

WOMEN AND DISABILITY MANAGEMENT IN RURAL HARYANA, INDIA

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ABSTRACT

This paper discusses disability from an anthropological perspective by locating it in the social context of rural Haryana State in India. Without going by the prevalent rhetoric of disability movements, an attempt has been made to understand the social conditions of disabled people in the context of their daily lives, where they negotiate physical and social barriers. Critiquing the essentialist notions of social structures as basically oppressive for disabled people, this paper explores the cultural and social resources, which have implications for state policy, community rehabilitation efforts and NGO action.

INTRODUCTION

The term disability is mired with definitional problems just as many other terms like 'impairment', 'physical handicaps', 'physically or mentally challenged' or 'different abilities', are often used to designate certain conditions in a layman's understanding of what is not considered 'normal'. Inherent in these notions is an idea of a perfect body, state of health and mind. Working through cross-cultural data, anthropologists argue that there is no universal definition of disability, rather, multiple meanings exist and in most societies disabled persons do not exist as a social group. People attribute meanings to conditions that construe persons as 'abled' or 'disabled.' Inherent here is the notion of 'normalcy' and 'ability.' People's cultural and cosmological beliefs get shaped by social and economic forces and the requirements of what is considered 'normal' in terms of everyday life, are expressed in terms of values and attitudes and expressed through ideas. Social structures thereby provide individuals with a number of choices to choose from and each individual negotiates and uses the agency to work within the framework of collectivity. It is thus argued here that disability should be understood as culturally constructed and socially negotiated.

Implications of disability for women who constitute almost 50% of the agrarian class are significant, both in terms of the kind of social lives they lead and their participation in the development process. Since a large number of disabled people live in rural areas, the absence of accurate information on the magnitude of the problem, has hampered planning of realistic policies and services for them. Various studies have argued that women with disabilities face multiple disadvantages, through their status as women, as persons with disabilities, and majority numbers as persons living in poverty. Thus, a culture-centred, gender sensitive, holistic approach has been adopted to explore the context of disabled women and their negotiations within the traditional agricultural context and the role of social support mechanisms in rural India. Generalisations from this micro level study may or may not be applicable elsewhere, as they emerge from a specific context.

WHAT IS DISABILITY?

There are several approaches in understanding disability. The medical model views disability as a personal tragedy. Disability such as the impairment of limb, organ or function has traumatic physical and psychological effects on a disabled person. Disabled people in this model, are regarded as people with limitations who cannot ensure a reasonable quality of life because of their impairment. The medical model expects individuals to find ways of adapting to society. In this model, the onus of adjusting and adapting to their environment and to the society is on the disabled people themselves.

The social model on the other hand, presents disability as a consequence of oppression, prejudice and discrimination by society, against disabled people. It is society that constructs economic, social, health, architectural, legal, and cultural and other barriers in order to deliberately prevent people with impairments to enjoy full benefits of the society. The social model shifts the onus from a disabled individual to the society and its disabling attitudes and environment

Adopting a culture centred approach, it is argued here that disability locates the individual in a compromised position which is not only a function of biology, but also the product of a complex interaction among non-biological factors like gender, caste, class, neighbourhood relations and the nature of kinship and family structures.

In an urban context, disabled people are recognised as a separate social category for their special needs. There are attempts to integrate people with disability into the mainstream of society through promotion of technical assistance in a formally institutionalised set-up like a special school or a training centre, to ensure that the individuals make optimal utilisation of their available faculties. The situation is quite different in a rural context. Here, disability does not contribute to the formation of any socially recognised group. In order to understand how people define disability in a rural culture, it is important to recognise its social fabric, work related requirements, cultural notions and the structure of gender relations. No policy can work here unless these factors are properly understood and policies be framed accordingly.

CULTURAL CONCEPTIONS OF DISABILITY

In the Indian context, Hindu scriptures explain causes of human sufferings through the theory of *Karma* i.e. if one has committed misdeeds in the previous births, one has to inevitably bear the consequences. Illness and disability are understood to be a punishment for the sins of previous births and one is called upon to accept it as divine retribution. Belief in the theory of *Karma* has very often led to a ready acceptance of disability, with little effort in the direction of improving the life conditions. It is argued that the acceptance of disability as *Karma* gives people some explanation of their suffering, which cannot be justified otherwise. It has been noted that the belief in *Karma* keeps the faith in a just world alive, even under adverse conditions it reinforces hopes that good deeds will ultimately lead to a good outcome (1). The positive role of religion cannot be dismissed here.

Disability in most academic approaches is understood as the deviance from normalcy. However, in Haryana, it is for theoretical purposes, explained as the ‘dependency’ of an individual on others in the community (*aashrit*). In addition to this, in the neighbouring state of Rajasthan, it is also understood in terms of a ‘fault’ in the individual. The Hindu idea of disability makes a distinction between ‘*viklang*’ and an ‘*angheen*’. The former is an individual who has organ but without having a use of it, like a deaf man with ears. ‘*Angheen*’ is one who does not have a certain part like an amputee or one born without ears or eyes. For ritual purposes a *viklang* is not discriminated against *angheen* is considered inauspicious.

The definition of disability remains ambiguous here and is often made synonymous with limb deformities. Haryana, being an extensively agricultural state, depends heavily on manual

labour in the fields. Hence, the sturdiness and robustness of physique in people are highly valued and the question of disability is understood as *viklangta* or *apangta* i.e. in terms of locomotor disorders. Also, a locomotor disorder is visually more prominent. Thus, society ideally maintains that people with limb deformities are the ones who are dependent on others.

The severity of the condition in case of limb deformities is not taken into consideration and in pointing out that the people with minor limb deformity might actually be well capable of looking after themselves, villagers quietly accept this, but such individuals remain in the category of 'disabled'. The blind or deaf are placed in separate categories of '*andhe*' and '*goonge-behre*' respectively. The enquiry as to how a blind individual can be considered as self sufficient is responded to, by conveniently shifting the category of blind into that of disabled. However, there is a constant debate on whether or not people with hearing and speech impairment should be included into the category of 'disabled'. More so, because they are physically able to perform all kinds of laborious tasks and the family of the individual concerned develops a fair amount of communication skills with him or her. The mentally challenged individuals were not included in the category of 'disabled'. They were often referred to as *bhola* or *bholi*, i.e. innocent. In the case of a mentally slow male, the individual was assigned work that was essentially identified with a woman, like fetching water, weeding in the field etc. Thus a male with reduced mental faculty was supposed to be able to perform the tasks of a woman. When a mentally challenged individual has other physical disability, the individual is included in the category of 'disabled'. Whether a person is considered *angheen* or *viklang* socially, he or she is not debarred from participating in any social ceremony. Moreover physical status holds a more significant value than the social status. Quoted here, are some local sayings to this effect (translated from the local language).

Who would call the king elephant names, even if he spoils all the fields in the area.

One who is weak is always reprimanded for wrong deeds.

A disabled individual is often stereotyped as hot tempered, sexually impotent and unreliable. This is reflected in the local sayings and folk songs. Some of these are as follows:

When a woman with a squint is married into the house, the property of the house is at risk.

A person who is impaired in one leg and one who is impaired in one eye has an extra nerve.

The extra nerve signifies hot temper. They are thought to be temperamental and prone to quick anger.

A folk song challenges a woman to go with a disabled man, saying that she will never be sexually satisfied. A disabled individual is not seen to be sexually capable or competent.

Disabled people are not seen as complete or even normal persons. Their disabilities are often exaggerated and they are made to feel small. They are addressed by terms with negative connotations, instead of their actual names. Disability acquires different meanings according to age and gender.

Causation and Cures

The causation of disability is understood based on a number of different variables. These could be recognised as either mutually exclusive categories, or in combination with each other. What remains true to all these causes is the supervening reality of fate. An individual's condition is essentially understood in terms of his or her fate or *kismet*, which is all pervasive in nature. Besides, there are many magico-religious beliefs and rituals performed by the villagers to avert such calamities. The various parameters responsible for disability in an individual, form a mutual cause and effect relationship with fate. The biomedical system of cure is highly sought after, leaving the people vulnerable to scams by quacks and other non-professionals. Going by local conceptions of disability, all possible resources are availed to find the cure for disability. The effort is towards finding a cure but not rehabilitation.

WOMEN, WORK AND DISABILITY

Historically, Haryana has been notorious for its high rates of female infanticide and lately misuse of sex selection technologies leading to large numbers of foeticides. Clinics performing such tests and consequent abortions are mushrooming in all the towns in Haryana (2). Since the 1981 census, lowering sex ratios have become a serious concern. Large-scale dowries, anti-women attitudes and a strong male preference are the often cited reasons for this. Strong patriarchal traditions, rigid gender segregation, widespread prevalence of the dowry

system, devaluation of women and the life long liability of the girl's family to endow her with gifts throughout her life (after her marriage), connote the girl as a burden. Women largely remain unwanted, as evidenced in the skewed sex ratio.

Dalal (1) writes that extended family as a basic unit, played its crucial role in uniting and supporting its members and giving them a social identity. Being a cohesive and stable social unit, families provided an identity and a sense of social security to its members, irrespective of their physical disabilities. The economic and caste status of the family and family networks also ensured the quality of well being of its members, which included disabled persons. Agriculture being a family based activity, ensured role allocation and division of labour in a common space of work and residence. Through work, one reaffirmed a sense of belongingness to the group. This scenario has not changed much inspite of all global, economic and technological changes affecting the local communities.

In rural Haryana, these propositions also hold true, as the state is dependent on intensive agriculture though there are changes in the traditional joint family structure. Young couples are now separating from the joint family within a few years of marriage, but primogeniture persists in authority. Despite separation in living space and land ownership, the family behaves as one for all other practical purposes. This kind of system helps in easy formation of disability management groups.

Women with disabilities do not form a homogeneous group. For example, the mentally ill and mentally retarded, visual, hearing and speech impaired and those with restricted mobility, all encounter different barriers, of different kinds, which affect them differently and which have to be overcome in different ways. For instance limb deformities are considered to be more disabling than being deaf. Mental illness is not taken as an illness or disability till it totally disables the person. As a group however, they are seen to be stigmatised from several social stereotypes that further marginalise them.

Scholars have pointed out the prevalence of anti-women attitudes in Haryanavi society, expressed through abuses, folk tales and stereotypes (3). Women's contribution to economy is significant in rural Haryana, as every woman is expected to participate in agricultural and household activities. Women not only participate in agricultural fieldwork, but animal husbandry, household chores and childcare is also primarily seen to be women's work. The notions of

good health for women are understood in terms of their capacity to engage in hard manual work. Farm work is seen as her most important responsibility. Stereotypes and folk songs nevertheless devalue women's work. For both men and women, physical strength and endurance are valued more than many other qualities. Physical disabilities are not taken very seriously, unless they threaten to disturb the working potential of the girls. Her capacity to work hard is a key factor for her marriage and future. Socially her contribution to economic activities goes unrecognised and is often devalued. A disabled girl is initiated into all of a woman's traditional responsibilities, to the maximum extent possible. Some concessions may be made regarding specific tasks, including offering her help in doing tasks such as fetching water, or lowering expectations for the intensity and hours of fieldwork. Female relatives, including the disabled girl's mother and sisters, often extend help to enable her to carry out these tasks.

These girls are ordinarily not treated differently from other girls of their age and family background. They are generally not excluded from games. Their siblings are often protective. The restrictions on other 'normal' girls are also applicable to them. There is very little playtime for any of the girls in these communities. Most of them learn to look after other younger children of the household and help their mother in completing household chores.

Girls and women remain discriminated in terms of food distribution and access to health care. It can thus be easily assumed that a girl and that too one with a disability would be totally unwanted. Some case studies reflect initial neglect in the case of a disabled girl child, where in a number of situations the parents actually admitted their eager anticipation of the child losing her life. But what is significant is the fact that when the child is able to cope up, fighting all odds in spite of neglect, the family comes together to support her. This neglect of providing basic health care to women of all ages is due to both gender discrimination and financial difficulties. Among the scheduled castes, economic hardships were mainly found to be working against the survival of the girl child. Women across all castes are accustomed to take their health less seriously.

Young girls are socialised in traditional gender roles, as the capacity to work is a key deciding factor for her marriage and future. Some concessions may be made for a disability as not expecting heavy work etc. They are also being sent to school; however, not much

value is attached to education. In the management of disability the role of family is significant. The mother and other female relatives look after the child and make the early diagnosis.

The location of the household based on caste, economic and social status is one of the main deciding factors determining the availability of resources available to an individual. A disabled person is not identified as an individual or a person, but rather, identified through the context of his/her family background, thereby helping to remove focus from the individual to the group he/she belongs to. Disability in this context is a superimposed category, not recognised as a group. What is important to note here, is that there is no segregation on the basis of one's disability; on the other contrary, there is a constant effort of inclusion of these individuals. It is not to say that there are any special efforts to accommodate them. They are taken as part and parcel of society. The attempt is to motivate the individuals to live life like any other individual placed in the same status –role bracket, though this can prove quite a strenuous experience for the individual as such, but it helps build the individual's self confidence in the long run, especially in the case of women. These adjustments are made more at the level of household, than society. This observation corroborates Erb and Harris White's work (4) who found a clear correlation between poverty and disability in south India by examining the economic costs associated with onset and management of disability. However, besides inadequacy of economic resources, it was found that lack of social capital of poor people also creates barriers in disability management.

A woman's destiny and social security is still being conceived in terms of marriage. The dearth of women in Haryana society, due to male preference actually acts to a disabled woman's advantage. The most support that a woman can get, is the sharing of her responsibilities with her sisters. For this, the disabled girl is often married into the same household as her sister, usually to a brother and at times to the same man as her sister. This type of marriage practice often comes to the aid of a disabled woman. Disabled women are also usually married to a disabled man, a widower, a man whose economic condition is lower than her natal home, or to a man who cannot find a spouse for some reason or the other (illiteracy, low income, caste endogamy etc.). There were also reports of heavy dowries paid by parents of disabled girls. A spouse is found for almost every disabled girl, because there is a scarcity of girls in society.

A disabled woman in the reproductive age group could be seen to be most vulnerable as she is pushed towards performing work like any other individual in society. This is explained in terms of rigid division of labour and indispensability of the woman's work, both within the domestic as well as agricultural sphere, especially after her marriage. No special concessions are made with the disability in mind (i.e. redesigning of house, exempting her from work); a girl child is initiated into all possible responsibilities. She may have a problem fetching water, as she cannot use earthen pots over her head, so she has to carry buckets. She could have a problem in performing agricultural labour. No special care is extended in terms of their specific physical/mental disability. Rural society does not perceive disabled people as people with any special requirements. This is more true in the case of women. Their traditional gender roles as worker and reproducer are strictly enforced, as in the case of any non-disabled woman.

The women of the family, usually the mother and the sisters and other female relatives, distribute the household chores to best accommodate the disabled individual. Efforts are made to ensure that the disabled individual is accompanied at all times. Though she is made to do all possible jobs, there might be a relaxation in the amount of load she carries, or the time she takes to perform a particular task. Work might also be distributed in a manner where the disabled person shares a greater load of the household chores while the others pursue agricultural labour. She often gets lot of support in her natal home, however, in her marital home she is expected to do all the household chores.

The Brahmin women enjoy a slight advantage because they are not expected to contribute in agricultural labour, unless the household is in a dire economic condition. The Jat and Yadav (other backward castes) women face a greater strain, because tending to the animals is also taken to be a part of the household chores. Most of the disabled women continue to perform almost all the household chores, including fetching water from the well, cutting fodder, cooking, cleaning etc.

New technology like fodder machines often work to the disadvantage of women, since a number of cases of amputation were found due to their use. Also, a number of them reported domestic strain and violence on this account.

The condition of a disabled woman changes with her age and status. In childhood, she enjoys parental care and support but is socialised into her duties of a woman. After marriage, she is

rigorously put to work, where this physical and mental exertion is the most strenuous phase of her life. With age, she gains more social and moral authority in household affairs. With the expansion of the family, there are more supporting hands in terms of sons, daughters, daughters-in-law and grand children, for her social and physical support.

The foregoing analysis, clearly reveals that disability is not the primary disadvantage of women in rural Haryana rather it becomes an additional burden to her marginalised gender position. Disability is engendered in specific ways. Though disabled women are stereotyped as incomplete, they are however, expected to fulfill all the gender duties and primarily expected to be working members of society. It is clearly seen here, that apart from extending support and help in their work, families do not necessarily create special opportunities for them in order to cope better. Management of disability in the context of a community is often related to a crisis situation and it is not in a permanent order. The more permanent form of rehabilitation is centred in the household where a disabled woman lives and with the help of several social mechanisms learns to cope with her state. No professional help is sought in most cases.

STATE POLICY ON DISABILITY

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 provides a broad framework and directions for state governments to make positive provisions for disabled people. The Disability Act, however, does not recognise the social and gender embeddedness of individuals with disabilities in their families and communities (5). The Act broadly treats disabled people as a group without concern for their stratification along caste and class, urban/rural factors. The Haryana state policy paper in fact talks mainly of concessions, scholarships and job reservations. There is no provision for children and those below eighteen years of age.

Women's education is a highly neglected area, opportunities for girls with disabilities to receive an education or to attend training courses are available to only a few. Girls with disabilities among some backward ethnic minorities virtually do not receive any education. Women's work outside the family is still not taken as a viable option. Therefore, these concessions provided by the State government are hardly relevant, largely due to heavy bias of the policy in favour of the urban educated middle class. Since needs of rural disabled women find no place in the policy framework, they remain marginalised.

The role of State agencies like department of social welfare is limited to disbursing of pensions, whereas village level government officials merely help disabled people to get information and access to concessions by the State. NGO initiatives are also few in this area. Owing to pressure of international agencies on the Indian state there is an emergence of number of governmental and nongovernmental agencies focusing on the different types disabilities in last 3 years, located mainly in more prosperous urban areas and very little extension work is being done in rural areas.

CONCLUSION

Women with disabilities in the rural societies like Haryana have specific needs and requirements. They are at a disadvantage on account of gender, caste and disability, and besides being located in a rural area. Unlike in the urban areas though, family and community support are still available to these people. State policies, however, have largely failed to provide for infrastructural support in education, health and agricultural sector. The programmes and policies for disabled people cannot be implemented unless other inequalities like gender, caste and class are also considered. Women with disabilities working in agriculture related work need extra support. Their educational and health needs require prioritisation. Unless state policies are informed by micro level realities and greater sensitivity to cultural nuances, the desired goals will remain distant.

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