ahead in the direction of creating a new kind of society based on equal opportunities and social justice.

The international campaign of Education for All (EFA) to serve children with disabilities in the mainstream has been a major path breaking exercise in this field. It was practically a paradigm shift from special education to inclusive education in India, though both go together well here depending upon the kind of disability that has to be handled. Starting inclusion does not mean winding up special school needed for a large number of students with a similar disability. Mild and moderate categories of disability can be educated in general school by simple teachers with the assistance of skilled teachers available at the school premises. Efforts have been made to introduce special education content in all general teacher preparation courses with a view to enrich inclusive practices. Any attempt to encourage inclusive education would need qualified persons to understand the different kind of difficulties of different children. The shift from charity to rights based advocacy has also made special education an integral part of the education system. J.P. Singh, member-secretary Rehabilitation Council of India in his article on

‘Approaches and Progress in Human Resource Development’ rightly points out “the Persons with disability are most creative if given the right type of opportunity, right environment by way of creating that environment according to the need” (Ahluwalia and Singh 29). An agreement has been signed with the United Nations Volunteers to bring the youth and other interested people who really want to serve the person with a disability. The real empowerment would come to persons with disabilities only when the institution reaches out to the parents and guide them and help them understand the different dimension of the specific disability.

Apart from the natural disability, man-made disasters like Tsunami, earthquake, wars or insurgency or home-wars can also lead to unlimited cases of disability. Their rehabilitation has to be handled at two levels. One is immediate short-term rehabilitation which includes shelter, food, aid and first-aid. Secondly, there is a strong component of counseling needed for accepting the reality of the disaster or disability that has come as a consequence of the disaster. The disaster vocational training and economic independence is also a part of the second type of rehabilitation. Children, who have lost touch of their schools due to such disasters and disability acquired due to them, should be put back to the same schools so that they can gain in self-confidence, and put on with their situation with new aids and appliances. The best way to come back to normalcy is to go back to normalcy as it existed before the disaster.

The social policy theorists suggest that society has to be restructured in its ways of looking at things and especially the economy. E-learning, e-diagnosis, e-therapy, e-counseling are emerging areas and web-based courses are on the anvil. Capacity building in a community for the purpose of human resource development can be achieved through NGOS, Government organizations, as well as through voluntary organizations. One should not forget inter and multi-disciplinary approaches and applications required in the disability sector. Job-oriented courses are to be introduced, patronized and taken care of. Flow of funds from the government should be smooth and hassle free. It should be properly monitored and reach the people it is allocated for, otherwise human resource development in the disability sector would remain a pipe dream.

What the constitution promises is the enablement of PWD to facilitate their full participation in education and as members of society by teaching social and life development skills to them. This includes learning of Braille, alternative modes of communication, sign language and mobility skills. But there are many limitations at the policy level, in the various acts that have been passed and in the methods and will power for implementation which deny persons with disabilities the opportunity to develop their capabilities. For instance, sign language though very popular with deaf, most schools of hearing impaired do not have Indian Sign Language (ISL) and teachers who are not trained to communicate through ISL insist the deaf children learn to lip read. Despite special provisions of the Sarv Shiksha Abhiyaan (SSA), Children with disabilities are forced to leave municipal schools as there is no specialized staff and the available staff is over-worked already, and it becomes difficult for them to meet the requirements of the disabled children. These loopholes and limitations have to be taken seriously and amended adequately in order to properly address the needs of the disabled and integrate them in the society with respect and dignity.

There is ample evidence to suggest that people with disabilities have contributed to society in no less a significant manner and these include actors, celebrities, singers, musicians, writers, educationalists, leaders and above all, a majority of common individuals whose extraordinary struggles for survival hardly find any mention or visibility. A disability can hamper physical, cognitive, intellectual or developmental functioning, and it may also be a chronic disease of severe implications yet all categories of disabled people have created histories in their own ways and have set such examples that would always pave the way for generations to come. There are also millions of people worldwide who may not have been famous, but the way they live and battle with their disabilities every single day of their lives, needs to be given due recognition at various levels.

Albert Einstein, the famous physicist and Thomas Edison, believed to be the greatest inventor, both had a learning disability and were unable to speak and read during initial years of their childhood. Fraklin D. Roosevelt, the President of the United States for four terms, had polio. George Washington, too, had a learning disability and could barely write. Helen Keller who devoted all her life to the cause of the disabled was blind, deaf and mute and was the first deaf blind person to earn a Bachelor's degree. She was a prolific author, a lecturer and a political figure who campaigned for women's suffrage, workers' rights and socialism. Along with her teacher Anne Sullivan she visited 39 countries to propagate the cause of the disabled. John Milton, an English poet, became blind at the age of 43 and still could create the most celebrated epic *Paradise Lost*. Beethoven, who was completely deaf for the last 25 years of his life, is regarded as one of the greatest composers in history. Virginia Woolf, one of the most representative Modernist writer, too, suffered from mental illness and bouts of acute depression. Frida Cahlo, a renowned painter who indulged in making self-portraits which reflected her pain and sorrow and her caged existence, had polio. John Forbes Nash, a Nobel laureate American Mathematician, whose work in game theory, differential geometry and partial differential equations, is considered ground breaking, was diagnosed with paranoid schizophrenia. An Academy Award winning film named *A Beautiful Mind* was inspired by and loosely based upon his biography. Stephen Hawking, British theoretical Physicist, whose world renowned scientific career spans over 40 years, is severely affected by motor neuron disease and is almost in a complete paralytic stage.

Most recently in May, 2013, a 26 year old woman from Uttar Pradesh, Arunima 'Sonu' Sinha, created history by becoming the first female amputee in the world to climb Mount Everest, the highest peak in the world. Sudha Chandran, an Indian actress who lost her leg in an accident, did not give up her passion for dancing and continued doing so with Jaipur foot. Anita Ghai, an Associate professor in University of Delhi, who is confined to wheelchair, is very actively working in the field of disability rights in the areas of education, health, sexuality and gender. Malini Chib, currently a Senior Events

Manager in Oxford Store, Mumbai and co-chairperson of the ADAPT(Able Disabled All People Together) Right group, defied all odds to emerge victorious in spite of a crippling disability and an indifferent society. Her autobiography entitled *One Little Finger* narrates her search for autonomous identity and her determination to live a meaningful life. Navin Gulia, who has turned his disability into a life-affirming force, writes in his book, *In Quest of the Last Victory*, that the bodies and minds of the disabled have infinite ability. In his own words:

> Our ability never restricts us, our thoughts do. If we think we can, we can; if we think we cannot, we cannot … It does not matter how many more difficulties we have to face in life. The only thing that matters is whether we get intimidated by them and give up, or we deal with them with courage and hope. (Gulia 36)

All these examples related to defying disability and attaining one’s goal clearly establish the fact that various kinds of disabilities, rather than being restrictions, make them 'able' in different ways, and goad them on to realize their dreams with greater vigour and determination. This applies equally to the daily struggles of millions of people faced with various kinds of disabilities, belonging to different caste, class and gender, whose contributions and achievements largely go unnoticed.

Equal opportunities for disabled persons will not come just by way of giving some facilities like education, rehabilitation, barrier free access and employment. Rather these should be perceived as some of the steps that are necessary to create an atmosphere of mutual trust and respect between the persons with disabilities and the society. What is needed is a radical change at the level of attitudes and perceptions. The government or the NGOs, in fact, are only small part of the whole society. They can not make a visible difference in the absence of an all out effort to radically change the attitude of others living around the persons with disabilities. The NGOs also have their own demerits in not being able to influence the members of the society at large to change their attitudes towards the issue of disability. The families are also to be influenced appropriately. There is also a need to make all round efforts to prevent the occurrence of disability. Some other steps crucial in dealing with the issue of disability could include early identification, provision of adequate support services and assistive devices, training and employment opportunities including self-employment within the locality, integration through sports, art and culture and facilitating awareness through media. Let it not be forgotten that the disabled are equal citizens of the country and have as much share in its resources as any other citizen. No country can prosper fully without the inclusion of its most marginalized sections in various kinds of economic, social and political processes. Any kind of discrimination towards them in any form whatsoever would not only be unjust to them and their families but would create larger and graver problems in the society in the area of equitable growth, balanced and forward looking strategies and development and particularly in the area of ensuring social justice.

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