

Rethinking 'Disability' as a Discourse

We live in a world of constructed norms and normalcy, where everyone endeavours to be normal and ranks one's intelligence, cholesterol level, height, weight, sex drive and bodily dimension along some conceptual line from subnormal to above average. Probably no area of contemporary life seems to meet standard parameters. This chapter aims to rethink and represent disability in light of this fabricated normalcy because people with disabilities are historically considered misfits and are rendered a status either of subhuman or superhuman. For example, disabled people are marked with the labels like lepers, beggars, the mad, cripples or parasites. One can think of the iconic Greek figure Oedipus whose very name means 'swollen foot' and he was cast out on the road for his hubris, patricide, and incest. It also gets reference in the seventh book of Plato's *Republic*, where he defines that physical disability is not only indicative of intellectual or cognitive deficiency, but also of spiritual, moral and ethical failing.

In this way, to understand the disability or disabled body, one must return to the concept of norm or normal body because we understand things in binary. This research delineates that the problem is not the person with disabilities, rather, the way normalcy is constructed becomes more problematic. The World Report on Disability (WHO and World Bank, 2011) estimates that around 15 per cent or close to one billion of the world's population is disabled. Out of them, approximately 80 per cent are located in the global South with two-third in the Asia- Pacific region. As per the census of 2011 in India, about 2.68 crore persons are disabled which constitute 2.21 % of the total population. Many of these people are said to live in rural areas of the southern space in

extreme poverty and this poverty further enhances the creation and maintenance of impairment. That is why, the number of disabled people continues to rise on account of hunger and malnutrition; inaccessible health care and rehabilitation; insanitary living conditions, poor workforce conditions, sexual and gender-based violence, ageing, environmental degradation, conflict and insensitive pace of the turbulent times. It is hard to measure their pain and misery and it demands deeper delving into the discourse. Over the last several years, disability studies has moved out of the applied fields of medicine, social work, and rehabilitation to become a vibrant new field of inquiry within the critical genre of identity studies in comparison to race, class, gender or sexual preference. Even, it is now flourishing in disciplines such as history, literature, religion, theatre, and philosophy in precisely the same way as feminist studies did twenty-five years ago. Although disability as a category has existed for a long time, its present form as a political and cultural formation could be possible in 1970s, and it has got greater visibility in late 1980s. The launch of the Asian and Pacific Decade of Disabled Persons in 1993 gave a definite boost to the movement. Later on, National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, was introduced in 1999. Despite adequate legislative provisions, 'disability' remains a complex term and it conveys different meanings to different people. Type and degree of disability vary from person to person and country to country. Various factors like gender, education, religion, occupation, income and nationality have significant impact on the level of disability consciousness. There is no single universally accepted definition of disability. The World Health Organization (WHO) first attempted to provide a

universally accepted definition of disability. Definition of impairment, disability and handicap as given by ICIDH may be explained as under:

Impairment: it denotes a sense of loss or abnormality of psychological, physiological or anatomical structure or function.

Disability: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for human being.

Handicap: A disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfilment of a role (depending on age, sex social and cultural factors) for that individual.

From the above discussion it is inferred that there is a crucial distinction between the biological impairment and the social disability. Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. Thus, it is not just a health problem; rather, it is a complex phenomenon, reflecting People with disabilities as misfits in terms of social, cultural and material ways. Their outcast status is literal when the shape and function of their bodies comes in conflict with the shape and stuff of the built world. In this way, the disadvantage of disability comes partly from social oppression encoded in attitudes and practices in the society where we live and it also comes from the built and arranged environment. In India, persons with disabilities (PWDs) are defined as people who are suffering from not less than forty percent of any disability as certified by a medical authority. But this standard is not universal and talks about the medical or individual model of disability whereas this research locates disability in broader perspective i.e. social model of disability, so there is a need to understand various models and stigmas associated to disability.

Models of Disability

Like sexuality, the concept of disability has also evolved with time. It has been viewed from different perspectives over the decades. It has been a journey from moral model of disability to minority model of disability. The moral model views an impaired body as the result of sins or misdeeds in the present or a previous life, as a consequence of either one's own misdeeds or those of close relatives, particularly of the mother. As Renu Addlakha a social scientist and disability rights researcher says:

Pity, segregation, discrimination and stigmatization became normalized in the management of persons with disabilities. Such constructions of the disabled by the non-disabled have the dual effect of not only justifying the complete marginalization and disempowerment of a whole population group but also leading to the internalization of such negative stereotypes by disabled persons themselves. (Addlakha, 2007, p. 1)

But the moral model is historically the oldest model and is less prevalent today. As the leading actor Amir Khan, in his show 'Satyamev Jayte,' argued that India is polio-free country at present but it does not signify that people are not committing crime today. However, there are still many cultures that associate disability with sin, shame and guilt even if these are not overtly based on religious doctrine. This model has been associated with shame and burden on the entire family of a person with a disability. Families have hidden away disabled family members, keeping them out of school and excluded them from any opportunity to play a meaningful role in society. In many countries, disabled people were treated as useless creatures or not worth living and consequently they were killed, abandoned to die or condemned to permanent exclusion in asylums. In the Greek

society, disabled babies were abandoned on desolate hillside and left to die. In China, disabled children and adults were thrown into river. Extermination of disabled people was carefully arranged and enforced by legislation in many parts of Europe. In Africa, the parents of disabled people kept them in isolated condition, preventing them from making any effort to develop their future life, being afraid of being laughed at and isolated by the society. Even in lesser extreme circumstances, this model has resulted in general social ostracism and self-hatred.

The charity or welfare model of disability views the person with disabilities as the problem and dependent on the sympathy of others and, therefore, it emphasizes on assistance, compassion and charity. Even, today, this is the philosophy of a number of disability organizations in India as well. Instead of enacting necessary legislation and executing them in letter and spirit, disabled people are pitied and sympathized. They are left to be looked after by their family members. Societal reaction to disabilities is marked with pity and charity which simply construe disabled people as facing retribution for their sins committed in previous lives. In this model, the disabled people have no option except to live a life of a pauper. So, the "charity model" arising out of a religious outlook toward disability, coincides with the welfare approach in the immediate post-independence period.

In Indian context, religions such as-Hinduism, Sikhism, Islam and Buddhism have more or less uniformly espoused charitable and pitiable approaches towards persons with disabilities. But such charity has no use because it rarely appears in terms of equality of esteem and of opportunity for disabled people. Religious texts have projected disabled people as dependent creatures and extra burden on their families who need constant

support system for their routine subsistence. Recently, the Prime Minister, Mr. Narendra Modi bestowed them with a label i.e. 'Divyang' instead of 'Viklang'. Such sympathy based approach erects attitudinal, physical and institutional barriers for them. They are viewed through the lens of prevailing system and are expected to modify themselves to adapt to it instead of making the system conducive for them. This attitude often creates alienation and inferiority complex among these people.

The medical model looks at disability as a defect or sickness and its proponents suggest that the remedy lies in medical or technological means. Medical interventions focus on repairing the body to make it fit in tune with the prevalent notion of the body in society, often disregarding what disabled persons themselves feel or want. It has gone by many names, but it is often referred to as an individual pathological model, due to its focus on the body of a person with disabilities as a personal tragedy of the person affected by it, which if at all, can only be cured by medicines.

The rehabilitation model is highly influenced by the medical model and believes that disability is a deficiency that must be fixed by rehabilitation professionals or other helping professionals. It focuses on therapies, exercises and special care to help people with disabilities overcome their constraints and approximate the ideal body.

The social model of disability defines it as a culturally fabricated narrative of the body or cultural construct which takes disability away from the individual alone and places the responsibility on society as a whole. It argues that disability is a result of social structures instead of deficits in the body or brain. Disability is defined by WHO as:

Disability is not an attribute of an individual, but rather a complex collection of conditions, many of which are created by the social

environment. Hence the management of the problem requires social action, and it is the collective responsibility of society at large to make the changes necessary for full participation of people with disabilities in all areas of social life. (WHO, 2001, p. 28)

The present social structures – predominantly shaped by people’s attitudes and understanding of disability – deny access to resources which disables an individual. The social model argues that people with disabilities are not victims but agents resisting oppression, overcoming challenges and thereby changing social structures. In this context, well known writer Siebers says, “Disability not as an individual defect but as the product of social injustice, one that requires not the cure or elimination of the defective person but significant changes in the social and built environment” (2008, 3). Michael Oliver, one of the originators of the social model of disability, clearly and concisely summarizes the position by stating that the cause of the problem is not individual limitations, rather it is society’s failure to provide appropriate services. In this way, this model brought the paradigm shift by identifying one central political strategy; the removal of barriers and to make the place more accessible. It also shifts our thinking from medicalized understandings of disability to cultural antipathy which is the cause of discrimination against disabled people and it advocates action to avoid and rectify discriminatory practices. But there are some shortcomings in this social model which are identified by Matthew Wappett and Katrina Ardent in their edited book *Emerging Perspectives on Disability Studies*. They classify these shortcomings as medical, social and ontological problems.

According to the medical critiques, the social model implies that no medical interventions are necessary to ameliorate arthritic pain experienced by those with disabilities. It recommends only to alter social arrangements to reduce the extent to which such an individual requires use of, for example, intricate movements of the hands in day-to-day activities to minimize the ill-effects of the impairment, but would certainly not eliminate them. The social critiques focus on the causal relationship between impairment and disability and tend to reinforce the interconnectedness of impairment to social oppression, while acknowledging the importance of impairment that social model proponents reject. Finally, ontological critiques say that disabilities are not *always* contingent. Impairments can have devastating effects on individuals. No doubt, social circumstances can exacerbate or minimize the effects of impairment, but oftentimes, even in the complete absence of the effects of social arrangements, impairments can negatively impact well-being. Ultimately, these critiques regard impairment as an important feature of the experience of disability and demand that we must, first, attempt to accurately characterize the notion of disability, prior to engaging in the political activity of promoting the rights of people with disabilities.

While the social model was gathering momentum in Britain, North American activists and scholars were developing their own culturally applicable minority group model. This was an identity forged model under an American 'ethic of individuality and achievement'. It was a clear challenge to ableism and demanded cultural redefinition. Dan Goodley, in his book *Disability Studies*, defines cultural and relational models of disability. The cultural model sees disability as a construction of culture and it can be understood in relation to the normal, normalcy and ableism. But relational model sees

that the people with disabilities are disabled through dynamic relationships of body/mind and the environment. In this way, disability has been variedly understood with the help of various models of disability and it shows that people with disabilities across the globe suffer as a result of human apathy and cultural antipathy.

Conceptual Understanding of Disability

Disability is a global phenomenon and it is experienced by each human being at certain phase of life because all human beings are temporarily able-bodied (TAB). In this context, a celebrated feminist writer Rosemarie Garland *Thomson* states, “disability as a significant human experience occurs in every society, every family—and most every life... And it helps integrate disability into our knowledge of human experience and history to integrate disabled people into our culture” (Thomson 26). Hence, disability can be understood as a kind of discourse that generates an “ideology of ability.” This concept of “ideology of ability” is introduced by Tobin Siebers in his book, *Disability Theory* (2010) as, “A human being is abled only when s/he fits into the category of what it means to be an able human being. If one does not fit into that category, one is considered abnormal, not fully human, different, deviant, other, and therefore disabled, beings fallen from the “baseline of humanness” (10). This conception of ableism in Indian society operates as master trope illuminating the fundamental tactic of oppression of the disabled people and the naturalization of their social inferiority as biological difference.

In this way, disability garners different negative cultural constructs or “ideological categories,” such as ugly, old, aberrant, deformed, dirty, derailed, debilitated or feeble-minded, insufficient, inferior, helpless, dependent, weak, vulnerable, and incapable bodies. All these perceptions devalue the human body while the concept of

beauty is always presented with positivity, goodness, ableism, powerful, superior and truth in any society. As the well-known poet, John Keats in his poem 'Endymion' says, "A thing of beauty is a joy forever" (Book I).

Further, this concept of an "ideology of ability" is sharpened by certain religious, cultural and social values that play a significant role. Those values reflect the patriarchal ethos in the society where attractive and able-bodied women are more valuable than disabled. But, these normative standards are culture specific because the same abled body in one sociocultural context can be a disabled body in another sociocultural context. Thus, there are numerous ideologies of ability. To borrow from postmodern theory, there are many signifiers to define ability as the concepts of ability get redefined with the change in socio-cultural contexts. To understand this, one needs to study the religious and cultural contexts and values of the society because human activities, perceptions, behaviours, and interactions are shaped by such values. In this context, Stafford & Scott observes that stigmas are a set of personal and social constructs and represent a downward view of life.

Further, it is contextualized by Goffman that no two human beings are exactly alike. They differ in countless ways like shape, size, skin colour, gender, age, cultural background, personality, and years of formal education etc. In part, stigmas are heavily dependent on the social context and reflect the value judgments of a dominant group to determine which human differences are desired and undesired. For example, in Indian mythology, Ashtavakra, who was physically disabled with eight types of disabilities since birth is depicted in a positive light which Garland Thompson would call as an "extraordinary body." In her book, *Extraordinary Bodies* (2004), she defines

'extraordinary bodies' as differently-abled bodies. Although some stigmatized conditions are temporary, some undesired traits have graver social consequences than others. Being a medical resident, being a new professor, being 7 feet tall, having cancer, being black, or being physically disfigured or mentally retarded, all can lead to feelings of stigmatization (feeling discredited or devalued in a particular role), but obviously these are not equally stigmatizing conditions. The degree of stigmatization might depend on how undesired the difference in a particular social group is. The most severely stigmatized differences are physical abnormalities because they represent some deficiency or distortion in the bodily form, and in most cases are unalterable. Other physically salient differences, such as skin colour, nationality and speech are considered very stigmatizing because they also are permanent conditions and cannot be changed. For example, black or Jewish or Japanese and Biharis and North Easterns within India feel stigmatized due to their skin colour, regional identity or nationality. A white American could feel temporarily stigmatized when visiting Japan due to a difference in height. Same is the case of black as Frantz Fanon in his book *Black Skin White Masks* talks about the prominence of white over the black because white skin is a desired trait. He starts with an outrageous statement, "At risk of arousing the resentment of my coloured brothers. I will say that the black is not a man" (1). Thus, the sense of being stigmatized is tied to social context. The definitions and the consequences of stigma are time and space bound, and often it results in a special kind of downward mobility. Consequently, most people want to ensure that they must be counted in the non-stigmatized 'majority'. This, of course, leads to more stigmatization and brings superiority and inferiority among individuals. To combat the stigma of disability or oppressive experiences, some have included stories of individuals who report

the best way to overcome such negative experiences. For example, positive role models like Stephen Hawking, Helen Keller, John Milton, Sudha Chandran, Preethi Srinivasan, Arunima Sinha, Javed Abidi, Deepa Malik etc. are cited to overcome the stigma of disability.

Today, in every society, there is little appreciation for disability as a social construction and very little understanding of human rights based approach. Surprisingly, the Millennium Development Goals (MDGs) do not include disability in their ambit. These goals include policies and measures addressing poverty reduction, health, HIV/AIDS, education, gender equality, humanitarian concerns, environmental and climatic issues. But there is no specific mention of disability issues. In the meantime, the practices of community-based rehabilitation (CBR), promoted by the World Health Organization, are introduced globally to fill this void. Besides, international organizations are also working in the so-called 'developing countries'. In most of the cases, disability is either taken as individual deficit or ascribed to God. Generally, the people with disabilities are defined and discriminated by their impairment and relegated to the fringes of society, resulting into their exclusion from the mainstream society. They also face the problem of 'othering' and are often suspected for their wholeness. They face attitudinal traits fostered by religious beliefs and values such as- mocking, playing tricks, fear and rejection, pity mixed with fear, alms-giving as a religious duty. Since ancient times, these beliefs have rendered a negative identity to the disabled people and the same notion is handed down to the successive generations.

Since antiquities, India's religious and legal texts, mainly Hindu texts, have widely held that disability and disabled people face disability as retribution of sins

committed in previous birth. This belief is supported by Manu who writes that idiots, dumb, blind, deaf and deformed men are born in consequence of a remnant of the crimes of the previous life. Still in many parts of India, such frameworks inform everyday perspectives on disability and get manifested in the lifestyle of the people in myriad ways. In the Medieval period, derogatory and stigmatic terms such as ‘lepers’, ‘deaf’, ‘dumb’, and ‘natural fools’ were extensively used to refer to differently-abled persons. Generally, people mockingly deride not only the disabled children but also the parents of such children. They curse the parents for their misdeeds in previous birth that might have caused the disability among their children. Persons with disabilities are perceived as pathological problems (and sometimes even deviant). They are seen as incapable of discharging their roles in the family and thus they are treated with pity and sympathy throughout their lives. This, invariably perpetuates the stereotypical notion that disability is worse than death. In this context, Jane Buckingham writes, “disability is as important as race or gender as an analytic tool in the historical understanding of oppression and disempowerment” (419). According to disability activist, Renu Addlakha, the exclusion of persons with disabilities from entering legal transactions is based on the premise that disabled people are incapable and incompetent to sustain the rational objectivity which is necessary for all legal transactions.

Surprisingly, there are many laws, which seemed progressive and can be invoked as eye-opener in the 21st Century. The media, academia and policy makers who deride disabled people by deploying derogatory and disrespectful linguistic expressions may derive inspiration from Kautilya, an advisor to Chandragupta Maurya in the 4th century

BC, who recorded one of the earliest 'politically correct' laws against discriminatory language. Kautilya advocates that-

Among abusive expressions relating to the body, habits, learning, occupation, or nationalities, that of calling a deformed man by his right name, such as "the blind", "the lame", etc., shall be punished with a fine of 3 panas. If the blind, the lame, etc., are insulted with such ironical expressions as "a man of beautiful eyes", "a man of beautiful teeth", etc., the fine shall be 12 panas. (Qtd. in Rich 115)

Further, Kautilya also advised the king to deploy disabled people as spy in enemy camps. Such enlightened view about the capacity of persons with disabilities is never imagined in modern day intelligence gathering strategies. Disabled people were considered as separate class of people. And their tangential representation in 'Dharmashastras' clearly shows that they hardly had rights to enhance their quality of lives. More frequently, disabled people suffered discrimination in multiple ways such as exclusion from testifying in court or from inheriting property. The Indian popular mythologies such as *Mahabharata* and *Ramayana* have also depicted disabled people in a degrading way. These texts projected disabled people either as powerful, cunning and mischievous characters or as beggars in a state of extreme pain and poverty. 'Shakuni' suggests the image of a disabled person as vulture like, mean, crooked and manipulative while in *Ramayana*, Manthara, the one-eyed and orthopedically impaired maid of Queen Kaikeyi, is portrayed as the responsible person for the exile of Lord Rama. It is evident from this discussion that Indian religious and ancient legal texts have predominantly projected demeaning images of persons with disabilities which continue to mar the progress of

these people in the 21st Century India. Hence, it can be easily construed that persons with disabilities did not have any opportunity to prosper.

Stereotypical perception about disabled people perpetuated through popular culture has permeated the length and breadth of the country and people in general are reluctant to embrace disabled person's existence as a productive contributor to a nation's overall development. Charitable approach adopted by people towards persons with disabilities in ancient times continues to influence policy formulations and it is visible in day-to-day interaction between disabled/non-disabled people.

The 'disability rights' movement led by individuals with disabilities began in the 1970s. The self-advocacy is often seen as largely responsible for the shift toward 'independent living' and 'accessibility'. The term 'independent living' was taken from the 1959 California legislation that enabled the people who had acquired disability due to polio to leave hospital wards and move back into the community with the help of cash benefits for purchase of personal necessities for their normal subsistence. However, the movement and its philosophy spread to other countries after the US civil rights and consumer movements of the late 1960s, and started influencing the peoples' self-perception and their ways of organizing themselves and their countries. The General Assembly adopted the provisions pertaining directly to mentally disabled and physically handicapped persons through the Declaration on the Rights of Mentally Retarded Persons, 1971 and the Declaration on the Rights of Disabled Persons, 1975. These two declarations can be marked as a shift from welfare and paternalistic perspective of disability to right based approach towards the disabled persons. Both these declarations

gave specific expression to the principles contained in the Universal Declaration of Human Rights (UDHR), particularly in favour of the disabled persons.

The year, 1981, was proclaimed as the International Year of Disabled Persons by the General Assembly to call for an action at all levels and to formulate the World Programme of Action Concerning Persons with Disabilities in December 1982. For implementing the objectives set out in the World Programme of Action, the General Assembly proclaimed 1983 to 1992 as the United Nations Decade of Disabled Persons. Meanwhile, the Declaration on the Right to Development, 1986 did not specifically mention any provision for the disabled person, through the right to development is the precondition of liberty, progress, justice and creativity. Being a core right from which all the rights stem, it naturally covers the rights of disabled persons. In 1993, the United Nations prescribed 'the standard rules on disability'. Though not binding upon the member states, it is still a significant mechanism for promoting voluntary implementation of human rights and appropriate treatment of persons with disabilities. The Constitution of India incorporates the principles of social justice and human rights. The preamble, fundamental rights and directive principles of the state policy enshrined in the Constitution reflect the commitment of the state to its people. However, there is no explicit provision in Indian constitution against discrimination on the basis of disability. Gradually, the state could initiate programmes in favour of the disabled on the basis of 'reasonable classification', which permits different treatment to be meted to different persons.

The Persons with Disabilities (Equal Opportunities Protection of Rights and Full Participation) Act 1995, is also very much influenced by the conventional pitiable mores and values prevalent in the Indian society towards disabled people. Disability is still understood as a 'personal tragedy' and disabling conditions imposed by societal practices or lack of structural infrastructures, which could enable disabled people to fully participate in public life, is widely ignored. Amartya Sen groups public debates on disability policies into three categories: (i) preventive policies which include policies on public health, especially polio vaccination and prenatal and postnatal care, workplace safety, cleaning up of mine fields, and public awareness education, (ii) policies to reduce 'earning handicap' (defined below) which include easier accessibility of the disabled person to schools and workplaces, and the prevention of discrimination against disabled persons in schools and in the labour market, (iii) policies to reduce 'conversion handicap' (defined below), which include providing resources for wheel chairs, prosthesis or other such special needs to the disabled. In his keynote speech in a conference organized by the World Bank, Amartya Sen states:

... the main schools of thought in theories of justice have tended to neglect this central issue, and how that neglect, in its turn, has tended to bias practical policies in the direction of inaction, and has even contributed to suppressing the sense of inadequacy that can reasonably accompany the failure to take a responsible view of the social obligation to the disabled.

(1)

He suggests to extend the existing theories of justice for income distribution to incorporate the 'earnings handicap' and 'conversion handicap' of the disabled people. He defines that to achieve the same level of opulence a disabled person may find it harder to get a job or to retain it, and may receive lower compensation for work. Further, a person with physical disability needs more income in comparison to an able-bodied person to meet the financial liabilities of an ordinary life. A crippled person needs assistance, or prosthesis, or both to move easily. In this way, the conversion handicap refers to the disadvantage that a disabled person has in converting money into good living. Being guided by such ethical and moral discussions on redistribution, by Sen or the guidelines of the World Health Organization and the World Bank, India has introduced quite a few disability policies in all the above three areas. The achievements are, however, not satisfactory. A lot more needs to be done to implement the existing policies or to introduce better policies. For instance, The Persons with Disabilities, (Equal Opportunities, Protection of Rights) and Full Participation Act 1995, India's first comprehensive disability law for empowering persons with disabilities has completed two decades. However, physical and psychological barriers which block full participation of disabled population, in public domain, still persist. The policy reserves a certain percentage of public sector jobs for disabled persons, yet there has been a decline in the employment rate of the working age disabled population from 43 percent in 1991 to 38 percent in 2002. Majority of persons with disabilities in India are deprived of quality education which could enable them for gainful employment. They are deprived more than even generally known deprived SC &ST (Scheduled Castes and Scheduled Tribes) population. Public places such as roads, schools, colleges and government buildings have

been constructed in such a manner that the disabled people find it difficult to navigate and demand their rights to live a dignified life. This act defines disability as impairments in terms of the medical model of disability which predominantly prioritizes treatment and cure for disabled people and perceives disability as an individualized experience.

During the late 1960s there were movements in the west waged by the disabled people to counter the overarching prevalence of medicalized understanding of disability. They proposed social model of disability which postulates that disabling physical and mental barriers in the environment are the real factors behind marginalization of disabled people. It advocates for the abolition of prejudice against persons with disabilities. It has now become the rallying point which has brought disabled people together for claiming rights from the states worldwide. The adoption of the United Nations Convention on The Rights of Persons with Disabilities (UNCRPD) 2006, which is known as the fastest negotiated human rights treaty in the 21st century, is very much inspired by social model of disability. The UNCRPD categorically asserts in Article 1 that “disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal base with others” (UN art.1). It proves societal factors as the stumbling blocks for disabled people. Thus the core tenets of social model of disability found solid expression in UN human rights treaty. At the international level, such developments, galvanized disability rights activists in India. Thereafter, India ratified the UNCRPD on 1st October, 2007, and activists started advocating for bringing amendments to the Persons with Disabilities Act in consonance with the UNCRPD.

The PWD Act 1995, is interpreted by scholars as welfares legislation which does not envisage provisions that guarantee human rights to live a dignified life. After many long years of struggles, *Rights of Persons with Disabilities Act* (RPD) that complies with the UN *Convention on the Rights of Persons with Disabilities*, was passed in December, 2016 amidst cheers and joy. The revised bill expands the list of disabilities from seven to twenty one, including Cerebral Palsy, Haemophilia, Multiple Sclerosis, Autism, Thalassaemia, disabilities resulting from acid attacks, and Parkinson's disease. Among the other changes, there is an increase in job reservations for the disabled individuals from three to four percent. The government has also increased the reservation for disabled students in higher educational institutions to five percent from the existing three percent. The time has come to disseminate proper understanding of disability issues and there is an urgent need to re-interpret the texts in the light of the present day challenges so that differently-abled people are not judged by the misplaced morals of our mythological texts that relegate disability and disabled people to the margins. Postmodern theory has been indispensable to disability studies because it has allowed not only for a challenge to normativity, but also for the destabilizing of narratives of national progress, social order, and identity

They also suffer from social ostracism because they do not fit into the social norms of what it means to be able-bodied. In this context, Garland Thompson, a prominent theorist of disability and feminism in her seminal book *Extraordinary Bodies* (2004), explains that disabled are deemed to fall under the category of "aberrant human beings" and she defines this cultural predicament as, "Culturally generated and perpetuated standards as beauty, independence, fitness, competence, normalcy exclude

and disable many human bodies while validating and affirming others” (7). One more celebrated Indian author Anita Ghai writes:

Within the Indian cultural context, disability implies a “lack” or “flaw” leading to a significantly diminished capability; images of the disabled are associated with deceit, mischief, and devilry. Disabled people are sometimes depicted as suffering the wrath of God, and being punished for misdeeds. Yet another strand of this cultural construction conceives of disability as eternal childhood, where survival is contingent upon constant care and protection. (51)

Although it has been acknowledged generally for most of this century that disabled people experience hardships in life, it is only in the recent past that the causes of hardships for disabled people have been examined in detail. From the 1970s onwards, academic discussions on disability and disabled people have moved away from the notion of impairment or ‘handicap’, and the concept of a social model of disability has been introduced. Margrit Shildrick, argues that the way forward for disability studies is to deconstruct the very categories that define disabled people as ‘different’ from their non-disabled peers. She suggests that such differences are not viable and neither are they sustainable; only by such a deconstruction can we further the position of disabled people and promote their inclusion and full social participation. But literary representations of disability open up discussions about some of the most pressing issues of our age i.e. inclusion, empathy, minority status, social care and citizenship and initiate a re-imagination and re-writing of literary and cultural history. As E.M Forster says, “... literature had always been a solace for him, something that the ugliness of facts could not

spoil” (Forster). Nietzsche also transformed grotesque in an aesthetic category, together with the sublime which subjugates terror by means of art. He is of the view that sometimes ugliness can be a stimulant to life. Aristotle is also of the view that ugly things can be made beautiful through imagination. From the outset of disability studies the focus for scholars was on assessing how disability is represented through literature. It has been presented as a restrictive pattern of characterization that did not allow for the full development of disabled figures both protagonists and villains. It is used in stereotypical or superficial manner to get advantage of its plot or rhetoric goals. Even in literature, they have been portrayed in stereotypical manner as helpless evil monsters who face textual exclusion as well.

This negative image of disability is associated with personal failure, tragic loss and excessive dependency of the persons with disability. But the contemporary approaches seek to transgress and re-signify these representations by establishing disability as source of creativity, agency, and identity in narratives that deconstruct cultural or social models of sexuality, motherhood, and beauty. In this context, one celebrated writer Quayson says, “disability in the real world already incites interpretation, literary representations of disability are not merely reflecting disability, they are refractions of that reality with varying emphases of both an aesthetic and ethical kind” (36). As a result, during the last few decades, there has been a growing awareness and concern among the people worldwide for the persons with disabilities, who are disadvantaged due to various reasons particularly for physical and mental disability. The worldwide awareness and human rights perspective recognizes that the persons with disabilities must be provided equal rights and opportunities at par with the able-bodied

population. The human rights or social model focuses on interaction between a person and his/her environment. This model highlights the role of society and challenges the stigma attached to disabled people as non-disabled people often have a sympathetic, biased and obscure reactions accompanied with avoidance or patronization towards disabled people. But it is not the only fact because attitudes towards these people are as diverse as people themselves. However, some of these attitudes can be grouped together as attitudes of fear, revulsion and pity which historically result into exclusion, segregation and sterilization of persons with disabilities. There are notable disability autobiographies in India including Ved Mehta's *Face to Face* (2013), about both loss of sight and the relations between India and England; Tito Rajarshi Mukhopadhyay's *How Can I Talk If My Lips Don't Move?* (2011), about autism; and *No Looking Back* by Shivani Gupta. Societal attitudes towards persons with disability have changed from time to time. Various factors contribute to these changing attitudes. Gender, education, religion, occupation, income and nationality have a significant impact on the level of disability consciousness in Indian English Fiction with special reference to *Trying to Grow* by Firdaus, *Clear Light of the Day* by Anita Desai, *Family Matters* by Rohinton Mistry, *Sunny's Story* by Pramila Balasundaram and *Shame* by Salman Rushdie. In this context, Alice Hall defines that:

Literary representations of Disability open up discussions about some of the most pressing issues of our age: about austerity, empathy, minority status, social care and citizenship. They provide creative opportunities for close reading, but they can also initiate a re-imagination and re-writing of literary and cultural history. (1)

This chapter primarily explores contemporary issues in addressing violence against women with disabilities as a pressing human rights concern. According to World Bank study in 2007 people with disabilities were among the most marginalised in Indian society, and 50 per cent out of them see disability as a “curse of God”. It explores some of the complex intersections across domains of ideological, ethnic, economic, social, and cultural factors that combine to produce pervasive gendered-disability violence. It also highlights the nature and foci of international activities and campaigns to address violence against women with disabilities. Due to the inaccessibility (either physically or cognitively) of institutions of justice for women with different types of impairment, the disabled persons frequently find themselves unable to report the violence they experience. The present chapter is an attempt to understand disability as social construct, and deconstructs all stereotypes and the sense of ugliness especially associated with disabled women through the critical analysis of Malini Chib’s autobiography *One Little Finger*. As life becomes a tear and a smile for her, Malini tells us the story of her heroic battle against adversity, prejudice, stigmas and stereotypes of her will to succeed and her search for an identity in an apathetic world. In the process of self-realization, she becomes a beacon of hope for everyone. She suffers from Cerebral Palsy, a neurological condition similar to adult stroke, which makes body movement and speech extremely difficult. However, the cognitive functions of brain can often remain unimpaired, as in the case of Malini. She recounts her experiences from childhood to adulthood, her struggles with motor skills and speech, managing day-to-day activities, and the apathy and indifference of people towards her and others who are disabled. She educates herself, learns to type with her little finger and speaks through the Lightwriter. She holds

international degrees in Women's Studies, and Library Sciences and Information Management, and is currently doing a job as an Event Manager in Mumbai. She has also founded Able Disabled All People Together (ADAPT) Rights Group. She has been awarded with the National Award for the Empowerment of Persons with Disabilities in the category Role in 2011 by the Ministry of Social Justice and Empowerment.

The recent movie *Margarita with a Straw* (2014) is based on her life, in which actress Kalki Koechlin played her character. Upon release, the film was a major critical and commercial success, and Koechlin won several awards for her performance. It seems her birth is the cause of a movement and some significant sweeping changes that have taken place in the disability sector in the country because her mother, Mithu Alur, to whom the book is dedicated, founded the Spastics Society of India. This is an organization advocating holistic aspect of education and rehabilitation services for persons with physical and neurological difficulties. In a newspaper article named "Disabled author of *One Little Finger*", Malini's mother Mithi Alur, recalls "I remember in the 70s, I had gone to meet a minister to talk about special health care for spastic people. The minister was so ignorant, he kept asking me if I was talking about plastic" (Firdous). She also shows her concern towards the fact that the majority of the disabled population of 80 million people lives below the poverty line. Despite all odds, she is hopeful for positive changes. Her rights group ADAPT in 2012 brought together more than 100 women in wheelchairs on the eve of International Women's Day with 100 non-disabled supporters in solidarity set to protest lack of rights in India and to force Mumbaikars to think: how long will women with disabilities face apartheid-like discrimination?.

Malini took birth in 1966 as a spastic child having Cerebral Palsy and doctors told her parents that she would be a vegetable and nothing could be done for her. Because at that time India was not a disabled-friendly country and Malini's parents decided to take her to England, where she was admitted to one of the best schools named Cheyne Walk that is known for nurturing the students with special needs. Her mother also took up a training programme in special education from London University and being introspective she became one of the first and finest special educationists in India. She set up the Centre for Special Education in Bombay as replica of Cheyne Walk of England. Now there are Spastics Societies in Calcutta, Delhi and Bangalore. Studies have shown various psychological effects that parents undergo when they are exposed to the disability of their child. It is similar to the stages of dying but here parents go through shock and denial – “No, it cannot happen to my child”, guilt – ‘I must have done something wrong. It’s my fault.’ sorrow – ‘why did it happen to my child?’ rejection – ‘I did not ask for a child with a problem’ and acceptance – ‘It’s ok. It’s my child. I will take care of her/him’ (). Most parents reach the acceptance stage, and that period continues a lifetime with the parents showering unlimited love and care to their child. But most often, with the Indian parents, self-pity is the case. They find alternative methods to vent their pity, that is, through ritualization, be it pujas, fasts or other religious activities performed under the instruction of a saint.

In her autobiography, she challenges stigmas of the disabled body by deconstructing the “ideology of ability”. She also shares her experiences of negligence and prejudice against her. She says:

Some people could not understand that although I did not speak, I could comprehend....The children too could not understand why I did not play the usual games with them. They too left me alone....The hostess gave all the kids their going away presents of balloons, hats and whistles while leaving me out. She said she was sorry but she did not think I would be able to play with them properly. I think the worst thing that can happen to a child with a disability is to leave them alone and not even talk to them.

(6)

Malini was exposed to humiliating and discouraging attitude of educational administration. She was surprised to observe the insensitive response of the Vice Chancellor of Bombay University who responded to the request of her mother for extra time for disabled students sitting in an exam as, "These exams are a waste of time. They are useless, and these students would be better kept at home" (49). That is why, there is this worldwide debate whether children with severe disability should be exposed to the normal world. Malini questions the concept of special education in the words:

Being trapped in a segregated environment was harmful. If I was in a normal school, I would have seen my normal peers interact. That would have encouraged me and given me a head start on how to be independent in my communication.... Some professionals believe that it would be better if the child is sheltered in a special school where his/her daily living needs are met.... I feel that if there is no exposure to the outside world how will any child develop later if he/she is sheltered? The disabled child will naturally imitate what he/she sees. I strongly feel that if the child is

exposed to a normal environment from a young age, then the child, however severely disabled he/she is would have a chance to be included and perhaps accepted by his or her peers and would use his/her own intelligence and social networking skills to develop. (25)

Malini also makes sarcastic comments on infrastructure barriers for disabled people when she mentions:

Break time for me was not a normal event. It was a huge obstacle, as far as accessibility was concerned.... Although I used an electric wheelchair, I needed help as there were ledges at the end of each classroom acting as barriers curtailing my independence. I was different and obviously I needed help with these barriers. What an absurd architect. Why do all normal people think that everyone in the world must keep to the norm of the walking pattern, and if one does not walk like everyone else, one will be left out of life? As I passed each classroom, the lecturer would stop speaking and the whole class attention would turn towards me, until I passed through. It was terribly painful being the cynosure of all watchful eyes and those few minutes always seemed like agony. (53)

According to Spivak, disabled women in India are the most suppressed and oppressed class because they are completely deprived of political and economic access. Disabled women fall under the subaltern groups as minority groups are unable to speak for themselves. Malini also depicts her plight as, "I applied for many jobs. Some called me for interviews, some did not bother. I felt that my speech was the biggest barrier. The actual fact is that employers could see only my disability, not my capability. In any job,

one requires speech and a limited amount of hand function. I did not get any job” (174). She got blacklisted from college for missing lectures but she takes joy of being included in the odd picnic, the lunch party, the cinema and even blacklisting which makes her realize that she is normal in all these activities. She believes that there is urgent need for the disabled people to be the part of mainstream and to interact with so-called normal people. She says, “...nobody is perfect; we are all, in some way or other, disabled. Our disability is more visible; others have what I like to call, an ‘invisible disability’” (103). She also believes in social model of disability and thinks that disability is socially constructed and defines, “if a disabled person could not access to offices, restaurants, libraries et cetera, it was not because she or he could not walk, but because of the faulty design of the environment, or the faulty attitude of society” (108). Further, she defines that everyone is inter-dependent or co-dependent – socially, emotionally, physically and intellectually. She defines mutual dependency as, “We depend on the plumber, the electrician, the computer technician” (149). She is the Chairperson of ADAPT which believes that both disabled and non-disabled should work together to form an inclusive society. It initiates change in access, attitude and policy for people with disabilities in India. In this context, Malini says, “If there is no ramp in certain places, it is not a personal problem, but a larger problem which affects all disabled people, not only me. Having access in certain places is crucial not only for disabled people but mothers who have small children in prams, senior citizens, people who have just had accidents, et cetera.” (145)

Religious and cultural values affect disabled women’s autonomy in general, and create even greater disadvantages for them in particular. Women with disabilities are subjected

to 'double disadvantage' i.e. of being a woman in a male dominated society and being disabled in a society dominated by able-bodied people. In this context, a disabled feminist writer and Project Co-ordinator at the National Centre for Promotion of Employment for Disabled People (NCPEDP) based in New Delhi, Sakshi Broota Hosamane in her article, "Developing the Gender Dimension in India's Disability Rights Movement", writes:

Both disability and gender are physical constructs.... To be a disabled man is to fail to measure up to the general culture's definition of masculinity as strength, physical ability, and autonomy. To be a disabled woman is to be considered unable to fulfil the role of homemaker, wife, and mother, and unable to conform to the stereotype of beauty and femininity in terms of physical appearance. (56)

They are discriminated far worse than men with disabilities or women without disabilities in terms of access to education, sexual and reproductive rights, entitlements, and quality healthcare. As Malini reflects:

...a woman is required to perform include child-care, spouse-care, cooking, feeding, soothing, nurturing a relationship and patching up tiffs with in family system. The stereotypical thinking is that women with disabilities are unable to provide this kind of nurturance for a man, nor are they able to satisfy his sexual and emotional needs. I have noticed that it is easier for a disabled man to get an able-bodied partner because society is conditioned to having and seeing women doing most of the house work; it

is unheard of men doing all the housework or being positioned as a carer.
(146)

She also talks about 'body beautiful' concept where woman who is called fair sex is considered to look beautiful to woo man but as far as a disabled woman is considered she always gets unnoticed because her body is different. The body of a disabled woman generally does not fit in constructed norms of beauty; rather, in the words of American feminist Susan Rendall they are considered as 'rejected body'. Malini feels that because of her 'rejected body' she has failed to have good relationship with men. She laments, "I have had a hard time accepting that I am trapped in a rejected body. A body that is not sexually attractive. Some people argue whether sex is that important? ... Sex is a basic physiological need that even animals have....Like most women, sometimes I craved to be in the arms of a man. Most men look at me as asexual" (146). She also shares her experience of college life and says that human beings are averse to crutch dancing. She innocently inquires, "I wondered if there would be a man in my life. Would a man see beyond my body? Would anyone put their arms around me and dance with me? Would anyone kiss me passionately? Would I ever be needed by a man emotionally or would I always be regarded as a burden for someone to take care of?"(65). In this way, she finds that society ignores the sexual urge of disabled women. Therefore, it is ironical to note that the essential common physical and emotional human needs are denied to the disabled women. She observes:

It is crazy but society on one hand thinks that disabled people should lead normal lives, but when it comes to the crunch of having an intimate relationship with a person who is disabled, they get scared and pretend

that the problem is not theirs. The thought of having an intimate relationship with someone who is different does not even cross their minds. Disabled people are often kept at a distance, as the so-called normal people think that becoming involved with a disabled person would be an onerous situation. (147)

Challenging these cultural stigmas, Malini celebrates her sexuality. Through her article, “*No Sex Please, You’re Disabled*”, published in the *Metropolis* in September 1996, she questioned the general tendency of considering the people with disabilities as undergrown children incapable of common adult thoughts, desires, feelings, passions and expectations. She mentions that the behaviour of so-called normal people toward “abnormal” people is often rude, inhuman, and hostile. Perhaps it is the result of commonly held belief that the disabled people are being cursed for their wrong doings of the previous lives. Her writing is a true reflection of her inner health and mind-sets. She shows the robustness of her body despite the fact that she is not considered able-bodied and hence had become object of social abhorrence or rejected body. She challenges social injustice and patriarchal control over her body, health, and sexuality by expressing love toward her own body. She was physically incapacitated, but she did not hesitate to openly and publicly discuss her life in terms of her hopes, dreams, and aspirations, including her sexuality, which is deemed a taboo subject for women in most of the societies. She gives the reader a powerful evocation of her body and sexuality that helps to celebrate her own body as agent in subverting the ideology of ability. Being a ‘normal woman’ encapsulates the ability of having traditionally accepted sexual intercourse with the capacity to bear

children and maintain motherhood. The mainstream ideology of ability negates the ability of the disabled.

In the context of South Asian countries like India, the ideology of ability is formed through the lens of certain religious, social and cultural practices. The identity formations based on social and cultural traditions enforce the ideology of ability and show the profound misunderstanding of disability by creating biases. In this way, Malini cultivates imagination and breaks the chain of stigmas that prompt one to internalize that it is better to die than to live 'disabled'. She dragged herself out of the constraints of her condition to establish herself as a powerful woman. TARSHI, a Delhi-based NGO that specializes on issues of sexuality and body images in society, in its report "Sexuality and Disability in the Indian Context" (2010), points out that women with disabilities in matter of sexual fantasies are similar to other non-disabled women but they are unable to express their sexuality because of faulty assumptions of the non-disabled society.

According to Renu Addlakha, researches on the lives of women with disabilities highlight that the sexual and emotional aspect of their lives is regarded completely irrelevant. So, to pay attention to sexual and emotional ramification is a relevant subject of academic discourses in India. A disabled activist, Anita Ghai also emphasizes that the discourse on disability ignores the harsh reality of disabled peoples' lives in India, where women are caught in social and economic marginalization. In this way, disabilities should be discussed as related to religious and cultural prejudices instead of personal tragedy, pathology, and any other medical problem. Jenny Morris, an Australian feminist, wrote from her own experience as a disabled person that "alienation and anger comes from the failure of feminism to integrate the concerns of disabled women into its theory,

methodology, research, and politics” (45). In this regard, Ghai, while researching on Indian women with disabilities, mentions that the ‘third wave’ women’s movement has not included disabled women into its agendas. Therefore, disabled women occupy a “multifarious and marginalized position.” (53)

Sexuality has been a peripheral topic in disability studies until about twenty years ago, and it continues to be under-addressed outside disability studies, as well in social policies and programs. The sexuality concerns of people with disabilities in India, are rarely acknowledged and, therefore, have not been considered an important area for study or research. We recognize that we cannot do justice to the complex range of sexuality and sexual and reproductive health related concerns faced by people with all kinds of disabilities in India. However, Sexual and reproductive rights are fundamental human rights. They include the right to autonomy and self-determination – the right of everyone to make free and informed decisions and have full control over their body, sexuality, health, relationships, and if, when and with whom to partner, marry and have children - without any form of discrimination, stigma, coercion or violence. Instead, systemic prejudice and discrimination against them continues to result in multiple and extreme violations of their sexual and reproductive rights, through practices such as forced and/or coerced sterilization, forced contraception and/or limited or no contraceptive choices, a focus on menstrual and sexual suppression, poorly managed pregnancy and birth, forced or coerced abortion, termination of parental rights, denial of/or forced marriage, and other forms of torture and violence, including gender-based violence. They also experience systemic exclusion from sexual and reproductive health care services. These practices and violations are framed within traditional social attitudes

and entrenched disability-based and gender-based stereotypes that continue to characterize disability as a personal tragedy- a burden and/or a matter for medical management and rehabilitation. In this way, a person with disability has to struggle on multiple levels like, personal, family and community level. But in absence of structural and auxiliary aid, majority of the persons with disabilities, despite their inherent capabilities, end up living dejected and non-productive life.

The year 1981 was declared as International Year of Disabled Persons and plan of action was called for. Consequently, an important formulation of World Programme of Action came into existence in the year 1982 which was adopted by resolution 37/521. In order to implement the activities recommended in World Programme of Action, the period of 1983-1992 was declared as UN Decade of disabled persons. In 1993, General Assembly adopted Standard Rules on Equalization of Opportunities with an object to emphasize on the responsibilities of the states in removal of barriers in promotion and protection of the rights and freedoms of the persons suffering from disability. In 2002, Biwako Millennium Framework was adopted with an idea to work towards an inclusive, barrier free and right based society for persons with disabilities. In 2006, a much awaited document, namely the Convention on Rights of Persons with Disabilities was adopted. The purpose of these documents is to encourage the implementation of international standards by government and ministries at the state levels and also to expand the opportunities for full participation of disabled persons. The Constitution of India gives an assurance in the form of Directive Principles of the State Policy which work hand in hand with fundamental rights to eradicate social stigmas associated with disabled persons. The wider interpretation of the provisions contained in Articles 14, 16, 21 along with Articles

38, 42, 43, 46, 47, 48, 249 and 253 can provide various rights to the persons with disability to further the right based approach towards the persons with disabilities. Indian Constitution does not specifically deal with the prevention of discrimination on the grounds of disability. But the Preamble, the Directive Principles of State Policy and the Fundamental Rights enshrined in the Constitution stand testimony to the commitment of the State to its people including disabled persons. These provisions envisaged a very positive role for the State in the upliftment of the status of disadvantaged groups. For example, Article 41 enjoins that, “the State shall, within the limits of its economic capacity and development make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement” (Qtd. in Parekh 47). But persons with disabilities in India have been understood by the policy-makers as the charitable and pitiable objects rather than human beings with inalienable human rights like other citizens.

In addition to the constitutional provisions there are many other statutes which deal with the promotion of the rights of disabled persons. In India, there is a long list of legislations and regulations which protect and govern the rights and interests of the physically challenged persons such as the Payment of Gratuity Act 1972, Equal Remuneration Act 1976, The Factories Act 1948, Dockworkers/safety, Health and Welfare Act 1986, the National Policy on Education 1986 and the Persons With Disabilities (Equal opportunity, protection of rights and full participation) Act 1995 (persons with Disabilities Act). One must understand that laws, judicial precedents, constitutional guarantees can only elaborate the policies and imperatives for the disabled. But if we really want to make a difference, we must change our negative societal attitude

by unlearning the deterring misconceptions and misplaced notions about disability. A sustained campaign for protection of human rights for the disabled is the demand of the day. Information on the rights of the disabled should be disseminated through assistance manuals, question-answer booklets, media campaigns, public awareness etc. Each and every disabled person and his family members should be given a disability rights manual approved by the government authority listing their rights. Disabilities are not to be viewed as conditions needing to be cured or healed, but as differences to be accommodated and accepted.

Disabled and abnormal individuals have historically received positions of alienation. A minority status has always been placed in opposition to a prescribed, majority-based notion of what it means to be able. If one is perceived as unable, he or she is pulled out of the community and kept away. In the present research the researcher has attempted to study the actual experience of disability and how able-bodied people look on disabled people as 'Other' and not as an individual possessing the self. The portrayal of disabilities in Literature undergirds the exclusionary environment and the discrimination that disabled human being faces. Disability Studies seeks to challenge our collective stories and our cultural representations about disabled human beings.

Clare Barker, in *Postcolonial Fiction and Disability* (2012), explores the politics and aesthetics of disability in postcolonial literature. The fictional lives of disabled child characters are frequently intertwined with postcolonial histories. The literary representation of 'disability' issues in postcolonial context underlines the concern of the writers for the vulnerability emanating from societal ignorance and insensitivity. Simi Linton, in her influential book *Introduction to Disability Studies* (1998), makes an

extended argument for “setting off disability studies as a socio-political-cultural examination of disability from the interventionist approaches that characterize the dominant traditions in the study of disability” (132). The essential basis of Disability Studies is that disability is a culturally fabricated narrative of the body, a system that produces subjects by differentiating and marking bodies. This comparison of bodies legitimises the distribution of resources, status, and power within a biased social and architectural environment. Studying disabled writers and their works in their particular cultural context and researching them is to bring them to the mainstream agenda and to make their case open to a larger audience. This research sheds light on the issues concerning women with disabilities. Through close reading of Malini’s autobiography one can understand what it means to be disabled and how one survives in such suffocated environment full of the flames of constructed ideology of ability. In other words, the writings of disabled people represent their disabled bodies through narratives that help one understand the disabled body as the cause of the ideology of ability rather than an embodiment only. Kristin Lindgren writes about the narrative of the disabled body:

They support neither Plato’s view of the unruly body as an impediment to knowledge nor a view of the body as a transparent medium through which self-enacts its project. Rather they suggest that embodiment experience generates knowledge and crucially shapes these projects... itself a conscious project, one that demands a strategic rethinking of self-identity. First person accounts of illness and disability demonstrate that knowledge by bodies in trouble can contribute in unique ways to theories of identity, subjectivity, and embodiment. (Smith & Hutchison 146)

On the basis of exhaustive discussion in the present chapter, it may be inferred that the meaning of disability changes with the change in central ideologies. The situated knowledge of woman's body deconstructs the idea of beauty as having to do only with appearance. The positive perspective these women are using and writing deconstructs the ideology of ability i.e. beauty is neither appearance, nor skin, but depends on how one perceives it. Deconstruction actually creates an affirmation of the woman's situated lived experiences. The human body is located in a specific social milieu, surrounded by social and cultural norms that define it, causing different kinds of bodies in hierarchy that privilege disabled women who are often denied opportunities to participate in women's traditional roles, such as motherhood, and this can make women with disabilities seem invisible. I argue, therefore, that disabilities cannot be deemed only as genetic or biological defects; rather, disability is a social and cultural construct lodged in the religious beliefs.

This study has outlined the grim reality of disabled women and how the disabled writers have been meeting such challenges. As discussed, many societies are patriarchal, and women and their positions in these societies are often seen as having miniscule value. In societies that prefer sons to daughters because sons are necessary to observe significant rites of passage, the birth of a daughter is given very little importance. If a woman is seen as ugly, deformed and sterile, she becomes a person of derision in that society and she is considered invisible entity having no identity of her own. Therefore, the lives of disabled women and their lived experiences are completely irrelevant to the mass of non-disabled people because they do not fit into the "ideology of ability." The cultural impact of religion and day-to-day norms enables researchers to gain a better

understanding of the roles and responsibility of women in societies touched and shaped by such norms. The understanding of ability is so biased that the disabled are still relegated to the realm of personal tragedy. They are seen as a cultural challenge and become victims of indifference and social apathy. Women with disabilities are doubly or even triply suppressed due to the hetero-normative model of patriarchal societies, further reinforced by religious values. This disability “narrative of self” authenticates who they are and what they experience, not by offering a model to society that looks down upon the women with disabilities in the particular cultural contexts. On the one hand, her body is disabled, but on the other hand her disabled body becomes a trope to communicate the message of her subjectivity, selfhood, and identity by rejecting the culturally and religiously prescribed norms. For example, Malini remained unmarried, but nonetheless, she claims the beautiful feminine qualities of her body and shifts the conception of disability from pathology to identity.

Disability, in any form, is merely a variation of humanity, but the disadvantages this diversity creates are the lived realities that should not and cannot be left unattended. What I find even more problematic is the idea of glorifying and romanticizing disability. Such a glorified notion of disability, I argue, becomes yet another means to oppressing the persons with disabilities. The “medical model” that some disability studies scholars have discarded can prove still relevant, particularly to South Asia. If disability activists and civil society organizations relish only in the rhetoric of disability as a “human rights” issue, and do not pay ample attention to the physical and mental realities of the persons with disabilities, the “rights-based” discourse could ultimately be counterproductive. India cannot shut its eyes from accepting at least one disabled person in 8.40% of rural

households and 6.10% of urban households. So, it is high-time to remove all negative stereotypes and to mainstream disability into all facets of life by creating disabled friendly infrastructure to enable lakhs of children with disabilities to get enrolled in schools. In that case there will not be any need to introduce special schools for the children with special needs. For example, a fabricated normal child studies with another child who has a disability, they intuitively become sensitized from a very early age while it becomes difficult to adjust and accommodate at a later stage. This is similar to the theory of learning a language by immersion, and hence the child can learn acceptance by immersion.

Our schools, colleges and universities should be barrier free where a student with disability is able to study with dignity and comfort. Even in the case of having some children who require extra attention, it should be within what is labelled as a “normal” settings so that even if they are not in the same classroom together, at least for all other activities like music, dance, drama, sports, painting etc. all children are together and are able to interact and learn from each other’s strengths and weaknesses. There is also a need to motivate and counsel parents to focus on the emotional and physical needs of the children with special needs and not to believe in superstition or re-birth theory. Once a parent realizes that his/her child can perform and achieve at par with other ‘normal’ children, things would be easier for them. We also need to bring about changes in the stigmatized attitudes and responses to disabled persons to make them contribute to different walks of community life so that they can realise the life with dignity as enshrined in Article 21 of the Indian Constitution.

The need of the hour is to introduce and recognize the field of Disability Studies as an autonomous academic discipline by Indian universities and academic institutions. This could go a long way in transforming the public perception about disability issues. As noted earlier, the disabled constitute ten per cent of the total population of India. So it is all the more imperative that like Women's Studies, Muslim Studies, Media Studies, Nehru Studies, Gandhian Studies, Area Studies, and other minority studies which are the thrust areas of higher education and research, the emerging field of Disability Studies must attract the attention of Ministry of Human Resource Development and funding agencies like UGC, ICSSR, ICHR, ICPR, ICMR, CSIR and also central universities/and academic institutions. There are just a handful of journals/periodicals focusing the publications on disability issues - such as, *Indian Journal of Disability and Rehabilitation* (a half yearly journal earlier published by the Ministry of Welfare - hereafter Social Justice and Empowerment), *Disabilities and Impairments* (another half yearly journal published from New Delhi); *Asia Pacific Disability Rehabilitation Journal* (Mumbai) and Action Aid Disability News/Newsletter (a monthly disability magazine published from Bangalore). Besides, a galaxy of journals/periodicals of other prominent academic disciplines cover the disability and rehabilitation issues. Most of the journals/periodicals are focused on certain specific aspects and, so to say, cosmetic and parochial in nature; as they hardly bother to provide an inter-disciplinary orientation for studying and analysing this unexplored area. There is, thus, an urgent need for various disciplines to focus attention to this neglected field of inquiry from interdisciplinary perspective. Scholars, intellectuals and social activists may contribute significantly in achieving the desired objectives for the larger welfare of the disabled population.

Everyone harbours a desire to travel, but for people with disabilities, it is mostly because of the lack of infrastructure that they cannot fulfil their dreams. Taking this into consideration, some organizations have come forward to spread awareness about the issue. The Better India is supporting the initiative, led by UMOJA, the first platform for accessible travel in India. Similarly, the NGO ADAPT (Able, Disabled, All People Together) and the Goa Tourism Department's organization Drishti, made Candolim beach wheelchair-accessible in Goa. The ongoing Beach Fest at Candolim is a celebration of joy, dreams and freedom for many people with disability.

India's disabled are woefully under-represented in many fields, with politics seeing some of the worst numbers. However, an increasing number of disabled people are joining local politics, including large number of women from many rural parts of India. As we all know, the Women's Reservation Bill faced several roadblocks, and its journey itself showed various facades of patriarchal society. Nevertheless, political participation of persons with disabilities is gradually increasing in India. There are several persons with disability who have made it to important positions on their own due to their dedication, commitment and perseverance. The newly enacted Persons with Disabilities Act provides for 5% reservation in poverty alleviation and developmental schemes for persons with disabilities (including persons with psychosocial disabilities). The most significant point about the Rights of Persons with Disabilities (RPWD) Act, 2016, is that it has promised to make public facilities accessible to the disabled. The key point of the Bill is that it raised the reservation in government jobs for the disabled from 3% to 4%. It also provides for imprisonment up to two years, along with a fine ranging between Rs.

10,000 and Rs. 5 lakh for those discriminating against the differently-abled. According to the Act,

The appropriate Government shall take suitable measures to provide,- facilities for persons with disabilities at bus stops, railway stations and airports conforming to the accessibility standards relating to parking spaces, toilets, ticketing counters and ticketing machines; access to all modes of transport that conform the design standards, including retrofitting old modes of transport, wherever technically feasible and safe for persons with disabilities, economically viable and without entailing major structural changes in design... (RPWD Act 4 1)

India is also a signatory to the 'Biwako Millennium Framework' (2002) for action towards an inclusive, barrier free and rights based society. In December 2015, Prime Minister Narendra Modi initiated the five-year Accessible India Campaign. The recently inaugurated Yeshwantpur-Hassan train service includes a coach for the disabled. Three major railway stations in India – Chennai, Kochi and Trivandrum – took measures to become wheelchair friendly. There is need to provide hydraulic lifts in most airports for PWDs in India. Attempts are also being made to provide ramps in all existing and future ATMs and at the entrances of bank branches. Earlier, the disabled people were treated as objects of pity but now social attitude has changed. We now have a slew of Indian films that have embraced inclusivity for the disabled by normalising portrayals like *Kabil* (2017), *Black* (2005), *Koshish* (1972), and *Angel* (2012). Apart from these a short film *A day in the Life of a Wheelchair* created by The Network for Javed Abidi of the NCPEDP, projects the everyday problems of young girl, Sapna, a wheelchair user.

The CRPD is one of nine international human rights treaties signed by 166 Member States of United Nations. It is the first internationally legally binding instrument to address the plight of persons with disabilities. The inclusion of disability component in the 17 Sustainable Development Goals (SDGs) is hailed as a major achievement and success, with aspirations and hopes running high. Moreover, the overarching principle of Vision 2030 is to 'leave no one behind'.

The National Centre for Promotion of Employment for Disabled People conducted a seminar in December 2016. The government, the private sector, and leaders from various development fields participated to take stock of the current situation and deliberate on how disability could be integrated in Vision 2030. A starting point was that the government, the NITI Aayog, and all the associated stakeholders should interpret the provisions of the SDGs in line with the requirements and spirit of the UN Convention on the Rights of Persons with Disabilities. (UNCRPD). Based on the changing disability landscape, the knowledge of MPs and State legislatures must be refreshed on the rights, needs and issues of persons with disabilities. The NITI Aayog must invest effort in building awareness for NGOs, academics, civil society, the private sector, etc., in order to articulate a disability-inclusive development agenda. The new national building code (NBC) prepared by the Bureau of Indian Standards, which was released by the Ministry of Consumer Affairs on March 15, 2017 appears to have now provided a solution to disabled-friendly and completely barrier-free smart cities. Despite the inclusive approaches being introduced and practiced numerous parts of the natural world will remain inaccessible to many disabled people: mountains, bogs and beaches are almost impossible for wheelchair users to traverse, while sunsets, birdsong, and other aspects of

nature are difficult for those lacking sight or hearing to experience. In urban settings, many barriers can be mitigated, although historic buildings often cannot easily be adapted. In these situations, it seems more practical to make other arrangements to overcome the problems. For example, Transport for London have an almost totally accessible fleet of buses. There is the trend to introduce barrier free access to libraries in educational institutes. 'Raahgiri' day for the persons with disabilities is a unique initiative by the Department of Empowerment of persons with Disabilities, Ministry of Social Justice and Empowerment, Government of India. This event was organised in view of the spirit of Prime- Minister's initiative 'Sabka Saath Sabka Vikas' which includes the persons with disabilities. It showcases the diverse range of unique abilities of the differently-abled children/ persons. 'Unique ID for Persons with Disabilities' project is implemented with a view of creating a National Database for PWDs, and to issue a Unique Disability Identity Card to each person with disabilities. The objective of this project is not only to encourage transparency, efficiency and ease of delivering the government benefits to the person with disabilities, but also to ensure uniformity.

Media portrayal oscillates between two extremes: pathetic and superhuman. Persons with disabilities are just as commonplace as other regular citizens of the country. There are existing stereotypes that mirror the prejudices which exist in society, through which media portrays persons with disability. Often, media tend to view disabled persons only in the light of their disabilities. The focus is on the impairment and not on the individual. This is reflected pictorially as well. The camera focuses on the disabled part of the person rather than the person as a whole. There are talent shows on Television which provide a platform to people to showcase their talents. If a visually impaired

person participates, the media pushes their cause based on their impairment, rather than their actual talent. The media should avoid this practice. Images of disabled fashion models in the media can shake up established categories and expectations. Commercial visual media are the most widespread and commanding sources of images in modern, image-saturated culture and therefore they have great potential for shaping public consciousness—as feminist cultural critics are well aware. Fashion imagery is the visual distillation of the normative, gilded with the chic and the luxurious to render it desirable. The commercial sphere is completely amoral, driven as it is by the single logic of the bottom line. This value-free aspect of advertising produces a kind of pliable potency that sometimes can yield unexpected results.

The theologian and sociologist, Nancy Eiesland, has argued that in addition to legislative, economic, and social changes, achieving equality for people with disabilities depends upon cultural "re-symbolization" (Qtd. in Davis 375). The literary study of disabilities has contemporary relevance as it helps physically or mentally impaired people to come into the mainstream society and to assert their self-esteem. It will be, therefore, worth pursuing for further research to have a better understanding of the lives of people with disability and generating not sympathy but empathy for the people with disability. The need of an hour is to do significant work by educating people across different cultures and notions to expose government inaction and provide recourse for violations of the human rights of people with disabilities. Lastly, anti-discrimination laws are indispensable tools, as the importance of achieving actual economic, social and cultural rights for persons with disabilities should not be forgotten. In the present context, social

policy needs to be adopted to put positive support in place that will truly enable people to access and enjoy their human rights. Justice A. K. Sikri has remarked:

If you have a mind and shall not reason, you are disabled.

If you have the opportunities and don't use them, you are disabled.

But if you are disabled and can think,

If you are disabled and are dedicated,

If you have talent and have skills,

If you have the will, then where do you go?

Only ahead, May even reach zenith.

That is the direction of joy, empowerment, achievement and adventure. (14)

In this way, the present study is significant from the socio-economic point of view because it address the issues of education, employment, social security and non-discrimination where the PWDs are lagging the most. It will assist in uplifting the conditions of this 'invisible minority.'

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