Women with Disabilities in South Asia

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Although disability leads to inequality and marginalisation of both men and women, people with disabilities are not a homogenous group. Women with disabilities from developing countries face certain unique disadvantages compared with disabled men, such as the difficulties in fulfilling traditionally expected gender roles, or the difficulties in accessing rehabilitation services which tend to be dominated by male professionals.

Traditional Gender Roles

For men and women, the expectations of gender roles are different, especially in traditional societies such as those in the Indian sub-continent, where each sex is expected to perform different roles in society, according to different criteria.

In these societies, men are expected to work outside the house, earn a living and support a family, while women are judged according to their physical appearance, and their ability to look after a home, their husbands and children.

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Disability can have a profound impact on an individual's ability to carry out traditional gender roles, particularly for women. As long as a disabled man earns a living, his chances of getting married and having a family are much more than those of a disabled woman.

A disabled woman is perceived as one who is unable to perform her traditional roles of wife, mother and home-maker because of her disability, even if she may be able to do so in reality. For example, if she has impaired mobility she may be perceived to need physical assistance in self-care and grooming, and therefore unable to carry out the domestic and child rearing tasks which require mobility and physical labour. There may be misconceptions about her disability being inherited by her children.

Women with disabilities may also have less access to information and health care services related to their special needs in relation to pregnancy and child-bearing.

In addition, because there are few positive role models for women with disabilities, many myths prevail about them. They have less chances of meeting potential marriage partners, because of restricted mobility and freedom. In a few instances, disabled women may be married off by their families to "wrong" persons, such as men who are already married, so that the families can "get rid of the burden" of caring for them.

Public education and awareness building have a role to play in removing misconceptions about marital, domestic and motherhood roles, and in bringing about changes in attitudes.

Access to Rehabilitation Services

Women with disabilities generally have less access to rehabilitation services than disabled men. In accordance with the traditional social and cultural norms in village societies, many women do not go out of their houses to seek help for health care, especially if the care-provider is a male. Most rehabilitation personnel, including community-based rehabilitation (CBR) workers in developing countries, are men. Thus, even home-based services provided by male CBR workers are out of reach for women with disabilities.

Although women rehabilitation workers are becoming common in the sub-continent, cultural barriers continue to persist, preventing women from taking up rehabilitation work in the community setting, because it involves visits to houses of strangers.

When mobility aids have to be fitted, women with disability experience a unique difficulty. A large majority of people with disabilities in the sub-continent, many of whom are women, require these devices because of polio and other physical disabilities. But since most trained technicians in orthotics and prosthetics are male, cultural taboos prevent women with disabilities from having themselves measured and fitted for mobility aids.

Participation in Community Life

Women with disabilities tend to have fewer opportunities to participate in community life than disabled men, mainly due to cultural reasons. Restricted mobility and absence of access provisions in the surrounding environment can also be a hampering factor, but this aspect is common to disabled men as well.

Their families tend to be over-protective, for fear that they may be exploited in some way because of their disability. As a result, many remain confined to their parental homes, without being able to play even the roles traditionally expected of women in society. This can lead to feelings of isolation, loneliness and low self-esteem among them.

In recent years, many self-help groups and associations of people with disabilities have been established in most countries in the sub-continent, but women are under-represented in these groups. The leadership at various levels tends to be dominated by men. Likewise, women with disabilities are hardly represented in the women's movement that has grown in these countries over the last decade, because they are seen as "different" or "disabled," and not as "women." As a result, the concerns of women with disabilities have tended to remain neglected by both the disability movement and the women's movement.

Exploitation and Violence

Women with disabilities tend to be more vulnerable to exploitation of various kinds, such as sexual harassment, domestic violence and exploitation in the workplace. Because of the relative isolation and anonymity in which they live, the potential for physical and emotional abuse is high. At the same time, their isolation limits the resources they can turn to for help.

Providing better education and employment opportunities will improve the situation of girls and women with disabilities by reducing their dependence on the families. Promoting self-help groups will play a major role in reducing their isolation, providing mutual support, and improving their participation in community life.

Strategies to Overcome Disadvantages

While women with disabilities form an important sub-group in most community-based rehabilitation programmes, usually there are no programmes that are specially tailored to address the unique disadvantages that they face.

However, in some countries in South Asia like Pakistan and Afghanistan, the need for culturally appropriate services have been recognised, and are being provided within the *purdah* culture, for women with disabilities and for female carers of children with disabilities. These programmes take special care not to contradict the prevailing cultural norms of behaviour.

Many of the disadvantages are related to traditional social and cultural perceptions and beliefs. In this context, CBR approaches may have to address some of the complex cultural, economic and social factors that are related to expectations from traditional gender roles.

Public education and awareness building have a role to play in removing misconceptions about marital, domestic and motherhood roles, and in bringing about changes in attitudes. On the other hand, issues regarding fertility and childbirth may need specialist referral support from medical services.

Efforts have to be made to build up positive role models of women who are able to fulfil their family roles and contribute to the family economy. CBR programmes can train young women with disabilities through home-based training or through peer support groups to focus on grooming, self-care, domestic, physical and social skills, in a one-to-one setting or in groups where feasible.

CBR programmes will need to explore how best to support women with disabilities in carrying out household tasks, through simple adaptation of the home and the surrounding environment. Assistive devices like low trolleys are appropriate in rural households where many tasks like cooking and cleaning tend to be performed at the ground level.

Lack of access to rehabilitation services by women with disabilities can be overcome by training more women community workers to provide services, particularly in fitting appliances. Most training institutions in orthotics and prosthetics also have not recognised this problem sufficiently. However, of late, there have been innovative attempts to address the issue by training women with disabilities as technicians to provide mobility aids for other women.

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It can promote economic self-reliance if they have access to income-generation activities through savings and credit and other schemes. In addition, self-help groups can educate women with disabilities about their rights and opportunities, and greatly reduce the chances of exploitation and violence against them.

CBR programmes need to sensitise disability rights organisations and women's groups to include the concerns of women with disabilities in their agenda. As an initial strategy, it may be helpful to promote groups of women with disabilities, to educate them about their rights, and to build up their capacity for advocacy and lobbying. Alongside, efforts will have to be made to include women with disabilities in the larger disability rights groups and in the women's movement.

To be a Girl/Woman With Disabilities

What does it mean to be a girl/woman with a disability? What special discrimination, hardship, abuse and pain are girls/women with disabilities made to bear? What must change in order for them to be seen and treated as girls and women and finally as human beings?

Over the last 40 years, a great many girls and young women have passed through the Association of People with Disability (APD). While some of their stories are beautiful and triumphant, some others are tragic. Family and community attitudes are the common thread running through these stories, and often, these attitudes can become more emotionally and mentally debilitating than any physical disability can ever be.

Telling some of these stories is meant to serve as an introduction to a larger discussion of issues specific to girls and women with disabilities in our society and to the question of whether there are gender-specific disability issues that require a gender-specific response and approach.

Independent Group Living

In 1995, APD and Mobility India (MI), an organisation that develops training programmes in the field of prosthetics and orthotics, made an agreement to enrol a group of nine young women with disabilities in a programme to provide intensive training in prosthetic/orthotic skills for a year. They would then be assisted in setting up a co-operative mobility aids workshop in Bangalore city in Southern India.

A key strategy in the programme was the experience of independent group living, in which the women were encouraged to live together as a group while training and working.

The year that followed brought tremendous changes for these women. APD decided to study these developments, in collaboration with Queen's University, Canada, to learn as much as possible about this new approach to women's training.

The nine women were aged between 16 and 25 years, with a mobility or/and communication impairment, but able to use their upper body and arms (these were the criteria for selection to the training). They were mostly from rural areas, small towns or Bangalore city, far enough to be inconvenient to travel home each day. In addition, all came from poor families, except for one woman.

The research studied the effect of the training experience and more significantly, the independent group living, on the personal, social and professional development of young women with disabilities. The study also examined other conditions in the women's lives to illuminate the complexity of individual development. Individual audio-taped interviews were conducted with the participants on two occasions, separated by approximately eight months. Other group discussions were also video- and audio-taped. The

data, in three languages, were transcribed, translated, coded into categories and analysed. The primary analysis centred on six of the women who lived together in a hostel. Secondary attention was given to the three women living outside the hostel.

The study reveals variations in the young women's development in their families, as individuals, as a group, in social awareness, and professionally over the course of the two-year training initiative. The factors involved were their prior level of personal development, family background, experiences while training, and living situations.

Overall, however, the women who lived together in the group hostel throughout the duration seemed to have a relative advantage in their ability to develop skills, mature attitudes, and independence. Those who lived with their families or outside of the APD/MI hostel appeared to benefit less, although they did develop in other significant ways as a result of the vocational training programme.

The Women's Movement and Disability Issues

A great deal remains to be done to put the issues of women with disabilities on the agenda of the women's movement. Some important points need to be discussed and understood:

- Women are involved in multiple home based-roles.
- In a negative family environment, women with disabilities are considered a burden. They are not made aware of their abilities, only of their disabilities. They lack self-esteem and self-confidence. Geographical distance and mobility problems restrict them from being involved in groups.
- Illiteracy and ignorance in the family prevent them from learning about different movements and the opportunities that might be available by networking.
- Family support and help are usually available whenever there is an immediate medical or monetary advantage.
- There are good examples of successful income-generating programmes for women with disabilities.
- Documenting these examples and creating awareness through TV and other media would help in replication to suit local needs.
- An important factor would be facilitation by either an individual or an NGO to get women with disabilities into the economic mainstream.
- Women with disabilities need to become part of the women's groups. Savings and credit groups are gaining credibility and are a good entry point for women to network.
- NGOs need to create a common platform where ideas, strategies (both successful and unsuccessful) for health, income generation etc., can be shared.
- Data collected on different aspects need to be systematically analysed and made accessible as tools for grassroots NGOs and groups in the area of health, income generation and education.

Websites on gender and disability:
Disabled Peoples' International, Women's Committe, http://www.dpi.org/women.html
Disabled women on the web, http://www.disabilityhistory.org

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