

Discrimination against differently abled children among rural communities in India: Need for action

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Abstract

Background: Persons with disabilities comprise at least 4 to 8 percent of the Indian population. Children with disabilities in India are subject to multiple deprivations and limited opportunities in several dimensions of their lives. Their families and caregivers also go through lot of stress and challenges in having a person with disability at home which ultimately leads to grave discriminatory practices towards these children. **Materials and Methods:** The article attempts to analyze and describe the common discriminatory grounds that children with disabilities commonly face from their immediate families and from the larger community through analyzing the filed visit reports of the Basic Needs India Staff providing on job training (handholding support) for the community based rehabilitation workers. **Results:** The case studies describes the various ugly forms of the discriminatory practices seen in the community towards differently abled children, same been categorized as denial of disability, physical restraints, social boycott, denial of property rights, decreased marital life prospects due to disabled member in family, implications on sexuality of people with disability, women with disability, discrepancies in state welfare programs, and problems in measuring disabilities. **Conclusion:** During the last two decades, there has been a growing realization that institutional care for the disabled is not entirely suitable for their individual needs, dignity and independence. A movement towards community based rehabilitation has picked up pace and contribute toward greater independence and self sustainability of the disabled.

Key words: Community based rehabilitation, discrimination, stigma

INTRODUCTION

Despite differing estimates, about 4-8% of the population in India are differently abled.^[1] One in every 10 children is born with or acquires a physical, mental or sensory disability.^[2] These translate into 40-90 million children's, which is a substantial number.^[1] Only 35.29% of all people living with disabilities have access to schools.

Despite improvement in the health care system in the country, the situation of differently abled children

remains deplorable, particularly in rural areas and among the lower socio-economic population. Differently abled children in India are subject to multiple deprivations and limited opportunities in several dimensions of their lives. Some these include, not being enrolled to schools, lower employment rates, limited awareness of entitlements and services available and lack of social welfare support.^[1]

The community-based rehabilitation (CBR) is a dynamic program globally for supporting differently abled children's to lead better quality of life and lead life with dignity, where in their rights are respected and guarded within their own communities^[1] and it creates platform for addressing the discriminatory practices in the community.

MATERIALS AND METHODS

We are working with nongovernmental organizations (NGOs) for including people with mental illness in the CBR program. Reports were generated after every field visit and case studies

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were recorded. We analyzed 2 years of field visit reports from 2007 to 2009. We have used few case studies from the visit reports to describe the prevailing forms of discrimination and stigma associated with disabilities in the rural communities.

Differently abled children are subjected to ugly forms of discrimination

Due to stigma associated with disabilities, families become victims of discrimination and human rights abuse. When poverty, physical neglect and social marginalization intersect, the impact on the disabled can be devastating. Differently abled children's are kept hidden away at their home, denied basic rights of mobility, education and employment. They are viewed as dependent persons.^[3] Such discrimination in some cases starts from the family members and spreads right up to the policy makers and state authorities.^[3] As a result of such discrimination the differently abled children's face chronic ill health, socio-economic burden and destitution. Sometimes it is so difficult to define the marginalization — they are outside the margin or within the community meaning, locked in the rooms, institutionalized, families isolating themselves, enrolling in special schools, not admitting that they have children with disabilities (CWDs), in the hospitals, etc.^[4] Social attitudes and stigma play an important role in limiting the opportunities of disabled people for full participation in social and economic life, often even within their own families.^[5]

Denial of disability

Predominantly in the cases of mental or intellectual disability, the family members are reluctant to accept the disability or refer to it as a physical illness and treatable condition. The pseudo-stigma attached to such disabilities, makes them hide the fact of having a disabled or challenged member at home ultimately leading to social isolation and restrictive behaviors.^[6] There is a fear that they would be victims of disgrace and indignity and thereby family members lose the status or acceptance they enjoy in the community. This denial becomes a hurdle for early identification and treatment.^[7,8] Such persons would be hidden somewhere and they expect, unrealistically, to overcome the situation without realizing the long term consequences of such self-imposed denial.^[9]

Mro K said that “I know my son is having less intelligence, may be some degree of intellectual disability, but I do not want to become member of the disability self-help group because I have two more daughters who need to get married, my association with disability self-help group would be self-certifying of my sons problem”.

Physical restraints

Superstitions prevailing in the communities also play a big role in subjecting the people with disabilities to various

harmful treatments.^[10] The black-magicians and quacks physically hurt people, subject them to food restrictions etc. Claiming to cure the “disability” leading to acquiring disability. Families often lock or chain their children with intellectual disability having behavioral issues, due to helplessness, ignorance and/or under social pressure.

Mrs. S, deserted women, during the care givers meeting expressed that “she need to tie her child with Cerebral Palsy under the tree, whenever she goes for her livelihood” she started crying as she does not have support from her in laws nor from her parents to take care of her daughter with cerebral palsy.

Social boycott

It is preventing of CWDs participating in any social events. Even the family members of the disabled often tend to avoid such social gatherings in shame or fear that someone would ask about their family member with disability.^[11] Differently abled children's are not exposed to any social gathering, nor does our community recognize the need for children's participation.^[12,13] CWDs are not been given opportunities in the areas of education, training and employment. Under these circumstances it is natural that the CWDs feel rejected or unwanted in the society.^[14]

Mother of 6 children, witnessed death of two children with muscular dystrophy, and three more children been diagnosed as having same illness said that “I do not have any interest in visiting relatives nor attending any social gathering (functions), mainly because people feel pity about my fate and would talk among themselves that I am paying for the sins done in my previous life.

Denial of property rights

As per the Indian laws, all kith and kin in the family are eligible to get their share of inherited property, but in reality, persons with disabilities are denied these rights. The siblings take responsibility of providing care and they would enjoy the property meant for the person with disability. Families perceive that CWD are incapable of managing their property, they are denied of their property rights and made dependent on the able-bodied siblings.^[3] Worst of all would be when family members ensure the chronic condition of the disability by denying treatment or other aids, so that the siblings enjoy the property.

During home visit, father expressed that “ my elder son need to take care of my younger son with polio, all the property of mine would go to my elder son and his children”. When asked why don't he share property equally to both the sons? Father said that ‘with his clutches he

cannot do agricultural work-need to depend on others, let that be my elder son’.

Decreased marital life prospects due to a disabled member in the family

In India the elders arrange majority of the marriages. If a family has person with disability, eligible boys and girls finding a prospective spouse is almost next to impossible because of the stigma and the disability being seen as a family illness.^[15] There are occasions where they hide the information and after marriage the problems erupts. It is also common a close relative getting pressurized to marry such a person.^[15]

Mrs. Y, said that “I was married at the age of 13 years, I realized that my husband do not talk nor can listen during my first night. When my son was born, even he did not cry, he also have same problem like my husband.”

Father expressed that “I would settle my son’s wedding with my granddaughter (daughters daughter) for two reasons, my younger son with disability would be taken care, secondly I may not be able to get good proposal for my son as we have a disabled person at home.”

Implications on sexuality of a person with disability

Sexual identity is a critical component of overall personality development and self-esteem, which matures during adolescence. CWDs are at a particular disadvantage in this regard as well. There is a strong attitude of overprotection toward the disabled child. Parents infantilize disabled children and imply that sex is only for the able-bodied and of no relevance to the disabled.^[16] These parental attitudes are transmitted to the child in subtle ways making him/her feel that she/he is inferior and unworthy of love. Parents of CWDs encourage dependence and share the general societal perception of disabled persons as essentially child-like, innocent and asexual.

Father of 18-year-old daughter in the caregiver meeting, while discussing about the marriage for disabled said that “we should not dream about marrying the disabled person, how can they manage their responsibilities and their spouse-it is not irrelevant topic to be discussed in the caregivers meeting.”

Women with disabilities

Due to differential gender-based role expectations, education is not considered a priority for disabled girls. Dropout rates for disabled girls are higher than for disabled boys.^[7] There is an over-representation of disabled boys in education, both in special and mainstream schools. Parents become more protective and restrictive, especially after a disabled girl reaches puberty. Travelling to school

is a huge problem, since, besides transport difficulties, the danger of sexual abuse and violation looms large. There is also the reasoning that there’s little point investing in a disabled girl’s education as they will anyhow never be able to earn.^[17] Unfortunately a girl child with disability is seen as a lifelong burden on the natal family because marriage is not a realistic option. Hence, it is concluded to be economically unsound to invest in her education or vocational training.

When we analyzed the annual report of an NGO, we found that men and women with disabilities identified, enrolled in self-help groups was 60: 40 even though there is no difference in prevalence of disabilities among males and females.

Discrepancies in state program

Children with disabilities come under the purview of the ministry of social justice and empowerment. Some of the issues like prevention and curative aspects are dealt by the health ministry. However, no single ministry has taken the responsibility of meeting the holistic needs of CWDs. Disability continues to fall in the area of “social welfare”. Although efforts are on to bring it into the “rights” perspectives, the thinking process is dominated by the charity mode, while providing services for people with disabilities. As disability being state subject, each state have their own program for persons with disability, but none of the states are able to see in holistic needs of people with disabilities.

Some states have been pro-active in increasing awareness among people with disabilities about commitments and entitlements (Tamil Nadu, Karnataka, and New Delhi) whereas others have lagged in implementing many of the basic entitlements enshrined in the PWD Act of 1995 (Bihar, Maharashtra, Orissa, Uttar Pradesh).^[18] In Karnataka, disability welfare department introduced personnel at the panchayat like Village Rehabilitation Workers, and Multipurpose Rehabilitation Workers to meet the needs of people with disabilities in their respective jurisdictions.^[15] Similar program, are adopted in other states.

Measurement of disability

Worldwide it is accepted to use International Classification of Functioning (ICF), disability and health,^[19] known more commonly as ICF, as measurement for quantifying disability, classification of health and health-related domains. These domains are classified from body, individual and societal perspectives by means of two lists: A list of body functions and structure, and a list of domains of activity and participation. Since an individual’s functioning and disability occurs in a context, the ICF also includes a list of environmental factors. Despite this common

measurement tool for assessing disability are lacking. In some states Individuals with Disabilities Education Act/WHO Disability Assessment Schedule/ICF are used.^[20,21] Due to nonharmonization of assessment tools generating national statistics are difficult.

Challenges in disability sector in India

There are several unmet challenges, which need to be addressed among disability sector in India.

1. Need for dignified life for children and people with disabilities.
2. Need to remove attitudinal barriers among communities and provide rehabilitation of CWDs.^[22,23]
3. Need to improve infrastructures in mainstream schools to make them disabled friendly and train teachers for optimal support.
4. Need to converge between various departments providing services for CWDs.^[24]
5. Need for national harmonization of disability welfare program.
6. Need to give executive powers and necessary resources to the commissioner of disabilities for effective implementation and safeguarding rights of PWD.
7. Need for promoting and monitoring mechanisms for service outreach below district level.^[25]
8. Need to improve effective collaborations between Government and NGO to avoid duplications.
9. Need to adopt to a down to top approach in policy design.
10. Need to improve community participation programs.^[26]

Community care for addressing discrimination against children with disabilities

Disability sector has recognized the importance of dignity, respect, inclusion, participation, equalization of opportunities and empowerment as key issues of rehabilitation.^[6,27,28] The negative attitudes and cultural representations of disability in society are challenged through vigorous awareness-generation and attitudinal change strategies. The issue of disability must consciously move beyond issues of special education and medical rehabilitation and be mainstreamed into other discourses such as the economy, polity, entertainment, sports, fashion and lifestyle.

During the last two decades, there has been a growing realization that institutional care for the disabled is not entirely suitable for their individual needs, dignity and independence. There has been relentless advocacy for community care despite the enormous stigma of having a disabled person at home.^[3,29] In India, where family support is the norm and the only form of support available for thousands of years, community care is been thought as a suitable program for meeting the challenges in the disability sector.

Community-based rehabilitation programs

Community-based rehabilitation is implemented through a joint effort between people with disabilities, their families and communities, and the appropriate health, education, vocational and social services. CBR attempts to combine physical rehabilitation through medical care with empowerment and social inclusion. CBR depends heavily on the development of positive attitudes and approaches among the people involved.^[30] Basic services are provided or facilitated by CBR workers who are minimally qualified, nonprofessionals, but who are highly qualified change agents from their own communities. CBR recognizes that breaking down barriers to inclusion in society is as important to the mission of the CBR program as is the functional rehabilitation of individuals with disabilities. Thus, the universal mission of CBR is to:

1. Enhance activities of daily life of disabled persons.
2. Create awareness in disabled person's environment to achieve barrier free situations around him and help him in meeting all human rights.
3. Create a situation in which the community of the disabled persons, participates fully and assimilate ownership of their integration in to the society. The ownership lies with the affected persons.^[30-32]

Community-based rehabilitation is very appropriate in the Indian cultural setting, where social and community bonds are strong and deep-rooted. The challenge is to harness the potential of these bonds for rehabilitation related social action programs. Nevertheless, CBR programs need to draw their resources from existing community development programs and should integrate with them. The concept and practice of CBR has come down a long road in India. CBR builds on and validates existing indigenous knowledge and information systems, while facilitating access to relevant information and ideas from outside the community.

CONCLUSION

Community-based rehabilitation as a strategy helps to address the ugly forms of discrimination existing in the community. The strategy also focuses on enhancing the quality of life for CWDs and their families, to meet their basic needs and ensuring inclusion and participation in their own development and also participating in the community development. The CBR aims not only creates awareness about the rights of people with disabilities among the community members but also guarantees opportunities for their participation in social activities and also exercising their rights with in their own communities rather than getting isolated into institutions. The CBR has become a multi-sectoral approach that empowers persons with disabilities to access and benefit from education, employment, health and social service.

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