

RESOURCE KIT

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Disability Awareness in Action

DISABLED WOMEN

Disabled Women

@ Disability Awareness in Action 1997

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"My main objective is to be an effectively contributing member of the community at large and thus contribute to the development of my country. The problem is the negative attitude in society towards the active participation of disabled people in community development. I have to counter the belief that a disabled person is an object of pity who always needs assistance from somebody else. This problem is compounded by the fact that I am a woman. Being a disabled woman is a double disadvantage in my community." Gloria.

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We would also like to record our thanks to all the disabled women whose experiences and achievements inspire this publication.

As always with our publications, we are indebted to the thousands of disabled people we have met and corresponded with worldwide.

People Don't See Me by Estella Jossam

People don't see me
They think I'm useless
Say any word they want.
Don't I think as they do?
I need to be recognised!

If I walk down the street
They say: "There's a cripple!"
If I handle my crutches
They move away quickly
As though a plane's taking off.

Don't do anything for me!
I need to be on my own.
If I go for work
They say, "No -give her this special, light job.
But "special" means "discrimination".

I need to express my rights
To say what I want.
And remember
My choice is not a mistake.
Don't be shy for me.

Let me be shy for myself.
Let me speak for myself.

INTRODUCTION

There is much talk of the death of feminism -that the war has been won and that there are few, if any, battles left to fight. Yet the media continue to stir up conflict between men and women, rather than focusing on the negative impact of gender discrimination. Similarly, disabled people are seen as at war with their bodies, desperate for cures and care. The serious issues which really limit disabled people's lives - marginalisation, abuse and poverty - are ignored.

From our own experiences and from the 1993 United Nations Report on *Human Rights and Disability* we know that the human rights of disabled people are violated all over the world. This is true for disabled women and for disabled men. Our organisations in most countries are working hard in difficult circumstances to change this.

It is vital that disabled women are involved in the struggle for social change at every level.

Disabled Women

The social status of disabled women varies according to individual circumstances and to the country in which they live. Disabled women in poor countries usually experience a particular disadvantage. Here, it is not just difficult but often impossible for a disabled woman to get an education or find a job. She easily becomes marginalised; has no place in society. She does not meet the requirements society places on women: she cannot be a "good wife", nor a "good mother", according to common wisdom. She cannot earn her living because of barriers of access and attitude.

Representation and Empowerment

Although the organised disability movement should represent and empower all disabled people, in practice disabled women have fewer opportunities to take part,

to take action and to make change. However, disabled women are beginning to organise at national, regional and international levels and disability organisations are increasingly aware of the need to embrace the experiences of all disabled people -whatever their gender, sexuality, ethnic background, age, religion, language or impairment.

Contact with the general women's movement is not so easy. Interest, when shown, is often at the last minute, when disabled women approach event organisers to ask why there are no disabled ~ speakers and are hurriedly asked to produce one. There is little focus in the women's movement on ~ disabled women's issues.

Experience and Responsibility

Many of the things discussed in this resource kit concern disabled women and disabled men. To make sexuality, parenting and abuse "women's issues" is a mistake. Disabled men can also be victims of abuse and of gender stereotyping. We need to share concern and responsibility with disabled men, and with non-disabled women and men.

We have attempted to collate what evidence there is on both the commonality and difference in experience, though official disability statistics are rarely broken down into gender.

Who Do We Mean by "Disabled Women"?

Disabled women are women who have one or more impairments and experience barriers in society. We include disabled girls and women of all ages, in rural and urban areas, regardless of the severity of the impairment, regardless of sexual preference and regardless of cultural background, or whether they live in the community or an institution.

“Pity can disappear from one day to the next. It makes you dependent on the whims of the person who is dispensing it. The issue of rights and equality is more lasting. It is that disabled people are increasingly demanding. Charity has too often robbed us of our dignity and our independence.” Khadija

Status of Disabled Women

General Picture

- 51 per cent of disabled people are women.
- A large percentage of people in developing countries do not get enough to eat. One hundred million people have impairments caused by malnutrition.
- International development programmes rarely address the needs of disabled women or include them in community development ventures.
- The problems of women are compounded by disability. For example, women are not targeted for prevention information campaigns on HIV infection. Disabled women are doubly ignored.
- Many disabled people, especially elderly disabled women, lead isolated lives -unable to go out of their own homes or even move around adequately inside them.
- Disabled people are often denied access to public places because of architectural barriers or discriminatory attitudes.
- Even in a rich country like Sweden, which has among the best housing policies in the world, of those not living in institutions, 85 per cent live in inaccessible housing.
- Most public transport is inaccessible to disabled people.
- In Zimbabwe, 52 per cent of disabled children get no education at all. In Asia, about 90 per cent of blind children have no access to education.
- Even in richer countries, education for many disabled children is still segregated and inadequate, particularly for those with learning difficulties. Despite integration policies dating back to the late 1970s, 28.4 per cent of disabled children in the UK still go to segregated schools. A tiny number (0.3 per cent) make it into higher education.

- In most countries, at least two-thirds of disabled people are unemployed. In Tunisia, 85 per cent of disabled people aged 15-64 are unemployed. Disabled women find it four times harder than disabled men to get work. In Zimbabwe, less than 1 per cent of disabled people contribute actively to the economy, In the UK and USA, 67 per cent of disabled people are unemployed.
- Access to communication and information, especially for those with visual, hearing or learning impairments, is limited.
- The democratic voice of disabled people is rarely heard in the formulation of policies and programmes that directly affect us.
- Fewer than 12 per cent of the world's parliamentarians are women, according to a recent survey by the Inter-Parliamentary Union. Most representative is Sweden, with 40 per cent women MPs; Norway, Finland and Denmark follow closely behind. The UK now has a record 18 per cent, following the Labour Party's election victory on 1 May 1997, bringing a total of 120 women MPs to Parliament. In the US, 11.7 per cent of legislators are women. The average in Arab countries is 3.3 per cent. Ten nations, including Kuwait, Papua New Guinea, Tonga and the United Arab Emirates, have no women parliamentarians. While disability has always been a characteristic to hide for parliamentarians, Uganda assures disabled people parliamentary seats and the UK has its first blind minister and first full-time wheelchair using MP - a Scottish woman. South Africa has also had a disabled woman MP since the new administration.
- Involuntary euthanasia for disabled people is becoming more and more acceptable.
- In some hospitals, disabled people with a variety of impairments who are not dying have "do not resuscitate in the event of heart failure" put on their medical records.

We have given some indication of the overall status of disabled people. Now we will examine in greater depth how disabled women are particularly affected in various life experiences.

"With the trauma of being abandoned by my mother at an early age, I always had to be reassured by those around me so that I would not feel neglected or rejected. It took me a long time to believe in myself and my abilities." Elisabeth.

"The disability has shaped my personality. I have become more withdrawn and introspective. I usually speak only when I am sure of what is being talked about. I rarely feel comfortable in other people's company. It does not make for much relaxation if you have to be constantly alert to understand what people around you are discussing." Eunice.

Attitudes: Isolation and Invisibility

- Stereotyped and negative attitudes towards disabled people devalue us. Much of the discrimination experienced by disabled women is based on an implicit notion that we are not the same as other women and so cannot be expected to share the same rights and aspirations.
- Women are generally discriminated against due to gender bias but disabled women face compound discrimination by being both women and disabled. The isolation and exclusion of disabled women even extends to mainstream women and women's movements, which deny us our rights and identity.
- Isolation and confinement based on culture and traditions, attitudes and prejudices often affect disabled women more than men. This isolation of disabled women leads to low self-esteem and negative feelings. Lack of appropriate support services and lack of adequate education result in low economic status, which, in turn, creates dependency on families or caregivers.
- Some societies go so far as to assign fault to a mother who gives birth to a disabled child, especially so if the mother is a disabled woman.
- Disabled women and men can experience different kinds of attitudes based on gender discrimination. While men are still seen as the major breadwinners and leaders of society, a disabled man, considered "less of a man", won't conform to that stereotype. Similarly, a disabled woman won't

conform to the feminine stereotype of wife, partner or mother and some lose the right to keep their children.

- Disabled women are not usually part of employment debates and initiatives. They are usually at least twice as unlikely as disabled men to get a job.
- Culture plays a big part in reducing disabled women's role in social, parental and economic life.
- Because disabled people are often excluded from society, the attitudes of the public are heavily influenced by how disabled people are portrayed in the media. Disabled women are seldom seen in ordinary roles as worker or mother.

Poverty

- If you are female, in any country, the odds are stacked against you in terms of provision of basic rights, such as a decent income, education, health care and employment. Disabled people in general are also grossly over-represented among poor people.
- While disability - the barriers of attitude and environment experienced by people with impairments - means that most remain desperately poor, poverty is also a *major* cause of impairments. Vitamin A and iodine deficiencies, malnutrition and unhygienic environments are widespread causes.
- Many disabled women in wealthy countries live below the breadline. For example, the allowance payable to an unemployed woman in the UK is not sufficient for her to have a decent diet or to ensure bearing healthy children. The same goes for a disabled woman, who may also be dependent on a specific diet for her survival. Disability benefits, where these exist, do not come close to covering the actual costs of disability, particularly in countries like Portugal and Ireland. Technical aids and adaptations are only reaching 2.5 per cent of disabled people in developing countries of which the majority are women.
- While disabled women in such countries may live below the breadline, with an extremely poor quality of life compared to their fellow citizens, in the poorer countries, there is often no bread at all and disabled people,

particularly young females, do not survive, because of preference for non-disabled male children.

"My pension is too low to secure a meal three times a day. I was eating only once a day and, as a result, I fell ill with diabetic gangrene. My flat is freezing and I have no money to live on." Woman from Latvia.

"Parents of a disabled child should be counselled to help them realise that the disability is not a punishment and that they are not to be blamed for it. Those parents who cannot afford to educate or care for their disabled child should be subsidised. When resources are scarce and parents have to make painful choices, they may reject a disabled child. The disabled child may not be seen as the most viable investment." Salome.

Health Care and Rehabilitation

- It has been estimated that services are reaching no more than 2 per cent of those in need in poorer countries. Rehabilitation is almost totally inaccessible to those living in rural areas and the international situation is thought to be no better now than 25 years ago.
- The new Convention on Human Rights and Biomedicine, adopted by the Council of Europe in November 1996, allows scientific experiments to be undertaken on people incapable of giving consent -even if the experiments are of no value to the disabled person herself. Many countries have policies to abort foetuses that may become disabled people. Some argue that euthanasia should be performed on severely impaired infants.
- Some conditions, such as heart disease, are experienced by women just as much as men, but it isn't seen that way. Operations and treatment can be delayed or even withheld. Fewer resources are targeted at women. Curing women, particularly if they are not in work, is not seen as being as urgent as curing men.
- Maternal health care is often denied disabled women, either because it is not considered right for them to bear children, or because the available services do not consider their particular needs.
- Some traditional practices, especially female "circumcision" disable millions of women.

Information

- lack of access to information has serious effects on disabled women's health, welfare, safety, opportunities and the exercise of their rights.
- For many disabled women, lack of confidentiality and invasion of privacy, along with prejudice and access difficulties, make control over personal finance impossible.
- A lack of information on HIV and breast and cervical cancer threatens the health of disabled women. Information is not targeted at or produced in formats accessible to many women (such as braille, tape or simple language).
- Information about sex and sexuality is often limited for disabled women. Relatives whose traditional role is to share this knowledge often ignore disabled girls. as they are not seen as marriageable. As well as being a denial of our rights. this can lead to unplanned pregnancy. abuse and disease.

"A disabled woman should be guaranteed some sort of training to enable her to earn a living because she needs to be more or less self-reliant." Olga.

"I must point out that the education I received was of paramount importance in my life. It is the foundation for what I am today. A proper education is necessary to put a disabled child on an equal level with non-disabled children." Apoka.

"A disabled woman must acquire a solid education, no matter what the cost. This provides access to intellectual pleasures, which are her rightful claim." Beatrice.

Education and Training

Many disabled people have been prevented from developing their skills because of discrimination in education and training. As with non-disabled women, the

situation for disabled women is compounded by the idea that education for women is an unnecessary waste of time and money. So, if education is inaccessible, it doesn't really matter if the child is female.

- A large proportion of blind and other disabled girls in South Asia remain illiterate, while the general rate of literacy among women has increased considerably in all South Asian countries.
- In India, 97-98 per cent of disabled male children receive no education. We have no figures for disabled female children, though, there is every likelihood that it is lower still.
- Even in the wealthy countries of Canada and Australia, 41 per cent of disabled children have only primary education.

Employment

Employment is a critical component in enabling disabled women to support themselves financially and to achieve self-esteem and social recognition.

- Women who are born with impairments are particularly disadvantaged.
- Even where disabled women do sometimes find work, it will be low-paid, low-status and in poor working conditions. In the UK, while 30 per cent of non-disabled men are engaged in professional or managerial work, the figures are 15 per cent of disabled men, 11 per cent of non-disabled women and 8 per cent of disabled women. By contrast, while 16 per cent of non-disabled men are engaged in semi-skilled or unskilled work, the figures are 27 per cent of disabled men, 27 per cent of non-disabled women and 37 per cent of disabled women.

The waste of human potential that unemployment ensures cannot be justified on the grounds that disabled people are not capable of working or are often absent from work -the opposite is true. High unemployment and limited opportunities are caused by ignorance, prejudice, a reluctance to make even minor changes to support disabled people and discrimination in education and training which means disabled people are less qualified than their peers. Even when disabled people find work, discrimination continues in the lack of promotion and training opportunities.

The Environment

Environmental barriers create disability, limit opportunities and deprive people of their human rights. Lack of environmental adjustments and the absence of accessible buildings hinder disabled women from enjoying freedom of movement around and between different countries and different parts of the built and natural environment.

- There is a lack of access for disabled women to women-only services, such as refuges, rape crisis centres, health centres, family planning clinics, dress shops, hairdressers, etc. - which underlines the assumption that we are not really women, not interested in our appearance or in control of our own sexuality and health.

Transport and Free Movement

Transport for all disabled people is an important key to the exercise of citizenship and participation in society. Women in general, and disabled women in particular, are less mobile than men - less likely to have access to a car; more confined to the home due to social and cultural patterns and to the actual or perceived threat of danger, especially after dark.

- In most places, most disabled people cannot use public transport.
- Public transport is often inaccessible, uncomfortable and dangerous for women travelling alone.
- Personal transport is often owned and used only by male members of a household.
- Being diagnosed as HIV positive prevents many people from travelling between countries.

No access to transport has serious effects on disabled people's integration and economic activity. It prevents them forming self-help groups or taking control of their lives. Reasons for not providing accessible transport are generally based on cost and ignorance. For example, a disabled man lost a case of discrimination against Dutch Railways in 1993. The judge said that as the company was providing a public service it should provide it equally to all members of the public. However,

since he didn't believe the man to be part of the public, he couldn't expect equal treatment.

"It is almost impossible for a blind person to use public transport without a guide or companion. The drivers are undisciplined and commuters compete viciously with each other to grab hold of a door handle or rail. Taxicabs could be easier. However, they are risky because few cab drivers are absolutely trustworthy and a blind passenger could be taken for a long ride to a nearby destination just to add to the taxi meter." Soledad.

"Buildings ignore the existence of disabled persons. During my school years access was a major problem, trying to go from one floor to, another in buildings that had no lifts or ramps." Apoka.

Sexuality and Relationships

- Disabled people are much less likely than non-disabled people to get married -the numbers range from 4 per cent less likely in Europe to 45 per cent less likely in the Philippines. Disabled women are less likely to marry than disabled men; they also tend to have a higher divorce rate.
- Disabled women are not encouraged to explore their sexuality. If they have a sexual relationship, it is assumed that they are lucky for whatever they can get and certainly shouldn't make any further demands or complain if they are mistreated.
- Disabled women are also often not seen as capable of intimate relationships or equal partner- ships. If they begin a partnership with a non-disabled man or woman, they are judged to be the weaker partner -an emotional and financial burden and an inadequate sexual partner. If they form a partnership with a disabled man or woman, the attitude may be that no one else would have
- them; that it wasn't a genuine choice.
- In cultures where marriages are arranged, disabled women are not considered suitable at all.

- Disabled people are denied control of their sexuality and reproduction -it is only relatively recently that sterilising people with learning difficulties has been seen as an issue which even requires consideration by legal process. In China, the law demands sterilisation of disabled women with hereditary conditions.
- Hysterectomy of teen-aged disabled girls has been justified by the argument that menstruation is difficult to manage.

Family Life and Parenthood

In most countries, girls have a lower status and enjoy fewer of the rights, opportunities and benefits of childhood than boys. Girls and women bear a major share of the burden of poverty. Poor rural women in particular are among the most deprived people in the world. They are generally sicker and more illiterate than men. What is true of women generally is particularly so of disabled women.

- In all countries, a woman's physical image determines her value and her chances of getting married or forming a sexual partnership. Whether she can bear children, in particular non-disabled children, and be judged a capable parent also determines her value as a woman.
- Research shows that pressure is put on disabled women to abort pregnancies and to be sterilised.

We are more than what we look like and more than machines for bearing children. Whether we can or cannot have children makes us no less human, no less female, no less capable of experiencing our sexuality. In addition, disabled people can make good or bad parents -just like anyone else. In many cases, our experience of oppression can make us emotionally stronger, more tolerant, patient and understanding -all ideal qualifications for becoming a parent!

Contrary to commonly held beliefs, although some disabled women may face extra challenges in pregnancy, child rearing and housework, countless disabled women have proved that they can handle them all -using the organisational powers and emotional strength developed by managing their impairments and living in an inaccessible world!

Developments in Genetics

In the field of medical treatment, and in particular genetics, there are many discriminatory attitudes. It may be felt more acceptable for a person's life to be ended (or for them not to be born) purely because they are disabled.

Prenatal diagnosis -of sex or impairment -aims to avoid the birth of groups of people defined as "inferior". In the case of impairment, selection is exercised in the context of an ideology that says it is morally acceptable to prevent disabled children. Resources are not usually readily available to allow women the "choice" to knowingly give birth to a disabled baby. The latest point at which abortions can normally be performed varies from country to country, but is generally between 22 and 26 weeks; in the United Kingdom and several other countries, abortion of a foetus suspected of having an impairment is legal up to the moment of birth.

- Forced abortion and sterilisation are surgical interventions that many disabled women have felt pressure to undergo. Many non-disabled women are also encouraged to feel that they are being irresponsible by thinking about going ahead with the birth of a disabled infant; that the "kindest" thing that they can do is to end the pregnancy.
- Disabled people are not usually involved in the genetic counselling of parents who are expecting a baby with an impairment.
- Economic and emotional arguments -that a disabled child will be burden to its family and a drain ~ on financial resources and emotional energy -are used to justify abortion, including the wider issue of responsibility to society to keep it "pure".
- The Chinese Government shelved its euthanasia and eugenics policy due to international outcry - but only temporarily, because they were hosting the Fourth World Conference on Women in Beijing in 1994. By the start of 1995, the legislation was on the statute books. The law "persuades" n disabled women to undergo sterilisation and all women to abort in the case of impairment.

"In our society a woman marries into the husband's family. She is expected to work for the family, i.e. physical work. Disabled women are not prime candidates for marriage. I am an unmarried mother and have never come close to marriage. I love being a mother and the responsibility I have for my sons makes my life worthwhile. However, raising two children alone is not an easy task. Occasionally, I miss the company of a male partner but I try to push the loneliness away by immersing myself in my job and family." Gloria.

"The most difficult part of my life was my adolescence. Many parents did not want me as their daughter-in-law. They chased their sons away when they saw us together. Or a boyfriend would come simply out of curiosity. without any feeling, and deceive me in the most cruel way because he was ashamed to have me for a wife." Marie-Therese.

"Some men consider a disabled woman an object of embarrassment and they could never think of marrying her. Other men believe that a disabled woman cannot assume full responsibility for the household and for bringing up children." Apoka.

"Now the time has come when society should start accepting disabled women. There are many disabled women who are capable and intelligent but are rejected by society. Why? And just because a woman is disabled, she cannot get married because the man's parents refuse to accept her as their daughter-in-law. The preposterous reason is that they adhere to the old tradition and give priority to what society would say rather than to their son's feelings about the woman." Nafisa.

"The day of our wedding was another trial for us. The church was full. Some people came simply out of curiosity. My husband's sisters cried during the entire ceremony. I cannot really explain why they were crying. Life in our home is still extremely difficult. My husband's family does not want to accept me. They tell my husband all sorts of stories to create conflict between us." Marie-Therese.

"It is necessary to lift the veil on certain aspects considered taboo or unacceptable for disabled women. Child-bearing has long been considered impossible for a disabled woman. The existing mentality is that the woman is at the centre of the household, doing the work and raising the children. In general, she is like a servant." Yawa.

"Getting appropriate contraception for family planning purposes was not easy for me as a disabled person. The nurses at the clinic had a very negative attitude."
Gloria.

Abuse and Violence

- Disabled people experience high levels of abuse of all kinds -physical, emotional and sexual.
- Abuse of disabled people is often carried out by women -on whom the person is more likely to be dependent.
- Statistics indicate that disabled women are more likely to be sexually abused than non-disabled women. Sometimes the abuser tries to convince the disabled woman, or others, that he is doing her a favour since few men will have sex with disabled women. It is very likely that cases against abusers of disabled people will not come to court.
- Because of the strong emphasis on physical appearance in every society, disabled women are made to feel less worthy than non-disabled women. This negative self-image, along with the silencing or non-belief of victims and the lack of prosecutions of alleged abusers, increases the risk of sexual abuse.
- Forced sterilisation without informed consent for the convenience of others is used to prevent disabled women having children and, mistakenly, to "protect" them from sexual abuse. It can do no such thing. It may prevent a pregnancy following rape but not a sexually transmitted disease or other trauma. Rape prevention needs different strategies. By contrast, men with learning difficulties -often also the survivors of sexual abuse -are not usually forced into vasectomies. However, this has been the case, to prevent reproduction, particularly in the United States and Canada, until relatively recently -just as women with learning difficulties are forced into sterilisations.

- **Female Genital Mutilation**

There is growing evidence that wide variations of mutilation are performed on female children in different countries. It is estimated that over 100 million girls and women in more than 28 countries in Africa alone are genitally mutilated. At the

current rate of population growth in Africa, two million girls a year -some 6,000 a day -are estimated to be at risk of female genital mutilation (FGM).

However, information available on total prevalence and rates by type of operation is incomplete. It is often based on anecdotal reports or biased samples using unclear or faulty methods of data collection. The only country with reliable nationwide data on FGM is Sudan, where three surveys included data on this group of practices.

Outside Africa, FGM is practised in Oman, north and south Yemen, the United Arab Emirates, Bahrain, Qatar and some areas of Saudi Arabia. Reports from doctors and midwives working in the Middle East indicate that the most severe form, infibulation, is practised widely by immigrants from Sudan and Somalia. However, the extent of the practice in the Middle East is unknown and research data is required to confirm its prevalence and type. FGM is practised by the Ethiopian Jewish Falashas who have recently settled in Israel.

Clitoridectomy is reported to be practised in the developing world by some indigenous people in Peru, Colombia, Mexico and Brazil. Again the extent of the practice is unknown. Excision of the external female genitals is said to be practised by the Muslim populations of Indonesia and Malaysia and by Bohra Muslims in India, Pakistan and east Africa.

In richer countries -Europe, Australia, Canada and the USA -immigrant women from areas where FGM is practised are reported to be genitally mutilated, but there are no studies on its prevalence in immigrant populations nor on the numbers of girls at risk. There is little doubt, however, about the physical and psychological consequences of these practices, which range from mobility difficulties, impaired sexual function and infertility because of infection, to an increased risk of HIV infection.

Multiple Discrimination

Many disabled people face discrimination on the basis of ideas about race, religion, gender, sexuality, marital or parental status, age and language as well as impairment.

- Women with learning difficulties and women with a history of mental health service treatment may experience discrimination from other disabled women in a similar way to discrimination from non-disabled women and men.

- The symptoms of hidden impairments, which include cancer, diabetes, epilepsy, arthritis and hundreds of other conditions, may come and go, leaving the individual and others with the feeling that they are not "really" disabled, especially if the ways in which these conditions limit an individual seem to be not as severe as people with more obvious impairments.

Strategies for Change

General

- Press for rights for disabled women at international level and in individual countries.
- Raise international, regional, national and local awareness of the issues affecting disabled women.
- Increase participation of disabled women in their communities and within disability organisations.
- Include disabled women in the mainstream women's movement to ensure full participation in development.
- Change societal attitudes and prejudices. and those of families and governments which stereotype disabled people.
- Increase the opportunity for education and training for disabled women.
- Increase access to services, facilities and transportation.
- Families with disabled members should be provided with education about the needs and rights of disabled women, and resources should be available for support in the community.
- Disabled women should be encouraged to form local groups and self-help organisations, which will help them increase their self-esteem.

"Every day I discover something new. Through the organisation I not only learned my rights but also my obligations to other disabled people and to my country."
Diarietou.

"Designers, architects, builders and engineers should keep in mind that disabled people also live in the city and that they have needs such as wheelchair ramps, designated parking spaces and special access. We are all part of society. " Paulina.

Organise media campaigns to make the public aware of the needs and abilities of disabled people" Marie-Therese.

International Action

Use the following documents to work for disabled women's rights. All articles in these documents are of relevance to disabled women in certain circumstances. We have given you any articles or clauses that specifically mention women or disability.

- The UN Standard Rules on the Equalisation of Opportunities for Persons with Disabilities. Disabled women and their organisations should be continuously consulted in the national and international follow-up.
- International Covenant on Economic, Social and Cultural Rights: Articles 2, 7, 10.
- International Covenant on Civil and Political Rights: Articles 2, 5, 6, 23, 26.
- UN Convention on the Elimination of All Forms of Discrimination Against Women
- Declaration on the Elimination of Violence Against Women
- UN Convention on the Rights of the Child: Articles 2, 23, 24d.
- International Labour Organisation Convention 159 Concerning Vocational Rehabilitation and Employment (Disabled Persons)
- ILO Recommendation No. 168 on the same subject

- European Convention for the Protection of Human Rights and Fundamental Freedoms: Articles 12,14.
- European Social Charter: Part and Articles 3,4,8,9,10,15,
- European Community Charter of Fundamental Social Rights for Workers
- Florence Agreement and its Protocol on the importance of educational, scientific and cultural materials.
- UNESCO Salamanca Declaration on Special Needs Education

You can get copies of all United Nations documents from your national UN information office or from the relevant agencies.

Regional Action

To meet the challenge of including disabled women in society is beyond the capacity of anyone organisation. It is crucial that the priorities of disabled women be addressed in partnership between development agencies, the regional bodies, national governments, women's organisations and disability organisations.

- Organisations of disabled people should unite on policy issues to have a strong impact on governments and societies and to emphasise an inclusive approach in all areas of equalisation of opportunities.
- Disabled women should meet at a regional level to discuss issues of common concern.

National Action

All states have a responsibility to create the legal base for achieving the objectives of full participation and equality for disabled women and men, in accordance with Standard Rule No. 15.

Legislation should not discriminate against disabled people and should include aspects such as social security, environmental access, transport, medical and technical facilities. It should take into particular consideration the needs of disabled women as a legal right.

- Disabled women can use any non-discrimination legislation relating to gender.
- You can use international instruments, such as the Standard Rules, at national level.
- You can combine disability and women's issues to lobby government.
- Organise representation on national committees and focal points- for women's issues, set up as part of the Convention on Elimination of All Discrimination Against Women, and for disability issues, set up in accordance with the World Programme of Action Concerning Disabled Persons. National focal points can link with others in a regional network
- In accordance with UN Standard Rule no. 17, national disability committees should be strengthened, if necessary, or established where they do not exist. Disabled women and their organisations should be active members.
- Disabled women should be actively involved in both disabled people's self-help organisations and women's organisations. Organisations of disabled persons at national and regional level should encourage the establishment of sub-committees of disabled women or independent disabled women's groups.
- Disabled people's organisations need to set up effective partnerships and cooperation with one another and with other organisations outside the disability movement, whether at the local or national level, including human rights bodies, women's organisations and groups concerned with bioethical issues.
- There should be a stronger presence of disabled women in national delegations to international meetings, committees and commissions concerning issues of either women or disabled persons.
- The participation of disabled women should be generally encouraged, not just supported when topics related to them are specifically on the agenda.
- Governmental and non-governmental national, regional and international women's organisations and bodies should include disabled women and

issues related to them within the general women's movement, implementing action plans according to the present recommendations, as well as the Platform for Action from the UN Conference on Women in Beijing in 1995.

Organisational Action

- Coming together as part of a disability organisation or a women's organisation is essential to work effectively at local, national, regional or international levels.
- Work with other women's groups.
- Ensure that any organisations you join have by-laws or guidelines that guarantee the representation of disabled women.
- Ensure that organisations have projects specifically focused on disabled women.

Individual Action

- If there isn't one, or not one that expresses your views, set up a disabled women's network, perhaps using a regular newsletter, in your city or country.
- Pass this resource kit on to a neighbour, friend or organisation 1 or copy parts of it to councillors, members of parliament or members of government.
II
- Build networks for disabled women and links with the mainstream women's movement.
- Support other women and encourage their development.
- Write to the UN Commission on the Status of Women about the inclusion of disabled women.

Training

- Disabled women should be encouraged to participate in training programmes within national bodies that organise leadership and management

development. Programmes should also be designed specifically for disabled women, as well as be considered an integrated part of existing women's training programmes.

- Leadership training seminars, educational programmes and job training programmes for establishing co-operatives and income-generating activities should be organised at local levels, including rural areas, to increase disabled women's awareness of their own situation at the grass- roots level and to stimulate their active participation.
- Special mentor programmes should be started and supported at local and regional levels, where women within the disability movement consciously support each other through the various phases of life in their personal development and empowerment.
- Various regional organisations as well as the UN system should assist disabled women in developing leadership skills through the elaboration of model curricula by ILO and UNESCO to be used at various levels of leadership in all countries and through technical co-operation. All efforts should be made to have disabled women as trainers.

Funding for Change

Organised activity cannot be effective if it is unsupported. The Standard Rules specifically encourage member states to fund disabled people's organisations.

- The UN, specialised agencies and various other international, national and local donor agencies should also include funding of programmes for disabled women among their priorities. Main- stream funding programmes should earmark support for projects related to disabled women.
- When priorities do exist in favour of disabled people or women, favourable considerations should be given to the inclusion of programmes or components of programmes for disabled women.

"Although there is a law on disabled people in my country, it is not put into practice. Nothing is done in our favour ...I participated in a seminar on disabled people which took place in Strasbourg. I am a member of the Bucharest branch of the National Society of Disabled People in Romania. That journey was a great experience. I will never forget those days spent in Strasbourg. I made some friends." Carmelia.

"The Government's way of solving the economic crisis is to put lots of people out of employment, starting with disabled people. , am one of them and there is no organisation or law to protect me. This is the case for all disabled people in Portugal. ..If I lose my job, I will receive only half my current salary -which means' won't be able to afford my house and will have to move to an institution. I would rather die than let that happen. Portuguese disabled woman.

"My friends don't go to theatres, cinemas and shops if they aren't accessible. They protect my rights but my government doesn't. We must end the apartheid we are living with." Sharon.

"Inclusion will not happen unless all disabled people, including disabled women, have equality." Rita.

Research

We need to have the facts and figures to support our demands for equal opportunities. These facts and figures must be accurate and based on our own experience.

- National governments should take early steps to incorporate the collection of gender-specific data on issues related to disability in existing statistical series. Moreover, each country should undertake nationwide surveys on disability to investigate the incidence of impairment in the country. its major causes and measures taken by individuals or families to deal with the situation.
- Of great importance is a model questionnaire for this purpose by the UN Statistical Office to highlight the issue of disabled women and which obtains such information as income level, employment and educational attainment, among others. Such a survey allows an analysis of the national situation and

permits regional and international comparisons. It would also be advisable to have personnel trained in data collection on disabled women involved in household surveys and censuses.

- The revision of the International Classification of Impairment, Disability and Handicap (ICIDH) should in every respect take gender-specific differences into account. In all aspects -impairment, disability, participation, environmental factors -the situation of disabled women and men is likely to differ. Manuals and any accompanying guidelines should all make reference to.. gender specific aspects of disability.
- Any development programme for disabled women should investigate the actual living conditions of disabled women both in urban and rural areas. Furthermore there should be research on the ways and means of improving the status. raising the living standard of disabled women and providing necessary facilities to them. Research should be stimulated and grants given to researchers in a large number of subject areas to investigate the situation of disabled women.
- Descriptions about their situation provided by disabled women themselves should be the most important source of information. Women's own interpretation and documentation of their experiences, which is now underway, can be the start of a worldwide research project on disabled women. It is suggested to gradually create an international network linked to the national focal point on disabled women.
- Other socio-economic and political studies concerning the social situation of disabled women should be encouraged.
- Particular attention should be given to the exchange of research experiences. In this context special attention should be given to recruit and educate suitably qualified disabled women as researchers.
- Research should be done on the situation of disabled female migrants, refugees and other homeless people.
- Large-scale research is also necessary to investigate the amount and kind of violence disabled women encounter.

Action for Change

There are thousands of successful projects which have made a profound difference to disabled women. We have focused on the activities or characteristics of a few of those known to us. Each of the solutions given here affect disabled women at a local level. They are appropriate, cost-effective and empowering.

Income Generation

Income generation is the solution to poverty for disabled women. Through projects that generate a livelihood for individuals, disabled women are able to contribute to the economy of the community. Income generation projects bring improvements to all aspects of disabled women's lives. They increase skills, allow social interaction and independence, give a new role and status to disabled women within family and community. They require funding to start and expand but returns are considerable, not just in financial terms.

Community-Based Services

Community based services are based on the idea of community development: when individuals are empowered to take action to improve their own lives, they become contributors rather than a drain on resources and the entire community benefits.

For example, a road that is improved to help villagers who use a wheelchair or scooter for mobility also helps people who ride bicycles, delivery people who use animals to carry heavy loads, and elderly people who have difficulty seeing and walking. An improved system of early detection of impairments ensure that children who might, through neglect, be more severely impaired are identified and treated as early as possible and to the fullest extent possible, thereby utilising fewer of the scarce community resources. The visibility of these children helps them to become "salespersons" of health services to parents who might not otherwise seek help.

Appropriate Technology

The basic idea of community-based services and independent living applies to appropriate technology: disabled people are involved at all levels in policy-making and service- provision. Through technology programmes, they not only get appropriate appliances for their individual use but also employment -not "sheltered", poorly-paid employment but dignified, useful work in a supportive environment.

Naturally, all technology should be appropriate to individual use and to the environ- mental context. It should take into consideration the socio-economic, cultural and technical aspects of the whole community. There are now a huge range of organisations producing technological support for disabled people. This work is enormously important in liberating disabled women and in providing models for work worldwide.

Empowerment

Empowerment involves disabled women understanding their right to be citizens and being given the tools for equality and participation. It is achieved principally through disabled women coming together to share their experiences, to gain strength from one another and to provide positive role models. It means breaking away from an identity of grateful passivity and finding the will and the power to change one's own circumstances. This is not an easy or comfortable process for disabled women or for the wider community. However, it is an essential component in the struggle for full participation and equality of opportunity.

Independent Living

Independent or self-determined living is the direct result of the self-advocacy of disabled people and is usually operated through local, non-residential centres of enablement. It is fundamentally important to stress that these centres are under the direct control of disabled people themselves, to provide the necessary support and services they require to lead fully independent lives, and to become fully participating members of an integrated community.

The role of centres of independent living is not to repeat existing services where these are satisfactory. Research, linked with practical experience, has shown that

there needs to be a major re-direction of resources in terms of planning, design and service delivery for, and by, disabled people. Independent living can also become a focus for developing services with existing agencies. Empowering disabled people in this way leads to more efficient expenditure of resources and, at the same time, increases disabled people's skills and enables them to lead an improved quality of life.

Education and Information

Accessible and relevant information on every subject is vital to disabled women. Similarly, accurate information about disability issues is vital to the community as a whole. The majority of disabled women do not receive an adequate education, due to access difficulties and prejudice, and this contributes considerably to their marginalisation and exclusion. These barriers can be overcome. Investment in disabled women's education benefits the whole society.

The power of the media to shape attitudes and beliefs is difficult to judge. What we do know is that television, radio and newspapers are powerful ways to convey ideas and to break down prejudices between people living a continent apart -and those living on the same street.

The development and expansion of information technology, much of it financially inaccessible to disabled people at present, could nevertheless liberate millions. Communications systems allow a few of the most severely disabled people to interact with those around them and in some cases to work. Talking computers allow people with visual impairments to gain employment.

The Standard Rules set down measures for member states to work towards the integration of disabled people. Integration cannot operate by adapting disabled people to existing structures, the basis of so much of what is called "rehabilitation". Integration occurs when societies begin to celebrate, not isolate, differences between people. It is based on mutual support and understanding and a sharing of resources and facilities among the many not the few.

Integration

Disabled women must be considered in all mainstream policy decisions and programmes. They form a significant part of every other group in society -such as refugees, children, racial minority groups. At present, disabled women are totally ignored, sometimes even in special disability policies, where these exist at all. Until disabled women are seen as an integral part of their communities and societies, with adequate provision for their needs within a community setting, the vast majority of the world's disabled women will remain isolated and destitute.

Examples

Most projects show some, if not all, of the elements described above,

Ramu is the leader of an Indian sangham [cooperative] and lives with her daughter, aged eight. Her husband has left her. She applied to the government for a loan to buy a pair of goats. Initially it was refused but with pressure from the sangham it was eventually granted. Ramu explains:

"By myself I did not have power to persuade the bank to give me a loan for the goats, but when the sangham come in behind me, they eventually agreed. The sangham gives me energy and strength. But it is not only because we can get loans through it: we are more confident in ourselves now. And because we are in a group, the other people in the village respect us more now. Before, we were just forgotten individuals. Now, we are people who can do something."

For disabled women, illiteracy leads to low self-esteem and drastically restricts the opportunity for social participation and employment. In 1991, ACOGIPRI, a self-advocacy organisation in El Salvador began a literacy project for disabled women. It has reached hundreds of disabled women from central American countries. The articles and poems written by these women show that they have developed self-esteem, raised their status within their family, community and organisations. Their chances of skilled employment are also considerably increased.

While 20 million people in developing countries need wheelchairs, less than 1 per cent own or have access to them. The Wheeled Mobility Center (WMC) in California aims to improve the mobility of disabled people worldwide. It does this by exchanging wheelchair designs and manufacturing technology with mechanics and small machine shops around the world, thus disseminating the specific skills required for building wheelchairs.

Since 1980, the WMC has helped to start 30 wheelchair production shops in 25 countries; over 250 mechanics have been trained and more than 10,000 wheelchairs have been produced. The WMC is also the communications hub of the Whirlwind Network, a web of independent wheelchair production shops in developing countries.

Since the WMC's start in 1980, women have been the source of critical design breakthroughs and provided leadership that kept shops stable in difficult times. However, women have often become marginalised in the male-dominated trade of wheelchair building. The WMC founded Whirlwind Women in 1994 to encourage women's participation in wheelchair design and manufacturing. Whirlwind Women has conducted training seminars in basic shops skills such as measurement, metal working and welding.

In Nicaragua, there is a programme for the integrated development of disabled women, consisting of nine projects throughout the country. These projects include the 'New Hope' coffee shop, literacy work, technical aids and training, a chicken rearing project, work with the local department of health and awareness-raising. In March 1995, women from each project met in Managua to share development experiences and ideas.

There are many national disabled women's networks. For example, disabled women in Uganda have formed a network representing and coordinating disabled women's work. It is a resource for development work with disabled women. It keeps up to date with international events and action relating to disabled women. In addition, many organisations at local, national, regional and international levels have set up women's committees, such as the Deaf Women's Wing of the Kenya Association for the Deaf.

Parentability is a British project supporting disabled people in pregnancy and parenting. It is part of the National Childbirth Trust and provides networks of information and support. One of Parentability's projects "Images of Disabled People as Parents" involved collecting positive images of disabled people for use in publications and as an exhibition.

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Division for the Advancement of Women, Centre for Social Development and Humanitarian Affairs, United Nations Office at Vienna, Vienna International Centre, PO Box 500, A-1400 Vienna, Austria. Tel: +43 I 21131 4248. Fax: +43 I 232 156.

DISWEB, the European Network of Women with Disabilities, Elisa Pelkonen, Chair, Mariankaro 24 E 40, FIN-00 I 70, Helsinki, Finland. Tel: +358 9 1357925. Fax: +358 9 68501199, or Dolores Schembri, Secretary, 4 Busewdien RD, Wardija St., Paul's Bay, Malta.

IMPACT, the international initiative against avoidable disablement. C/o WHO, 20 Appia Avenue, CH-I21 I, Geneva 27, Switzerland. Tel: +41 22791 3732/3. Fax: +41 22791 0746.

Inclusion International, Galeries de la Toison d'Or, 29 Chaussee d'ixelles, #393/32, B-1050 Brussels, Belgium. Tel: +32 2 502 77 34. Fax: +32 2 502 28 46.

INSTRAW, International Research and Training Institute for the Advancement of Women, PO Box 21747, Santo Domingo, Dominican Republic.

Mobility International USA, PO Box 10767, Eugene, Oregon 97440, USA. Tel: + I 503343 1284. Fax: + I 503 343 6812. E-mail: miusa@igc.apc.org

NOSEVI, the Network of Disabled Feminists Against Sexual Violence, Dinah Radtke, Zentrum fur Selbstbestimmtes Leben Behindertere. V; Erlangen, Marquardsenstr. 21, 91052 Erlangen, Germany. Tel: + 49 91 31 205022.

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World Blind Union, c/o CBC ONCE, La Coruria 18, 28020 Madrid, Spain. Tel: +34 I 571 36 85. Fax: +34 I 571 57 77. Women's issues: Kristina "Kicki" Nordstrom, Swedish Association of the Visually Impaired, 12288 Enskede, Sweden. Tel: +46 8 39 90 00. Fax: +46 8 39 91 77.

World Federation of the Deaf, 130, Chemin du levant, F-O 121 0, Ferney-Voltaire, France. Fax: + 33 4 50400 I 07. Women's issues: Anne Marie Wikstrom, Granvagen 9, S- 793 33 Leksand, Sweden. Textphone: +46247 12186 or +46 247 64112. Fax: +46247 14165.

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We came here because we are women.
We came here to expose our abilities.
We came here to share our experiences.
We came here to strengthen networking among women with disabilities and other
women.
We came here to make ourselves visible.

Now we are leaving with our expectations partly met:
We have made some impact.
We have made people aware of us.
We have socialised and gained contacts allover the world.

But we are aware that there is a lot more work to be done before we achieve our
basic goal
of equality with women in general in our respective countries.

Watch out!
Women with disabilities are on the move!

**from *Women Walk on Water*, published by the delegates of the Swedish
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