

# Equity to women with disabilities in India

(A strategy paper prepared for the National Commission for Women, India)

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## Introduction

Women with disabilities are multiply disadvantaged through their status as women, as persons with disabilities, and majority numbers as persons living in poverty.

In May 2002, ESCAP adopted the resolution “Promoting an inclusive, barrier-free and rights-based society for people with disabilities in the Asian and Pacific region in the twenty-first century”. The resolution also proclaimed the extension of the Asian and Pacific Decade of Disabled Persons, 1993-2002, for another decade, 2003-2012.

“There are currently some 5.6 billion different people in the world. Some have a difference called disability.” — Disability Dimension in Development Action: Manual on Inclusive Planning United Nations. The 1970s marked a new approach to disability. The concept of human rights for disabled persons began to become more accepted internationally. The Declaration on the Rights of Disabled Persons, adopted by the General Assembly on 9 December 1975, encouraged national and international protection of the rights of the disabled. Recognition was given to the fact that disabled persons were entitled to the same political and civil rights as others, including measures necessary to enable them to become self-sufficient. The declaration reiterated the rights of disabled persons to **education, medical services, and placement service**. It further recognized their right to **economic and social security, to employment, to live with their families, to participate in social and creative events**, to be protected

against all exploitation, abuse or degrading behavior, and to avail them of legal aid. Realizing the need to promote the full participation of the disabled in the social life and development of their societies, on 16 December 1976, the General Assembly declared the year 1981 International Year of Disabled Persons (IYDP), stipulating that it be devoted to integrating disabled persons fully into society.

"Around the world, women make up just over 51% of the population. Women with disabilities are the most marginalized in Indian society. They are deprived of political, Social, Economic, and health opportunities. The problems of women with disabilities become very complex with other factors such as social stigma and poverty. Women with disabilities have been largely neglected when it comes to research, state policies, the disability and women's movements, and rehabilitation programmes, and this has become a widely accepted fact in recent years. Also, “due to numerous societal standards, they continue to be left out of the decision-making

According to census 2001, there are 2.19 crore persons with disabilities in India who constitute 2.13% of the total population. This includes persons with visual, hearing, speech, locomotors and mental disabilities. 75% of the persons with disabilities live in the rural areas, 49% of the disabled are literates and only 34% are employed. The earlier emphasis on medical rehabilitation has now been replaced by the emphasis on social rehabilitation. There has been an increasing recognition of abilities of persons with disabilities and emphasis on mainstreaming them in the society based on Capabilities. The government of India has enacted 3 legislations for the persons with disabilities viz.

processes. This reality is especially true of women with disabilities in cultures where the role of wife and mother is considered to be the primary role for a female." Irene Feika, Deputy Chairperson of Underrepresented Groups, Disabled People International.

Although this may seem to be of minor importance, the pattern of ignoring and isolating disabled women is repeated throughout national and international publications and websites of people with disabilities.

## Education:

**Women with disabilities do not form a homogeneous group.** For example, the mentally ill and mentally retarded, the visually, hearing and speech impaired and those with restricted mobility or with so-called "medical disabilities" all encounter different barriers, of different kinds, which have to be overcome in different ways.

Throughout the Asian and Pacific region, public attitudes are changing regarding the value of educating and training women with disabilities. The prejudice surrounding their ability and value continues to perpetuate the view that educating them is futile. Opportunities for girls with disabilities to receive an education or to attend training courses are available to only a few. For example, the then International Council on Education of the Visually Handicapped estimated that only two per cent of visually-impaired children in developing countries receive any formal schooling. In China, where there are some 5 million disabled children aged between 7 and 15 years, only 6 per cent are enrolled in schools. It is reasonable to expect that the number of girls included in those estimates is significantly less than half.

One report on women with disabilities in the Raichur district of Karnataka State, India, indicated that the literacy rate of such women was 7 per cent compared to a general literacy rate for the State of 46 per cent.

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-Irene Feika, Deputy Chairperson of Underrepresented Groups, Disabled People's

## International

Traditionally, schools for disabled children are most commonly segregated institutions for those with visual, hearing and intellectual impairments. Girls with extensive physical disabilities have even less opportunity for schooling. The few special schools, concentrated in large cities, have residential facilities; the residential system discriminates against access by girls. So long as education for people with disabilities is largely confined to a segregated system, only a few disabled girls and women will be benefited.

Evidence also indicates that a predominantly segregated school system for disabled children is unlikely to be adequate and accessible for this group of children, and that it is also educationally inferior. A study of disabled girls, both in special (usually residential) schools and in regular schools, found that those in special schools were less proficient in basic literacy and numeric skills, had lower expectations about their own capabilities and lacked confidence in social settings. Thus, it is obvious that mainstreaming girls with disabilities into society must begin at school.

Education is the key to the advancement of women and girls with disabilities as it provides access to information, enables them to communicate their needs, interests and experiences, brings them into contact with other students, increases their confidence and encourages them to assert their rights. Without a basic education, their chances for employment are almost nil. Hence, there is an urgent need to consider policies and programmes that will place greater emphasis on the participation of women with disabilities in the mainstream education system. Certainly the challenges are great. *In the year 2003 Ministry of social justice and empowerment has introduced novel scheme of providing scholarships for people with disabilities to pursue higher education. The important feature of this programme is it reserves 50% of scholarships for women with disabilities.*

### Employment:

**Women in general face discrimination in employment.** For women with disabilities, this discrimination is far greater. In situations where there is high unemployment, opportunities for remunerative work tend to be severely limited. When disabled women do find jobs, they receive considerably lower wages. For example, even for an industrialized country, studies have shown that a disabled woman working full-time earns only 56 per cent of the salary of a full-time employed disabled man. In fact, disabled women earn the lowest wages compared to disabled men or non-disabled women.

Furthermore, in addition to the prejudice and discrimination barrier, the inaccessibility of the physical environment (e.g., buildings, roads transport and toilet facilities) is a serious obstacle to disabled women working outside their homes.

Since the lack of mobility limits disabled women from obtaining raw materials and marketing their products themselves, engaging in piece-work is the most common form of income-generation available to them. Examples of piecework by disabled women and girls include labour-intensive and poorly paid activities such as weaving, sewing, basket making, the assembling of toys and production of handicraft items.

#### CBR-Sustainability

After five years of CBR in a village the community was asked to become self sustaining. They were very angry as the NGO said they have no option to leave them (high and dry) as there was no more funding. Community did appreciate the good work done by the NGO. But the local wisdom of the people of the community said something else. They felt if the NGO has shared in the beginning that the community has to become self sustaining after sometime they would have planned and managed CBR in a different way at one fourth of the cost and half of the time and using methods suitable for the village community and its culture!

The materials are delivered to their homes and finished products are collected by agents. There is no legal or social protection. Disabled women and girls may be exposed to unsafe materials and subjected to excessive hours of work under harsh conditions. **Even where disabled women have jobs, their rights as workers may be overlooked. Faced with discrimination, little job mobility and few skills, disabled women workers may be forced to endure oppressive working conditions.**

### Stakeholders speak on CBR- Heart - Here is what they said....Case study of Sharada

I was born without any disability in a village near Chinthamani in the Kolar district of Karnataka. In my family I was the eldest of all the sisters. One day, when I was thirteen years old I was caught in a traffic accident and my spine got damaged. All of a sudden my life changed completely, I could barely walk and not go to school anymore, as it was too far away. Even though I really wanted to continue studying I couldn't because the school had no toilet and with the bladder problem resulting from the accident it became impossible. My teacher suggested that I could continue my studies in the National Open School, and so somehow I managed to complete 12th standard. Sometimes I don't even know how I did it, as there were so many problems I had to face. The classes and exams held for me were conducted on the third floor of the building, so my father had to carry me upstairs.

I started to feel like a burden to my father and the rest of my family and when I noticed that I started to gain weight and how difficult it was for my father to carry me, I quit my studies and started looking for a job. I really wanted to contribute to the family as the need for some extra money was great, but I ended up with nothing, it was impossible finding any work. No skills' training was available in my village and everybody was self-employed so there was no need for me. The government had reservations for disabled people like me, but there were no recruitment policies and no jobs available. It is so, very sad that I could neither continue my studying nor get a decent job; I started rolling "agarabhatis".

My mother died two years ago and now I live with my father. My two younger sisters have got married and are living happily with their husband's families. I survive on the disability pension that the government provides, but it is a very small amount and the money never reaches me on time.

Life has been so unfair to me, the only time I feel happy is when I play with my nieces and nephews, but even then I become sad because I want to have children of my own. I feel depressed when I see other women, no one will ever love me and I will never get married. Instead the people in my village look down upon me and call me names.

All I wish is that women like me should be able to finish their studies and then

### Social exclusion:

Women with disabilities, especially from rural areas, are likely to be left out of family interactions and community activities. In addition, they are exposed to social stigma and stereotyping within their community, which leads them to feel devalued, isolated, and ashamed.

A study conducted (Emily.et.al 2002) demonstrated culturally appropriate form independent group living to have a beneficial impact on the women's levels of sociability and their confidence to venture out in public or to social functions.

Living among other women with disabilities and in a non-judgmental environment helped in raising self-esteem and in developing social skills. All of the women who resided in the group house felt accepted, sociable, and confident to venture. Together, confidence in their abilities was strengthened and they could carry out their business with mutual support. Thus, independent group living helps in Social Development (Increased sociability, public confidence and ability to support) and Personal Development (improved self-image, independence and professional motivation)

Despite the most optimistic outlook for change in employment opportunities for women with disabilities, the present reality is that the best hope for productive **work may lie in self-**

**employment or group employment probably on a cooperative basis.** While numerous projects exist which provide skills training for disabled women, they frequently fall short of meeting the ultimate goal of providing a means of adequate income.

A critical need remains for programmes such as credit schemes, entrepreneurial skills training and advisory services for disabled women and **to develop a niche in the market for the goods and services they can offer. For women with disabilities in rural communities more attention has to be paid to developing options for productive and remunerative work, and the requisite training.**

Incest is very common in India. Women with disabilities are the easy prey for the exploitation within the family. We also do not discuss these issues in public. The large demand of parents of mentally retarded daughters for compulsory sterilization speaks volumes. There is a need to tackle this issue by creating awareness and strengthening the existing laws to punish the offenders severely.

Abandoning girls with disability is another issue that needs strengthening. The measures required are to prevent abandoning by creating awareness and to improve homes for them, which are often the centers of exploitation.

Adoption of children with disabilities is another issue, without which these children stay homeless. There is a need to start SOS homes for these children instead of allowing them stay in orphanages forever.

Apart from economic independence, work is an essential means of enabling a person to develop a sense of identity and self-esteem. Thus, **gainful employment** is an important means of promoting the social integration of disabled women. *From the perspective of the State, investing in the education and training of women with disabilities, and promoting opportunities for their employment, is sound economic and social policy. Gainfully employed women with disabilities contribute actively to the economy (Hidden sisters, 1995)*

## **Health:**

Health problems of older women will become an increasingly important issue in developing countries partially because of the sheer increase in absolute numbers. Today, two out of three of the world's 469 million women older than 50 already reside in developing countries. By 2020 three out of four will reside in developing countries, an absolute increase of 408 million.

It is imperative to keep in mind the heterogeneity of developing countries. **Aging and disability have close association. Older women constitute a distinct population that requires interventions very different from a population of younger women, who need an emphasis on maternity care. Obviously health problems of women are not homogeneous and cannot all be addressed through the traditional maternal and child health services.**

The pattern of the health problems older women face reflects to a large extent the level of development of their region and country. Additionally, a woman's well being is a result of all her previous experiences, including factors such as urban or rural residence, marital status, number of children, education, income, and nutrition. Furthermore work has a tremendous

influence on women's physical and mental health. Indeed, occupational health problems are emerging as a result of the increased number of women in urban industrial jobs.

Two other issues that emerge as critical, but that are rarely discussed by disabled **women's groups are terrorism /riots and its impact on disabled women and AIDS among disabled women.**

AIDS poses a bigger threat to disabled women. It is estimated that as much as 10 percent of the population in many Asian countries is already infected by AIDS. Given the extremely poor health care and lack of appropriate AIDS prevention information received by women with disabilities all over the world, the AIDS rates are expected to be very high.

Policy directions and programs towards prevention of mortality and morbidity among women older than 50, and major causes of disease burden are required.

### **Advocacy:**

In general, the burden of work for women with disabilities falls squarely on the shoulders of disabled women themselves so that disabled women's issues can be addressed and information and resources shared. Women with disabilities have been an integral part of the history of movements for disability rights. In spite of their contributions, however, disabled women's issues were largely ignored and their accomplishments minimized.

In addition, within disabled women's organizations the focus seems to be on organizing and advocating for women with physical or visual disabilities. **There is very little attention paid to women with other disabilities such as women with mental retardation, cerebral palsy, and mental illness even to the point of lack of access to these organizations.**

With the realization that their future lies firmly in their own hands, women with disabilities around the world are focusing on their enormous strength and emerging resources to directly change the picture. Since the beginning of this current movement for Independent Living, women with disabilities have been active organizers and advocates for the rights of all people with disabilities.

A BBC report states that "War, poverty, lack of health care and lack of decent working conditions and safety regulations are the fundamental causes of most disabling impairments. The problem is circular: poverty means few resources; few resources perpetuate poverty at the same time as they cause disability."

Disabled women in India face numerous challenges. "In the absence of well coordinated government policies aimed at integrating disabled people in mainstream activities, disabled women live under extremely difficult conditions, for not only are they women but most of them are in the rural areas. The women with disabilities in India are discriminated against equality. Discrimination deprives disabled women of vital life experiences, and therefore by denying them the opportunity to participate fully in community affairs they are deprived of equality of opportunity."

Without effective remedial action, the consequences of disability will add to the obstacles to the development of women with disabilities. Hence it is essential that we include immediate, adequate and appropriate measures for the equalization of opportunities for girls and women with disabilities in the following areas:

<p><b>Parents of children with disabilities</b></p>	<ul style="list-style-type: none"> <li>• We need good education for children Good medical facilities</li> <li>• We need assistance in the care of children when we go to field to work</li> <li>• We need baby sitting centres for our children as no crèche admits our children</li> <li>• We need a good hospital closer to the community for professional advice about our children, regular check ups, assessments aids and appliances and repair facility</li> <li>• We need free transportation to take our children to hospital and school.</li> <li>• We want anganwadi centers(pre schools run by government )to admit our children and train them.</li> <li>• We want flexible working hours as we cannot leave our children for long hours under other's care</li> <li>• We want income tax exemption as we have additional costs for health, education and</li> <li>• We need toilets suitable for our children in school otherwise we cannot send them to school</li> <li>• We want free medicines</li> </ul> <p><b><u>Final word</u></b> We want funds and our own organizations to manage our affairs</p>
<p><b>Young people with disabilities</b></p>	<ul style="list-style-type: none"> <li>• we need training and jobs we can do</li> <li>• we need recreational facilities</li> <li>• we need awareness in the community about our Rights</li> </ul>
<p><b>Women with disabilities</b></p>	<ul style="list-style-type: none"> <li>• We are third class citizens. We hardly exist for general society. We need 'respect' in the community.</li> <li>• We want to marry and be happy in our homes</li> <li>• We need money to buy land and build accessible houses and money to build toilets in our houses</li> <li>• We want jobs we can do.</li> </ul>

	<p><b>Final word</b> We want funds and our own organizations to manage our affairs with the support from government</p>
<b>Senior citizens with disability</b>	<ul style="list-style-type: none"> <li>• We want decent pensions to take care of ourselves.</li> <li>• We want free medical facility near the Community.</li> <li>• We want home based care givers we want help in day to day work like buying vegetables etc.</li> </ul> <p><b>Final word</b> We want funds and our own organizations to manage our affairs with the support from government.</p>
<b>Local governments and community</b>	<ul style="list-style-type: none"> <li>• We have no idea what we can do</li> <li>• We want guidelines and budgets from government resources as to what to do in rights based CBR</li> </ul>

### Some of the key areas of concern to disabled women include:

- **Awareness:** to highlight the plight of women with disabilities, especially in rural areas.
- **Education:** Disabled girls are less likely to attend school than disabled boys.
- **Training:** Professional and Vocational- limited access into training programmes.
- **Employment:** Disabled women are less likely to be granted loan facilities or be employed.
- **Violence:** Women and girls with disabilities are particularly vulnerable to violence, especially within the home situation. Sexual abuse is quite common, especially among women with mental and/or hearing disabilities. Abuse by physicians and caregivers, e.g. forced sterilization, is common.
- **Health services:** Refusal of health workers to advise disabled women and girls on appropriate family planning services and methods
- **Empowerment**

### Some of the needs to be addressed:

- Public education and awareness programmes to promote positive perceptions on the potential of disabled women in society.
- Career-oriented education for disabled women.
- The right to control their own fertility.
- Legislative provisions to promote and protect the human rights of disabled women.
- Accessible, well-equipped resource centres and clinics that will provide information on issues affecting disabled women.
- Provisions in the social security system that will deal specifically with the needs of disabled women, especially young disabled mothers.

- Development of specific measures to redress the social and economic exploitation of disabled women in rural areas and informal settlements.

Among approximately 40 countries in the Asia and Pacific region, 25 countries already have self-help organizations of disabled persons. Twenty of these organizations are nation-wide cross-disability organizations.

One Indian disabled woman frames the situation this way: "The issues of women with disabilities are same as other women in India plus more [complex] as they lack access to education, resulting in all the problems linked with illiteracy such as poverty, lack of decision making power and lack of available options. Because of disability they are not considered to be women who can fulfill the traditional roles of Indian women. Worst of all I have seen that most women with disabilities who are leaders themselves really believe in this notion. So the issue, which needs attention, is lack of recognition of rights. The concept that a woman has rights is well adopted by the women in India, however not by women with disabilities."

An Indian disability activist says: "In a society where the practice of gender inequality has become a convention, disabled women are the most isolated and marginalized. After years of struggle, disabled men have succeeded to some extent in making their voice heard. A special initiative is required to make sure that disabled women are also heard."

### **Tools for Empowerment:**

Non-governmental organizations can play a powerful role in counteracting the cycle of oppression through which disabled women are denied access to support and resources that would empower them to reach their potential and contribute to the community.

The need for funding support presents a critical challenge for women with disabilities. One survey respondent summed it up: "there is much to be done and not enough resources to do it with."

#### **Isn't this a special need?**

Senior girls in a school in Manvi in Karnataka do not go to school for five days every month because the school has no toilet! But they somehow manage!

Kamala in Pavagada in Tumkur district says she uses the toilet of a house near the school.

### **Some of the recommendations to NGOs to more effectively include women with disabilities:**

- Disability organizations, leadership training projects and independent living services must collect data on involvement of women and girls with disabilities and conduct specific outreach efforts to include women with disabilities.
- Mainstream organizations must support and work in partnership with organizations led by women with disabilities.
- Women with disabilities must be involved in all policy and decision making processes, and at every level of the projects: as staff, volunteers, participants, and evaluators.
- Education, vocational training and rehabilitation programs must include women with disabilities, to prepare women and girls for careers and gainful employment.

- Rehabilitation and adaptive technology must be available for women with disabilities, and women with disabilities must be involved in the development and production of adaptive devices.
- Health service personnel must be trained to offer informed and sensitive service and education addressing the health needs of girls and women with disabilities. Non-governmental organizations must work with women with disabilities to pressure governments to effectively implement the recommendations, which have been made over the years by various UN bodies and non-governmental organizations, particularly at the Fourth World Conference on Women in Beijing in 1995.
- Entrepreneurship development cum pre vocational training cum Vocational Training cum placement multipurpose centers to promote self and group employment (with a cross disability approach) for women need to establish at least one in each Taluk/block level with hostel facilities. After successful training and placement in the open employment/self or group employment independent living houses need to be supported by the government. Such houses should be identified from the government housing projects and houses in the ground floor with accessibility should be provided in addition to providing loans to purchase accessible taxi/auto rickshaw/cycle rickshaws for commuting to the work place. NGO's who are interested in building such housing facility for workingwomen with disabilities need to be supported with grants.
- Women with disabilities working in the agriculture related work needs extra support..

### **Other Recommendations:**

Aligning with the **Biwako Millennium Framework** for action: towards an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific

### **The Commission has to set the following targets:**

1. By 2005, Governments should ensure anti-discrimination measures by forming special task forces to protect women with disabilities.
2. By 2005, self-help organizations adopt policies to promote full representation of women with disabilities,
3. By 2005, women with disabilities should be included in all the policy making bodies from panchayath to parliament levels
4. Set up state wise task force to prepare white paper on the quality of services available for girls/women with disabilities and all the institutions managed or supported by the government and other donors.
5. The Commission should insist on 50% Reservations for girls with disabilities in schools and colleges (out of the existing quota) as well as 50% of the total of job opportunities, reserved for persons with disabilities, ranging from a minimum of 30% and to a maximum of 50% as per the PWD Act, 1995.

6. In order to improve the quality of life of women with disabilities in the rural and urban India, district CBR Societies for women with disabilities should function in cooperation with CBR societies for persons with disabilities at the district level, with the District Commissioner as the Chairman of the and the Deputy Director, Women & Child Development as the Secretary. All organizations working for women with disabilities and all organizations of women with disabilities and Self-Help Groups of Parents of adolescent girls with disabilities should become members of the society. A sample of the By-laws of the District CBR Society for persons with disabilities is enclosed and By-laws for district CBR Society for Women with Disabilities need to be developed.
7. In urban areas in addition to the reservation, women with disabilities are finding it extremely difficult to get hostel facilities. Therefore, a 3% reservation should be made in all existing women's hostels for women with disabilities.
8. There is a need for a scheme to support Self help mutual aid groups of women with disabilities on the lines of Sthri Shakthi in Karnataka and the DFID Velugu programme in Andhra Pradesh for women with disabilities and this should include a seed money to start both self and group employment. In addition to promoting self and group employment, there is a need for EDP programmes, both rural and urban, for women with disabilities to start their own cooperatives on the lines of SEWA, both in Khadi Commission and all the poverty alleviation programmes. Industrial development corporations. Women's development cooperatives should provide skill development, financial support and marketing linkages. In all the shops and malls owned by government or cooperatives or quasi government, out of the 3% reservation, 50% reservation should be made for women with disabilities and it should be allotted at 50% of the cost.
9. Finally, about movies and media, initiatives should be taken to regulate the media, which are mainly focusing on women's external beauty to promote the brands and nothing beyond. We can promote this on the lines of the Eriksson Company; Finland which states women with disabilities should also promote the popular brands. This will help to fight for the age-old image about women and help people to appreciate inner beauty.
10. Under Sarva shiksha Abhiyan a special programme for the inclusion of girls with disability in ICDS and elementary schools should be launched on the lines of Joyful inclusion and Udisha Portage programme launched by the Women and child Development Department, Government of Karnataka in cooperation with CBR NETWORK (South Asia).
11. The existing practices of discrimination based on degree of disability or economic criterion should be removed for children with disability up to the age of 0-14 years for the educational purpose to scale up the access to basic educational services.

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