Developing the Gender Dimension in India's Disability Rights Movement

By Sakshi Broota Hosamane

isabled women's rights! What rights are we talking about? Has the women's movement in the world had any impact on this marginalised group of disabled women? Has the disability rights movement in the world made any difference in their lives? They are overprotected, discriminated against, exploited and marginalised. The rights movement of disabled women will require a lot of nurturing, support, positive discrimination, equal opportunities and then empowerment and leadership! It is a long way ahead.

Both disability and gender are physical constructs that totally ignore the person. 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. But yes, being a disabled woman fits well into the stereotype of passivity and dependency!

India is a vast country with a population of more than one billion and nearly 70 million people with disabilities. About 48 percent of them are women.



World Disability Day, 3 December 1998, New Delhi. Disabled women activists in a rally organised by the National Centre for Promotion of Employment for Disabled People

NCPEDP

Women in India have been struggling to get their rights. The women's rights movement itself is in its initial stages. They are fighting all the stereotypes that have been ingrained in the national psyche.

We glorify the *Sati*, the widow who jumps into the burning pyre of her husband, not because of love or devotion, but probably because she sees no hope without her male counterpart! We then build temples in her name and worship her for her devotion and courage!

Then there is the dowry system, a greed for material things, that makes us burn the wife if she fails to bring enough money with her in the marriage! And what exactly defines enough? The dowry system is so deep rooted that the girl is always seen as a liability, a burden! Even before the birth of a child, we go in for a gender test and get the female foetus aborted. We find innovative methods for female infanticide. In a household, the last priority is assigned to the education and even the proper nutrition of girls.

The Status of Girls With Disabilities

In a society where women have low status, one can imagine the reaction to the birth of a disabled girl child. A newborn with Spina Bifida was starved to death by her parents and family in Haryana despite the intensive counselling, support and medical assurances of an NGO and the doctors.

Infanticide of the disabled is widespread, with baby girls being at higher risk. The medical, nutritional, educational, emotional, psychological, sexual, recreational and employment needs of a disabled daughter are the last in the list of priorities of a family. She is also more vulnerable to physical and mental abuse. Being a woman, belonging to a poor family and having a disability, is a triple disadvantage that she has to withstand!

Let us now consider the quality of services available to a girl with disability in India. A research study was conducted in 1998 by the National Centre for Promotion of Employment for Disabled People (NCPEDP), gathering data mostly from non-governmental organisations providing services to people with disabilities.

The percentage of girls with disabilities going to school (38.34 percent) was found to be much lower than the percentage of boys with disabilities (61.66 percent) getting an education! In India, only 54.16 percent of all women are literate. With such a high rate of illiteracy among women in general, the chances of girls with disabilities of getting an education are extremely poor. Thus, many women with disabilities spend tedious hours employed in cottage industries, in work for which little education is necessary, whereas with a proper education they could be lawyers, administrators, etc. The NGOs themselves are not giving adequate attention to the issue.

Even when it comes to vocational training, the study showed that out of the 5,618 people with disabilities enrolled in vocational training in one year in the respondent NGOs, only 35.85 percent were women. It is probably because the traditional role of women is to be at home, looking after the household. It is not considered important to give them technical and professional training, and more so if they are disabled. Out of all the people with disabilities placed in jobs in two years, only one-fourth were women.

And because very few opportunities exist for the woman with disability for productive work or gainful employment, she is perceived as posing a greater burden for the family. With their enforced financial dependency, they form the most vulnerable group in the world.

In another finding, the research study showed that only 28.95 percent of girls get hostel facilities in the respondent NGOs. More than 70 percent of the beneficiaries of hostel facilities are men. Another startling finding was that out of the total number of beneficiaries who receive

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aids and appliances from these organisations, only 27.25 percent were females.

The problems that confront women with disabilities are even more severe in the rural areas. The inadequate or total lack of access to information, health care and rehabilitation services is further compounded by much higher illiteracy rates, longer distances to services and facilities, if they exist at all, and more severe conditions of poverty than in urban areas. In addition, traditions and prejudices that discriminate against women are more likely to be widely practised in the rural areas.

In a pilot project by Disabled Peoples International, Pakistan, a baseline survey was conducted of 500 households of a colony in Karachi in 1998 to identify the target group of women with disabilities whose status, socio-economic problems and community attitudes would be studied. Among the 20 women and girls with disabilities, 90 percent were illiterate, 90 percent had received no skills training, and not a single one had knowledge of any welfare organisation or agency. The family and the women themselves

were not aware of the various sources of help in the community.

Why are services not reaching the girls and the women? Is it because parents do not approach the NGOs for the girl child? Is it because the NGOs are not giving adequate attention to the issue in a pro-active manner?

Unequal Participation in Decision-making

Decisions regarding the lives of women in India are generally taken by their fathers, brothers or sons. And again, it is more so for women with disabilities.

The National Centre for Promotion of Employment for Disabled People (NCPEDP) study shows that although women formed more than 50 percent of the professional workforce in the 119 apex-level NGOs, the percentage dropped to a mere 28.45 percent at the decision-making level. The data regarding women with disabilities is even more startling. Their percentage amongst professional staff was found to be as low as 4.47 percent! The figure dropped further to 3.71 percent when it came to their numbers in the decision-making bodies of these organisations!

Eunice Fiorito and Jim Doherty discuss this issue in detail in the book *Women and Disability*. According to them, the male bias, which pervades rehabilitation and vocational training schemes for people with disabilities, is also clearly reflected in male domination of decision-making in rehabilitation organisations. Women who choose rehabilitation as a professional field, somewhere along the line, become abruptly conscious of this situation once they reach a certain level in the hierarchy. They often join as volunteers and are very soon told how good they are with their clients. As a result, women tend to be concentrated in low and mid-level positions.





National Disability Convention, 2-3 December 1998, New Delhi. Panelists of the session on 'Women and Disabilities' organised by the National Centre for Promotion of Employment for Disabled People

The rehabilitation system is deprived of the rich experience women have in this area, as they are not allowed a fair share in programme direction and leadership. If it is valid to say that women are especially effective in working with people, then the system loses a great deal when the ability is confined to lower levels.

Women with disabilities—are discriminated against not only by men—whether disabled or not, but also by non-disabled women themselves, and even in the disability sector itself. It is this power equation that needs to be changed.

Changing the Power Equation

We now consider disability as a development issue. As Peter Coleridge mentions, disability is a development issue because it dehumanises. It dehumanises because, on the practical level, disabled people are left out of development planning and their voice is not heard in decision-making circles. On the

philosophical level we know instinctively that if we deny the humanity of another, we ourselves are dehumanised.

So when we talk of empowerment, we are talking of a change in power relationships from which everyone ultimately benefits, the disabled and non-disabled women and men. There is not much point in empowerment if it means that the oppressed become the new oppressors.

The Disability Rights Movement in India

The disability rights movement in India started only in the early 1990s. The launch of the Asian and Pacific Decade of Disabled Persons in 1993 gave a definite boost to the movement. In that year, the Indian government organised a national seminar in New Delhi to discuss the various issues concerning the disabled citizens. The main need that emerged from the seminar was for a comprehensive legislation to protect the rights of persons with disabilities. However, it was

only after intense lobbying of the Disabled Rights Group (DRG) that the crucial legislation was passed in 1995. In a single day, both Houses of Parliament passed the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act. This was a landmark in the disability movement in India.

The DRG was a group of like-minded people, mainly persons with disabilities, who came together in 1994. They included Mrs. Anuradha Mohit, a woman with visual impairment, who went on to become the first woman Deputy Chief Commissioner for Persons with Disabilities in the country. Probably for the first time in India, persons having different disabilities joined hands to fight for a larger cause, ignoring their individual differences. It was the beginning of a movement that was to change the course of the lives of 70 million disabled citizens!

Disabled Women Activists: a Few Exceptions

In 1997, NCPEDP organised the National Advocacy Workshop on Speedy and Effective Implementation of the Disability Act. This workshop in New Delhi led to several similar events being organised by other NGOs at the State level. The most heartening development in India was the emergence of several advocacy and self-help groups in different parts of the country, led by people with disabilities. A few women leaders with disabilities had started emerging.

The movement was further strengthened when NCPEDP launched Disability 2000, a national campaign in which it collaborated with disability rights organisations, advocacy groups and local governments and formed the National Disability Network. In each of the 32 States and Union Territories, a partner was identified, who would work together on various disability rights issues affecting the nation.

The national disability network saw the emer-

gence of various women with disabilities as leaders like Jayshree Raveendran, Meenu Bhambhani and Sruti Mohapatra. Meenu Bhambhani has now become the Deputy Commissioner for Disabled People in the State of Rajasthan.

The reactivation of Disabled Peoples International in October 2000 also saw the active participation of disabled women from all over the country. Four of the eleven members of its Executive Committee elected in the National Assembly were women.

Moving Forward

The disability rights movement is very strongly supported by mothers of children with disabilities and by female professionals. However, this is just the beginning. Much more is needed.

Women with disabilities need to be more proactively involved. Organisations working on women's issues can play a major role in taking the disability movement forward.

Much however, depends on how soon organisations realise the immense potential in the strength of women with disabilities and their capabilities in taking the disability rights movement of the country forward. What is needed is introspection, education, awareness, and more and more role models to break the barriers of attitudes and stereotypes.

Sakshi Broota Hosamane is actively involved with Disabled Peoples International India. She coordinated the research study mentioned in the article, on the role of NGOs vis-à-vis the employment scenario in India with reference to people with disabilities. At present she is the Project Co-ordinator at the National Centre for Promotion of Employment for Disabled People (NCPEDP) based in New Delhi. She has also worked with the Spastics Society of Northern India where she received training in basic developmental therapy, and with Deepalaya, working with persons with disabilities in the slums of Delhi.