SOCIAL ATTITUDES TOWARDS PEOPLE WITH HANDICAPPED /DISABILITIES IN INDIA: A REVIEW

Social Attitudes towards People with Handicapped/Disabilities in India: A Review

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Abstract – Disability has been defined as "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being. The major preventable causes of disabilities are malnutrition, communicable diseases, early childhood infections and accidents at home and work place. Early detection of impairment, combined with early and effective curative care can make a significant impact in minimizing or compensating for impairment and its consequences. There was no comprehensive study on the attitudes of society towards disabled children in rural India which has necessitated us for this study to make suggestions to the institutions involved for the positive attitudes.

Societal attitudes towards persons with disability have changed from time to time. Various factors contribute to these changing attitudes. A comparative international project on disability attitudes, beliefs and behaviours was carried out in India in collaboration with partner institutions and researchers. This paper presents an overview of the preliminary findings across all communities, and includes information on sample and scale characteristics, and scale distributions.

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INTRODUCTION

Disability has been defined as "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being". According to World Health Organization's estimates, approximately 10% of a given population suffers from disability of one kind or other. There were no comprehensive surveys to know the exact incidence of disability in India.

Persons with disabilities who belong to poor families are marginalized and disadvantaged by variety of factors such as lack of access to productive resources & to opportunities, and lack of information and skills which enable participation in social, economic and political process. Some groups such as women and girls are more vulnerable to disabilities. It was estimated that only 2 to 3% of disabled in the need of rehabilitation have access to the services.

Persons with disabilities frequently live in deporable conditions, facing barriers that prevent their integration and meaningful participation in mainstream society. The basic human rights to freedom of movement, access to education and health care are often ignored. Because they suffer the additive difficulties of their disability, marginalization and invisibility, their health, especially their mental health may deteriorate even further .

The persons with disabilities and their family members are socially, economically and emotionally affected. The negative attitudes of the abled persons in the family and in the community are the greatest obstacles to full participation and equalization of opportunities.

Society's understanding and approach to the issues of the disabled has been fast changing for the past 30 years. Newer advances in technology, new civil rights movements, greater number of disabled people making their marks in different social, political, economic and other sectors have helped in mainstreaming of the disabled citizens.

The establishment of Rehabilitation Council of India has been a major move for quality assurance in the education, training and management of persons with disabilities. Persons with Disabilities (Equal opportunities, Protection of rights and Full participation)Act,1995 fixes the responsibilities on central and state governments to provide services, create facilities and give up support to the people with disabilities in order to enable them to have an equal opportunity in participating as well as productive and contributing citizens of the country to their fullest extent .

A new strategy termed Community Based Rehabilitation (CBR) was evolved and found extremely useful to rehabilitate persons with

disabilities in the community setting and with community participation.

People with disabilities form a significant part of the world population. The exact numbers are hard to discern due to suspected underreporting and differences in the definition of disability between countries, and cultures (Yeo and Moore, 2003). It is estimated that approximately 650 million people of global the population, or ten per cent of the total population, live with disability. It is also estimated that approximately 80 per cent of the global population living with disability live in developing countries (UN, 2006). The global prevalence of disability and impairment is expected to rise due to factors such as increase in population, ageing, accidents, malnutrition, conflict, HIV and advancements in medical treatment which preserves and prolongs life (Thomas, 2005a). The experience of people with disability varies depending on their personal circumstances, availability of resources and other external factors. Similarly, students with disabilities represent an emerging population in higher education institutions, whose perceptions and experiences of higher education are ultimately shaped by their sociocultural experiences, the existing of environment, and the availability of specific facilities, required by them. Despite notable progress in legislations and policies for these students in higher education institutions, many of them still face various challenges in completing their studies successfully. Unfortunately it was also found that there is a dearth of research studies in the Indian context.

This paper explores evidence on attitudes to disability in India, and their implications for public policy. Attitudes of society, families and PWD themselves contribute to converting impairments into disabilities. Research in India has consistently found substantial social marginalization of people with disabilities. The attitudes of specific societies are critical in assessing both the intensity of disability (i.e. how disabling a given type or level of impairment becomes for the individual disabled person) and in assessing areas where collective action is likely to fail the disabled community, and hence public action be desirable. In addition to the attitudes of the general society, the attitudes of persons with disabilities and their families are important, in some ways even more important. At the same time, the different sets 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.

Much of the literature on disability in India has pointed to the importance of the concept of karma in attitudes to disability, with disability perceived either as punishment for misdeeds in the past lives of the PWD, or the wrongdoings of their parents. As two Indian authors have put it, "At a profoundly serious and spiritual level, disability represents divine justice". 1 At a more mundane level, people with disabilities are traditionally perceived as somehow inauspicious.

Much qualitative research has found considerable social marginalization of people with disabilities in India, though most also acknowledge that the social status of the PWD's family has an impact on their potential acceptance in society. Box 2.1 discusses images of PWD in Hindu mythology and Bollywood cinema by way of illustrating popular culture perceptions of people with disabilities.

Since the turn of this century the number of workers, professional and lay, in industrial societies who work in the field of disability has increased enormously. Almost every aspect of the life of a person who is disabled has its counterpart in a "profession" or voluntary organisation. Potential and real control over the life of a disabled individual is a modern fact. This has resulted in the attitude that the disabled individual is obviously particularly dependent upon others for help. The growth of professional "expertise" in the field has also meant that these helpers have had an almost absolute monopoly in defining and articulating the problems of disability to the public at large. One result of this has been the appearance of disabled people as passive, the objects of research and help. The numerical increase in helpers has also necessitated the need for a team approach to the disabled individual. While the helpers have grouped together, gaining confidence in their roles from their colleagues, they have done so to help the disabled individual Disability, therefore, has been seen as a personal misfortune.

The increasing help has also facilitated greater numbers of disabled people functioning independently in the community. Disabled spokesmen and spokeswomen have become increasingly active in articulating their own perceptions of their situation. Since the Second World War there has been a rapid growth in the numbers and size of organisations of disabled people and increasingly, particularly during the past decade, a growing group identity.

The most immediate impression of disability, therefore, is paradoxical. On the one hand there is the appearance that disability implies a personal tragedy, passivity and dependency. On the other hand disability can be seen as a form of group discrimination, involving constant struggles and independent action. The paradox of disability confounds any attempt to discover uniform attitudes towards disabled people. It is also a challenge to helpers to face squarely their role in a conflictual social relationship.

"Disability", it should be noted, is given a particular definition in this work and much of the discussion is concerned with its real nature. It is defined in terms of the special form of discrimination, or social oppression, that is faced by people who are in some way physically impaired. In a sense, the whole monograph can be viewed as defining disability and as attempting to raise some of the issues involved in changing attitudes towards this paradox, called disability.

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The monograph is addressed principally to those workers entering, or already working in, the rehabilitation and welfare services (whether professional, lay, fulltime, part-time, disabled or non-disabled workers). It is also hoped that the monograph will be of interest to the "consumers" of help, disabled people, as well as their friends and relatives.

Over the last 60 years, India has evolved into an important player in the international arena. During this time, it has achieved a number of accomplishments including becoming a leader in computer and communications technology. Even more impressive, India boasts one of the fastest growing economies in Asia. Despite such progress, 25% of the population lives below the poverty line, 40% of the population is illiterate and approximately 70% of the population live in rural areas and lack access to adequate medical care and support services. Furthermore, India is still very enveloped by cultural standards and norms that have prevailed for hundreds of years. In a society of competing dualisms between rich and poor, urban and rural, developed and undeveled, it is not hard to imagine the conditions and challenges that the most vulnerable members of society face. There are certainly many vulnerable groups present in India, but one of the easiest to forget are the 31 million individuals with intellectual disabilities (ID) in India.

Presently, most individuals with ID in India have not been formally identified and even among those who have been identified, the majority are excluded by the rest of society. As a result, individuals with ID are not afforded the same opportunities as people without disabilities. To fully understand the challenges that individuals with ID are facing within the Indian society, there first needs to be some understanding that these barriers are primarily rooted in religious beliefs, cultural norms, and misinformation or a lack of information regarding disabilities in general.

The predominant religion in India is Hinduism, practiced by more than 80% of the population. Hindu's believe that an individual will be reborn or re-incarnated after death until they have attained salvation. With each birth, it is believed that if the individual has good karma, he/she will be born into a higher caste. If an individual has bad karma, he/she will be punished in their next birth, usually by entering a lower caste2. Historically, disabilities have been considered punishments for sins committed in a previous life by an individual or their family members. In some cases, families regard their children as "cursed" and a burden that they must deal with, which at times leads to the neglect and rejection of the child; the child might even be hidden from the community as the family fears they might be rejected by the community (Girimaji, et al. 2001).

In addition, one of the most significant barriers to inclusion for individuals with ID in India is the rigid social structure within the society. India is structured in such a way that an individual's capabilities can influence their position in society often times without regard to their caste membership. However, the perception of capability is not always based on competence, but rather on stereotypes of class, gender, religion, ethnicity, and language for example. There is also a lack of information available on intellectual disabilities that could help to demystify the cause of the disabling condition and allow for the questioning of existing stereotypes. At present, individuals with ID are seen by the majority of people in India as fundamentally "flawed" and perceived to have diminished capabilities, thereby placing them at the bottom of the social structure regardless of their caste identity (Ghai, 2002).

CONCEPT OF DISABILITY

This section discusses the conceptualization of disability. Although various attempts have been made, it is very difficult to develop a universal definition of disability. This is mainly due to the fact that the perception and the understanding of disability are formed through influence of history, society and culture and how these are related to various aspects of the lives of people. It is important to keep in mind that understanding the term disability does not necessarily mean understanding persons with disabilities. A number of other factors must be taken into account for a proper understanding and analysis of disability (Pfeiffer 2000). However, in disability research, there is no consensus on what constitutes disability.

Disability has been defined differently by different disciplines due to various reasons. Here, an attempt has been made to examine how disability has been described from bio-medicine/rehabilitation, sociology, disability studies and political science perspectives and how definitions of disability have been developed and used in different contexts. Various operational definitions have been used for rehabilitation, policy and administrative purposes. The ubiquitous question of understanding disability in social science research reveals the importance of the issue for people with impairments, activists, researchers, academicians, the national government and international governments.

The International Classification of Impairment, Disability, and Handicap (ICIDH) classification of disability has been criticized and rejected by many disabled people themselves, although it has been widely accepted by professionals in Rehabilitation and Community Based Rehabilitation (Kuno, 2008). The major criticism is that it fails to examine the cultural, social and political structures that equate 'difference with deviance' and 'pathology'. In this classification, the focus is on the impairments of

persons as the ultimate cause of disability and perceives disabled people as passive objects, rather than actors.

The Sociology of disability is associated with medical sociology, or specifically, it's sub-group such as the 'sociology of chronic illness and disability'. It is formed by the idea that disability is caused by illness and impairment, and brings about suffering and social disadvantages. These kind of divergent approaches suggest that there is no unitary sociology of disability. But this discipline continues to offer quite different perspectives of the nature of disability. An attempt is made here to examine how these sociologies understand the nature of disability. In this section, initially some of the sociological approaches through the 1960s and 1970s that analyzed disability as a form of social deviance and sickness and stigma have been outlined. Secondly, critique of sociology of disability by disability activists and academics is outlined. Disability study is an interdisciplinary field that deals with the development of paradigmatic shifts in relation to the ontological and epistemological ground of disability policies, theories, research and practices (Goodley and Van, 2005). Disability studies are an explicit commitment to assist disabled people in their fight for full equality and social inclusion by creating greater awareness among policy makers and professionals in the disability service arena. In this growing new discipline, 'disability' is defined as a fundamentally social, cultural, political, historical and relational phenomenon (Oliver 1992, Shakespeare, 1998). Literature in Disability studies in the last two decades is found to be enriched with materialist, feminist and postmodern/post-structural perspectives in understanding disability. In brief, materialist perspective dealt with the relationship between disability and the economy. The feminist perspective underlined the importance of understanding the personal experience of disability and its relevance to disability politics and the postmodern/post-structural perspective looked at issues of history, culture, and language with regard to. All these perspectives sought to provide various and sometimes complementary ways of understanding disability. In this section emergence of disability studies has been initially elaborated. Secondly, understanding of disability from the above mentioned perspectives has been explored in some depth.

ATTITUDES TOWARDS DISABILITY

According to Lowenfeld, the social and economic history of the Western blind may be divided into three distinct stages: (1) the primitive period; (2) the era of the asylums; and (3) the age of social integration. This is true in the case of people with all other disabilities. The initial stage occupied all of prehistory and pervaded the ancient period, when the blind and other persons with disabilities were generally regarded as an economic liability, unworthy even of the fundamental right to live. During antiquity, they were treated with the utmost scorn, and begging became their traditional

form of livelihood. Some even believed that during this period, they were not only neglected but also to be left to die and in some places the unimaginable cruel ways of killing them were adopted.

The second phase began with the rise of Christianity in Rome and ended in the late eighteenth century with Valentin Hauy's founding of the first school for the blind in Paris in 1784.

During this long middle period, the right to life was recognized, but education and independence were not encouraged. The blind and the disabled were still considered helpless, capable of a decent existence only through the benevolence of others, preferably as wards of the Church and other similar religious places. The final stage commenced with the French Enlightenment and the advent of systematic education for the disabled. Once equipped with the skills requisite for self-support, the blind started becoming integrated into mainstream society, as full-fledged members; but this process of assimilation has been slow and piecemeal and remains even today only partial. Owing to a ubiquitous pattern of discrimination, particularly in the economic sector, the disabled have yet to achieve their rightful place in society.

COMMUNITY ATTITUDES TOWARDS DISABLED PEOPLE

Disability is commonly associated with religion, sometimes attributing to disabled people almost godlike powers. It was commonly believed that disabled people possess extraordinary powers and gifts, and therefore do not actually perform common, everyday activities, such as having to eat and sleep. The attitudes reported by some of the disabled people interviewed were indeed very positive, which contrasts strongly with the popular perception in India that the root cause of disability is attributed to sin and destiny - karma. This may be accounted for by the fact that many of those interviewed live in urban areas, where western conceptions of the etiology of disability and impairment are more common place. Furthermore, those interviewed lived in rural areas where NGOs were already providing some disability services, and it is likely that local communities will have received and benefited from some form of disability awareness education or campaign.

The ability of disabled people to participate within society, particularly when they are children is exacerbated by the fact that many mothers feel very conspicuous when taking their children into public places. Members of the local community would often stare at the disabled child, causing the parents to feel miserable. Furthermore, it was stated that some parents with non-disabled children actually forbid their children from playing and interacting with those with disabilities, fearing that the impairment may be contagious and may also be related to anger from the gods.

Children with disabilities are likely to experience further isolation and exclusion from their local communities, because some parents feel a great deal of shame, remorse and guilt because of their child=s physical or cognitive condition. In such situations, there is a tendency for parents to attempt to shun away their children. I have been told of instances where children have literally been locked up in their houses, in an attempt to hide them, thus avoiding their public disgrace. During the course of interviewing Mrs Chatterjee, Principal Secretary at the Ministry of Welfare, New Delhi, I was told of an instance where one very high ranking civil servant had an 18 year old son with cerebral palsy. The father, because of his high social position was fearful of the public disgrace that would be inflicted on his family because of his disabled son, and had actually incarcerated his son in a bamboo cage for the first 15 years of his life. This action indicates that social standing within society is all important within India, even to the extent of being detrimental to members of one=s immediate family. However, there is evidence to suggest that this instance of abuse is not an isolated case, but is commonly encountered by disabled people, particularly in the case of women.

Disabled people not only encountered hostility and negative social attitudes from members of their local communities, but were also subject to exploitation by local government officials. The group of trainees interviewed at TRDC, the majority of whom had polio, stated quite explicitly that they had to pay bribes to local government officials in order to receive medical certificates that certified that they were in fact disabled.

CONCLUSION

Changing societal attitudes to people with disabilities, even among people with disabilities themselves at times, presents many challenges. However, a basic starting point is facts. The leprosy campaign and its impact are clear demonstration that part of the stigma attaching to disability is driven by ignorance (see Box 2.4). It will thus be critical that various public health, educational, and other general awareness campaigns of government and non- governmental sectors drive home the causes of disability, and that disability is not a pre-ordained event.

The concept of disability involved has changed from time to time, culture to culture and country to country. The significant facts which are enumerated are that the level of consciousness has increased to a significant positive degree as of now disability is considered a human right issue as compared to the dark ages when disabled were eventually killed. Different phases in history have indicated that the attitude has significantly changed from negative to positive aspect in various dimensions and manifestations.

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