

Disabled People in International Development

Edited by
Diane Driedger
International Development Officer
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Introduction

"Disabled persons in the developing world, instead of taking a wait-and-see attitude and remaining passive, are getting organized to change public attitudes on the one hand and to demonstrate the role they can play in the development of their

countries on the other."
Tambo Camara, Mauritania

Disability and international development are related. The World Health Organization has estimated that 10 percent of the world's population has a disability and 80 percent of the world's people with disabilities live in the developing regions: Africa, Asia, Latin America and the Caribbean. When families of disabled persons are considered, the United Nations estimates that disability impacts on 25 percent of the community in most countries.

"Disability" is a functional limitation within the individual caused by physical, mental or sensory impairment; whereas, "handicap" means the loss or limitation of opportunities to participate in the community on an equal level with others due to physical or social barriers.

There are many causes of disability in developing countries. The UN has estimated that in some countries malnutrition and communicable diseases cause disability in 20 percent of the population. Diseases such as polio are still prevalent in many countries due to a lack of resources to immunize the population.¹

Women often become disabled due to their disadvantaged position in society. They tend to receive less food than males and thus they are weaker and more susceptible to disease. In parts of Africa and Asia women are also disabled by female circumcision, the process of removing the clitoris and sometimes the labia in young females. This procedure is done for religious and cultural reasons and is often performed in unsanitary conditions. The procedure can result in pain that inhibits walking, as well as pelvic and urinary infections and mental illness invoked by trauma caused by the procedure.²

While disabled people in the developing world share many of the same barriers to their participation as disabled people in Canada, they have even fewer opportunities. They are in situations of double jeopardy--they are disabled and from the developing regions. And if they are disabled women they experience triple discrimination. In addition, most of these people live in rural areas isolated from appropriate rehabilitation services, and few disabled persons receive training or employment. In the midst of these situations, people with disabilities have been organizing themselves into self-help groups all over the world. In many cases they have lobbied government for changes and started their own income-generating projects.

Attitudinal and Physical Barriers

In the developing world, many people with various disabilities--mental, physical or emotional--are hidden away by their families. Communities may blame a family for the presence of a disabled member, inferring that someone must have sinned and offended God. These attitudes will be discussed further in this booklet under the "What Kind of Development?" and "Attitudes Towards Disabled Persons" sections.

Even when disabled persons venture out into the community there are barriers to their participation. Public buses are few and far between in many developing countries and those that exist are not accessible to disabled persons. There are stairs onto the buses that mobility-impaired persons cannot negotiate. In addition, public attitudes often mean that disabled people are ridiculed if seen out in public.

There are few opportunities for education for disabled persons. Again, if the school is far away, especially in the rural areas, there will not be accessible transportation, and a disabled child may not be able to walk to the school. If the child is able to travel to school, then there may be stairs that bar a mobility-impaired child, or a lack of teachers trained in

sign language for the deaf child, or teachers trained in Braille for the visually-impaired child.

If there are any opportunities for education, it is usually disabled boys who receive them, and then it is usually through special church or charity run schools operated for disabled children, usually blind or deaf schools. Disabled girls are then kept at home to do housework. Disabled women's low educational levels will be discussed in the "Women with Disabilities" section of this book.

In the area of employment approximately 99 percent of disabled people are unemployed in the developing countries, and this contrasts with about 61 percent unemployment among disabled Canadians. Lack of employment relates to low educational levels, lack of training and public attitudes that disabled people should be hidden away and taken care of by charities. Due to this situation, disabled people themselves have started their own employment schemes through income-generating projects. Some of these will be discussed further in the section on "Disabled People's Projects" in this booklet.

Disabled People in the Development Process

While conditions in the developing countries present vast barriers to people with disabilities' participation in everyday life, disabled people have organized themselves to confront these barriers. In the early 1980's, disabled people in developing countries in all regions of the world formed self-help organizations. These organizations both lobby the government for changes and promote public awareness about the abilities and concerns of disabled persons. In addition, many of the groups have started or are starting income-generating projects for their members. This booklet further outlines some of these projects in the "Disabled People's Projects" section.

There are organizations of disabled persons in over 70 countries and they belong to a worldwide network, Disabled Peoples' International (DPI). The Coalition of Provincial Organizations of the Handicapped (COPOH) is the Canadian member of DPI. It is through DPI that COPOH became interested in working with disabled colleagues overseas. Indeed, DPI's self-help philosophy of disabled persons speaking for themselves on their own concerns provides a common ground for disabled people in both the developed and developing worlds.

In its international program, COPOH works in solidarity with disabled people overseas on common issues and learning from our disabled brothers and sisters. (See the last section for more). This booklet is presented to create an increasing awareness of disabled persons in the development process for both the disabled persons community and non-governmental organizations involved in international development.

Diane Driedger, COPOH International Development Officer

1. United Nations, World Program of Action Concerning Disabled Persons (New York: United Nations, 1983).
2. Robin Morgan and Gloria Steinem, "The International Crime of Genital Mutilation," in Gloria Steinem, *Outrageous Acts and Everyday Rebellions* (New York).

Attitudes and Disabled People

"Religions of the world exhort their followers to act for the benefit of the weak

and needy, sick and disabled. Exhortations to do good are rarely needed unless the circumstances are conducive. But building credit towards an afterlife is an inducement. Dropping coins into the beggar's bowl may lead to avoidance of punishment in the afterlife.... If the unseen forces present a poor family with a deformed baby, it is the family's duty to exploit the deformity for financial gain."
M. Miles, Pakistan

Disabled People and Attitudinal Barriers

by Javad Hassan

At the first Asia/Pacific Regional Convention of Disabled Peoples' International (DPI), held in Australia, the question of prime interest was: Why are disabled people at the "bottom of the barrel" in society and how can they improve their self-image?"

This question should merit special attention by the Third World as it is here that disabled people are at the "bottom of the barrel" and it is here that the image of disabled people needs to be overhauled.

Developed societies in Australia, North America, Western Europe and Japan are solving this image problem through equalization of opportunities in education and employment and through the provision of social security. In these countries, accessibility is improving and phrases like "a twisted mind in a twisted body" are seldom heard.

In a Third World country like Pakistan, the situation is much different. Here, mass poverty affects disabled people the most (they are the poorest of the poor). Inadequate education and employment opportunities, "internalized oppression" (a kind of psychological warfare), stereotypes borrowed from medieval English literature, the charity model and the lack of a cohesive movement and a united voice, have collectively ensured disabled people stay at the "bottom of the barrel". Poverty cannot be helped; it's the developing countries' fate, "kismet", or lot, to remain poor. As the rich get richer and the poor become poorer, disabled people will remain the biggest sufferers for reasons not difficult to understand.

Inadequate education and employment opportunities for disabled people are two more reasons why people with disabilities have low status in a developing society. Some schools simply refuse to accept disabled children on the plea that "they will have a bad influence on the non-disabled students!"

Special schools are inferior to normal public schools and children who pass out from these schools are not accepted for higher studies in "normal" schools and colleges, either because of their disabilities, low standard of education, or the commonest of all excuses: inaccessibility. (In one particular case, a home taught disabled student who had passed public school exams was refused admission in a college because the dean was of the opinion that "your presence would disturb others.") Small wonder that few disabled persons in Pakistan are qualified enough to land good jobs.

As a result of such attitudes and unequal opportunities, many disabled children are forced to seek vocational training in trades like dress-making, book-binding, basket- and chair-weaving, etc. without completing even their primary education. Although this gives

them a measure of self-esteem by affording them a chance to earn some money and not be a "burden on society," their lack of education and lowly jobs ensures their status, and therefore, self-image, will remain poor. In some cases, parents also hesitate to invest in their disabled children's education thinking it's a bad investment.

In a society where even well-qualified, non-disabled people have a tough time getting jobs, what chance do people with disabilities have? Even if a disabled person is as qualified as his non-disabled competitor (which is rare), the employer will always prefer the latter.

Social security, like unemployment allowance, is unheard of for disabled persons in developing countries, forcing many disabled persons who cannot get jobs to remain dependent on their parents, brothers, sisters and other relatives, or resort to begging.

Internalized oppression is a process whereby disabled people are made to believe what is said about them is true (i.e. terms like "invalid", phrases like "twisted mind in a twisted body" and stereotypes). They are "pushed" to agree to or accept the invalidating feelings. Thus a disabled person will believe that he/she is "sick" or at least, "inferior", has forfeited his/her right to a full life, cannot make decisions for him/herself, is the victim of a malevolent fate rather than a malevolent social system, is a burden on society and that his/her needs are met only by the kindness of people, based on their compassion and not their respect. Such image- and ego-destroying tactics are quite common in our society.

The disabled person's image and self-esteem also suffer because of the charity model. Traditionally, disabled persons have been looked upon as objects of charity and pity. Their institutions are usually run on charity and donations: funds are raised through emotive appeals and disabled persons are often portrayed as pitiable beings in need of sympathy.

Charity does not only mean giving money. It often comes disguised as quota systems within employment markets and educational institutions. Under such systems, disabled people are admitted to schools/colleges and employed in various government and semi-government departments whether they deserve to be or not. The quota must be filled! Isn't this charity? The proper thing to do would be first, to provide for an accessible educational and employment environment and then to ensure equal opportunities through legislation.

The self-esteem of disabled people can be greatly enhanced if they are given equal chances in education--including higher education.

And in employment, merit, and merit alone, should be the criteria. Certain jobs in which disabilities do not present any handicaps (like sedentary or desk jobs for people using wheelchairs) should be made available to properly qualified disabled persons.

Social security in the form of an unemployment allowance for unemployed and unemployable disabled persons is a must if they are to be saved from becoming a burden on their families or on the community. Similarly, families supporting disabled members should be given some form of support to ease their burden.

Other factors or influences which contribute to low self-image of disabled people are the following:

- Advertising, which glorifies "beautiful people" and implies that people with disabilities are misfits without a place in society. We must lobby for more realistic advertising which includes people with disabilities.
- The work ethic, which makes people valuable only if they can contribute work and taxes

to the community, implies that people with disabilities, who cannot easily produce goods or services, are inferior second-class citizens.

- The medical model, which portrays disabled people as "sick" and the permanent recipients of medical care, has also played its part to instill a poor self-image. We are all familiar with the term "invalid" which is Latin for "worthless."

The most important reasons for the low self-image of disabled people, however, is this: the lack of opportunity to handle their own affairs. History bears witness to the fact that people who can handle their own affairs or are strong enough to snatch this right from others, are always looked upon with respect and enjoy greater self-esteem than those who sit back and allow things to be done to or for them.

In almost all the developing countries, the affairs of disabled persons are controlled by non-disabled persons. Their institutions, special education centres, training centres and sheltered workshops are all planned and run by non-disabled "experts". Money is provided by non-disabled people, the highly educated and rich are all non-disabled. So where does this leave disabled persons? At the bottom of the barrel, of course!

Unless people with disabilities learn to fight for their rights and until they learn to be truly independent (meaning able to handle their own affairs by ridding themselves of the guardianship of non-disabled people), they will never be able to enhance their image and self-esteem.

The independent living movement and Disabled Peoples' International (DPI), with which we all are familiar, offer some hope. They are beacons of light at the end of a long dark tunnel. The light has reached the West. When will it reach the East?... In twenty... forty... fifty years, maybe more? If it is to reach us at all, it will require a revolution of thought and practice on the part of the disabled people.

Javad Hassan is President of the Association of Physically Disabled Persons, Islamabad, Pakistan. This article first appeared in Vox Nostra No. 2 (1990).

The Power of the Pen: Empowering Words

by April D'Aubin

Language, a powerful tool, affects our perceptions about ourselves, our neighbors and the world we inhabit. Recognizing the power that words have, people with disabilities have been working to create a new language of disability which portrays disabled persons in a positive manner. Publications produced by persons with disabilities and their organizations reflect this new lexicon on disability.

Currently efforts are underway to convince the media to adopt this new terminology, because they are the image makers in our society as they reach a mass audience. Many disabled persons have made an individual commitment to this change process by becoming media monitors.

A media monitor acts as a watchdog for negative portrayals of disabled people and responds to these by contacting the responsible source to provide constructive feedback. Media monitors may want to watch for the following:

- the use of emotional descriptions such as unfortunate, afflicted, stricken, confined, burden, defective;
- articles treating disabled persons as a homogenous group, eg. "the disabled";
- pieces which arouse fear, guilt, pity;
- reports which cast disabled persons as superhuman;
- pictures which show persons with disabilities as passive recipients of charity, services, etc.;
- cartoons which utilize negative stereotypes of disability to make a point or joke;
- photos which maximize the differences between disabled and non-disabled people.

When responding to a negative portrayal, a monitor may want to raise the following points with the media person responsible for the piece:

- A disability does not limit all areas of activity
- Impairment, disability and handicap are not interchangeable terms. The UN's World Program of Action defines these terms.

Impairment: any loss of psychological, physiological or anatomical structure or function.

Disability: any restriction (resulting from an impairment) of ability to perform an activity considered to be within the norm for human beings.

Handicap: a disadvantage that limits or prevents the fulfillment of typical social roles. Handicap is the function of the relationship between disabled persons and their environment.

- Reports should treat disabled subjects with respect and dignity.
- Disability and sickness are not synonyms. Disabled persons should not be portrayed as being sick. Avoid medical terminology (i.e. "the patient").
- Describing technical aids in factual rather than emotive terms. (Instead of saying wheelchair bound or confined to a wheelchair substitute wheelchair user or person who uses a wheelchair).
- If disability is not a central element in the story, don't report it.
- Avoid obsolete words that refer to physical and mental/psychiatric disability (i.e. cripple, feeble-minded, idiot, moron, imbecile, lunatic, etc.).
- Focus on the relevant issue rather than the disability. Avoid portrayals that have as their theme tragedy, suffering, struggle against insurmountable odds.
- In photos and graphics present disabled persons in integrated settings performing a variety of activities.

Avoid Old Speak Terminology:

Victim, cripple, wheelchair bound/confined to a wheelchair, wheelchair architect, the disabled, deformed, feeble-minded, idiot, moron, imbecile, mongolism, incompetent, insane, lunatic, maniac, unsound mind, mental disease, mentally ill.

Substitute New Speak Terminology:

Disabled citizens, disabled persons, persons with a disability, person

who uses a wheelchair, architect who uses a wheelchair, people with disabilities, person who is disabled by (name condition), person with mental disability, person with psychiatric disability.

Members of the media are encouraged to adopt New Speak Terminology.

April D'Aubin is COPOH's Research Analyst.
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Women and Disability

"So the blind girl leads a vegetable existence with nothing to look forward to except a dependent life as a burden on the charity of parents or relatives. She is usually hidden from visitors and strangers because the family is ashamed of her and because if the fact that there is a blind girl in the family were to become known, it might prove to be an obstacle in arranging the marriage of her siblings..."

Dr. Fatima Shah, Pakistan

Thoughts On Women And Disability

by Zohra Rajah

In the world at large, whether in the business, scientific or educational fields, we women are already considered second class citizens. But as disabled women, we experience dual discrimination--firstly because of our sex, and secondly because of our disability.

The discrimination can be quite severe, it can affect all aspects of our lives: education, employment, economic status, marriage, family and rehabilitation.

Education

Many disabled women are being deprived of their rights and society is being deprived of their talents and abilities do to lack of education. In many societies it is difficult to convince people that able-bodied women need to be educated; for disabled women it is worse. Due to traditional role perceptions, disabled women are given less encouragement to continue with education, despite the fact that, more often than not, they will need to be self-supporting.

The abilities of disabled women are often underestimated and channeled into vocational abilities like needlework, handicrafts, dressmaking, carpet weaving, etc. Very few foresee that disabled women may have the potential to be good business people, lawyers, administrators and programmers. Without education she earns a low income and lacks the opportunities to improve her skills.

Employment

Disabled people in general, and disabled women in particular, often find themselves unemployed, underemployed or in low-paying jobs.

Two laws have been passed in Mauritius--one for employment and the other for vocational training of disabled people. Our hope is that these new laws will facilitate disabled women getting the chance to be trained and get better jobs.

Marriage and Family

In marriage too, disabled women encounter more discrimination than able-bodied women because society judges physical appearance before considering our true selves. As disabled women it is doubly difficult for us to be accepted and our own sexuality discovered. The more obvious the disability, the more likely we will be thought of as asexual. Frequently, as disabled women, we begin to believe that we have no rights to sexual feelings.

Society may delude itself into believing that we are asexual, but this is certainly not true. We have the same feelings as any other person. Our disability may have some effect on our inner emotions, but it does not kill them as society assumes. In Eastern countries especially, people think that a disabled woman has no feelings. If an able-bodied man loves her, his parents will make fierce objections if their son attempts to marry a disabled woman.

If a woman becomes disabled after her marriage, she is sure that her husband will leave her for another wife. Or if she has children she will be judged incapable of looking after them. The children will be put in the care of grandparents.

Disabled women are further subjected to various other problems concerning pregnancy, child rearing and household work after marriage. Yet a recent study showed that a woman even with her lower half paralyzed can give birth to and rear a healthy child.

Organizations

There is a lack of women's organizations. We disabled women should continue to group together. The disabled women's movement should focus on all types of women and deal with the oppression they face. By expanding society's awareness to women's issues concerning their second class status, we will also help disabled women to push for equal rights. As disabled women we need to be considered as women first and our disabilities as a part that makes us special.

We need legislation for buildings to have ramps, free from stairs and other obstacles, so that disabled women can do their work on wheelchairs or crutches and not depend on others.

Disabled women need to become more involved in all aspects of life. We need to educate society to look beyond our physical problems and accept us as we are. After all, there are quite a few disabled women who have given us the proof that our handicaps should not stop us from going ahead with our lives, such as the young Indian girl, who after having one leg amputated, now performs classical Indian dance.

Zohra Rajah of Mauritius, Africa,
Deputy Chairperson of Disabled Peoples' International (DPI).
This article first appeared in Vox Nostra No. 2 (1989).

Literacy For Whom: Women With Disabilities Marginalized

by Diane Driedger and April D'Aubin

Almost half of the people with disabilities in Canada are illiterate,¹ and even greater numbers are illiterate in the developing regions of the world. Disabled women are less likely to be literate than disabled men.

There has been much discussion on issues pertaining to literacy during the United Nations International Literacy Year, 1990. Many articles focus on such topics as: the definition of literacy, the value assumptions underlying literacy campaigns,² why literacy is an important concern, programming components, the social benefits of literacy and enhancing literacy skills at various stages in the life cycle. Such topics address the important questions of what, when, where, why. Consideration also needs to be given to WHO requires literacy programming, because those with low literacy skills are not a homogeneous group. Disabled people, particularly disabled women, must be given specific consideration within the learner population. Literacy is both a gender issue and a disability issue.

Disabled People Forgotten

It is readily apparent that disabled people are not always considered when literacy is examined by mainstream researchers. For example, Broken Words, the Southam News Report on Literacy in Canada, failed to look at people in chronic care institutions or nursing homes when calculating the numbers of people who cannot read in this country.³ The World Charter on Education for All, the mission statement for International Literacy Year, mentions disabled people only once. Disabled activists report that major international conferences on literacy, such as the UN World Conference on Education for All, fail to address the needs of disabled people in a meaningful way.⁴

If the systemic barriers encountered by women and men with disabilities within education programs are to be eliminated, it is essential to consider disabled people's needs. Without attention to the needs of people with disabilities society, "will continue to produce an underclass which has the double whammy of disability and illiteracy."⁵ This article will highlight the barriers facing women with disabilities in becoming literate in both developed and developing countries. It will also discuss how to make literacy programs accessible to women and men with disabilities.

International Literacy Year intersects the UN Decade of Disabled Persons (1983-92). The UN's World Program of Action Concerning Disabled Persons established for all countries the goal of equalization of opportunities, which it defines as, "the process through which the general systems of society, such as the physical and cultural environment . . . educational and work opportunities, cultural and social life . . . are made accessible to all."⁶ The equalization of opportunities concept implies a vigorous program of barrier removal.

Equalization of opportunities remains a major concern confronting organizations of disabled persons. All over the world people with various disabilities have formed their

own self-help organizations to advocate with one voice for improvements in the status of disabled persons. There are many similarities between disabled people's struggle for empowerment and the feminist movement. In Canada, the Coalition of Provincial Organizations of the Handicapped (COPOH), a national cross-disability advocacy organization of disabled persons, works to ensure that the needs of disabled people are addressed by generic service delivery systems as opposed to segregated approaches solely for disabled persons, such as separate school programs for disabled children. Organizations such as COPOH and Disabled Peoples' International (DPI), the international self-help organization of disabled people, work to decrease disabled people's marginalization in society.

Historically, disabled people have been oppressed and marginalized, and continue to be disadvantaged throughout the world. In Canada in 1986, 39.2 percent of disabled persons aged 15 to 64 were employed compared to 70 percent of the non-disabled population in the same group. Statistics Canada's Health and Activity Limitation Survey (HALS) also indicated that 4.3 of disabled people have a university degree compared to 10.3 of the non-disabled population. Severe disability has a negative impact upon educational attainment.⁷ A Decima survey found that 45 percent of severely disabled respondents had eight years of education or less compared with 25 percent of people with mild disabilities.⁸ Yutta Fricke of Disabled Peoples' International (DPI) asserts that, the vast majority of the world's 500 million disabled people are illiterate and suggests that 350 million disabled people living in developing countries are without education.⁹ The disadvantaged position of disabled people is a direct function of the systemic discrimination they experience in every facet of life.

Disabled Women Marginalized

Women with disabilities experience double jeopardy, because they experience the negative effects of sexism and disability-based discrimination. In Canada, disabled women's take home pay is just slightly more than half of what non-disabled women earn. In 1986, HALS indicated that non-disabled Canadian women earned \$8,800 per annum whereas disabled women earned \$4,810.¹⁰ Disabled women in all societies are the poorest of the poor.

Women the world over are more likely to be illiterate than men. And disabled women are even more likely to be illiterate. Women with disabilities have added barriers that keep them from learning and these barriers are most acute in developing countries. Barriers such as lack of accessible transportation, steps into the school and families wanting to keep their disabled daughters at home to do chores prevent women with disabilities from attending school. Some disabled women's personal stories will be shared to illustrate these concerns. As Helen Levine, a feminist writer, explains, "The point in sharing one woman's experience, any woman's experience, is to get at the commonalties in every woman's life, to link personal and political in the service of change."¹¹

Joyce Joseph, a woman from Trinidad and Tobago disabled by polio during childhood, received little schooling growing up. She walked with difficulty, so her father built a small go-cart to pull her to school in as a small child. When she outgrew the cart, at age eight, her formal schooling ended. She then received some lessons from a tutor, but this did not last long as the tutor moved away. Thus Joyce describes herself as self-taught. Joyce learned dress-making skills from her sister and started her own business. Why couldn't Joyce just use a wheelchair, crutches or ride the bus to school? A wheelchair or crutches were not available to her, her family did not have a car and the bus seldom travelled into the area where she lived. These were barriers to education.

Korisha Mohammed, also from Trinidad and disabled by polio as a four-year old,

received little education. Even though her disability was not severe, she wears a leg brace, her family decided that she should remain in an institution after she became disabled. She lived there until she was thirteen years old, and received an elementary schooling during this time. After she was released from the institution, she was unable to continue her schooling, because there was no transportation available to the school and her parents could not afford a private tutor. But she has had secretarial training and has endeavored to complete her education. She is currently studying for her "A" levels (university entrance) in English literature. She is also working as a Stenographer III in one of the government ministries. Korisha says that because she was in a "special" school, she was not able to interact with other children. As a result, "I feel socially handicapped as an adult still."

Eileen Giron, a Disabled Peoples' International World Council member from El Salvador, explains that in Latin American countries families do not view education for disabled women as a priority. Families continue to be very protective of women with disabilities, especially blind women, not allowing them to go outside the home unaccompanied; consequently, it can be very difficult for these women to receive training of any type. Inaccessibility compounds the problem. Giron reported that the Catholic University in San Salvador is inaccessible, and that its administration is unreceptive to suggestions to retrofit the campus.

While more developed countries have government subsidized public education systems and a higher overall literacy rate for women, they are not immune to erecting barriers to disabled women. Judy Heumann, a disabled American activist described her educational experience as a wheelchair user: "I'd ride the bus for two hours in the morning and two in the evening--I'd get to school and not exactly get down to hard learning. Then I'd have lunch, then an hour rest period...In between that, we were being taken out for physical therapy and speech therapy. Every once in awhile some academics were taught, but nothing to strain the brain very much."¹⁴ There is still a tendency for the school system to believe that disabled children do not really need an education as they will not be working or contributing to society. The assumption is that they will either work in sheltered workshops or stay at home. Indeed, in Judy's class, this was the scenario in the late 1960's. Judy was the first student from that classroom program to enter high school. Eventually she became a teacher.

Obviously, attitudes are a large barrier to disabled girls receiving an education. In developing countries many girls are kept at home to help with household chores and rarely leave their yards to appear in public. Often, in developing countries families are ashamed of their disabled children--the community views the presence of a disabled member as a punishment for some sin that the family has committed. Fatima Shah, a founder of the disabled people's movement in Pakistan, reiterates, "So the blind girl leads a vegetable existence with nothing to look forward to, except a dependent life as a burden on the charity of parents or relatives."¹²

When there are few opportunities for basic education or training, disabled boys, not girls, usually receive them. And often blind or deaf boys will go to special schools run by the churches. In a few cases, disabled girls may also receive an education in church institutions. Rosallie B. Bukumunhe of Uganda came to the attention of two Anglican church missionaries who helped her gain an education. She is now a stenographer in her country, where fewer women than men in general receive a basic education.¹³

Society tends to view disabled women as less important to educate, as it maintains that they are passive recipients of care. As Zohra Rojahn, a mobility-impaired activist from Mauritius and Deputy Chairperson of Disabled Peoples' International, explains: "In many societies it is difficult to convince people that able-bodied women need to be educated; for disabled women it is worse. Due to traditional role perceptions, disabled women are given

less encouragement to continue with education..."¹⁵

Literacy can be viewed as a cross-disability issue; that is, it affects not one disability group, but all groups (physical, sensory, mental). Some disabled people have been denied the opportunity to obtain an education. This is especially true of people who have been labelled mentally handicapped. Peter Park of People First, a Canadian organization of people labelled mentally handicapped, explains the consequences of institutionalization, "Few members of People First know how to read or write. Many of us were not educated because we were institutionalized. Many of us are afraid to speak our mind or even organize for fear of being put back into an institution. We rely on tape for information but we need not only books on tape but also notes from meetings along with reports and other information. Most of the time it is really hard to get those kinds of things on tape."¹⁶

People with other disabilities also experience poor attachment to the education system. Decima researchers found that 21 percent of their disabled respondents, who were disabled while in school, reported lengthy interruptions in their education. Twenty percent said that they changed school because of their disability and 20 percent of that group reported attending segregated classes.¹⁷

Segregated education continues to be a reality even in industrialized countries of the world such as Canada, and in some developing countries they are considered to be the preferred route to follow. Ed Wadley of Frontier College in Toronto states, "People who are disabled tend to be slotted. We have a system that labels, categorizes, and pigeonholes people, especially those with cerebral palsy. They're thought not to be capable and they're streamed by appearances."¹⁸

Deaf people have many concerns related to education and literacy. And the issue is colored because cultural issues are involved, as American Sign Language (ASL) is a bona fide language. This factor prompts deaf people to prefer and advocate for education in separate deaf schools, just as Francophone Canadians insist that French be the language of instruction for their children. Many deaf people call for ASL to be the medium of instruction in deaf classrooms. Canadian deaf activists Carver and Doe write, "Education, however, as a social process does not begin in kindergarten and end at university or post secondary studies. Education or access to education becomes possible at the earliest age and ends with death... For the deaf the experience of education is equally lifelong but it is also oppressive."¹⁹ For Carver and Doe the education of deaf people is oppressive, because it is controlled primarily by upper class hearing men.²⁰ Deaf people are calling for greater involvement in and control of deaf education.

The Canadian Association of Children and Adults with Learning Disabilities points out that some people with learning disabilities are considered to be functionally illiterate. One critical issue for people with learning disabilities is access to books on tapes. A medical certificate is required currently to get access to talking books in libraries. This acts as a significant barrier to literacy for people with this disability, as medical doctors have little contact with learners and often no particular expertise in this area.

Where to From Here?

The problem of illiteracy affects the general population of every country. The barriers that confront disabled women will need to be confronted by the public education system in every country as a matter of course, not as a special consideration or afterthought. A two-pronged approach is required: improved access in the generic education system and adult literacy programs which include the needs of disabled people.

Like all disadvantaged groups, people with disabilities often require remedial measures to address past discrimination. Any remedial programming, such as adult literacy training, needs to pay special attention to the concerns of women with disabilities, as these women are most likely to be in need of such programming due to the consequences of double jeopardy. Adult literacy programs must not replicate current barriers found in education systems throughout the world: inaccessible architecture, discriminatory attitudes, medicalization of disability. Adult literacy programs should ensure that they reside in accessible locations, include line items in their budgets to meet access needs of disabled students (ie. alternate media supplies such as taped books for blind and print handicapped persons), ensure that programs are located in areas serviced by parallel transportation services, consult with organizations of disabled people for advice on how to best meet the learning needs of disabled people.

Generic education systems all over the world must begin to prioritize the needs of disabled students. For example, Khalfan Khalfan of DPI reports that the government of Zanzibar/Tanzania does not allocate any funding for the education of disabled people. When the needs of disabled learners are recognized and addressed, disabled children, particularly girls, will receive the same quality of education as the rest of the population, not a "watered down handicapped version". The integration approach, disabled persons argue, is the only way for disabled children to learn about how the rest of the world interacts and learns. Indeed, other children will be exposed to disabled peers and learn that they are the same as any one else. Attitudinal changes happen most effectively with children.

With acceptance from one's peers and educational opportunities, disabled girls will be in a better position to choose the kinds of careers that they are capable of doing. Often, as Zohra Rajah of Mauritius explains, "The abilities of disabled women are often under-estimated and channeled into vocational abilities like needlework, handicrafts, dress making, carpet weaving, etc. Very few foresee that women may have the potential to be good business people, lawyers, administrators, programmers..."²¹ With education, the women with disabilities of the world can achieve their FULL potential and contribute to our societies.

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Disabled Women Meet

by Diane Driedger

Disabled women from 12 Caribbean countries, Canada and the U.S. gathered in Dominica July 18 - 22, 1988 to share with each other and to identify and to develop leadership skills. The women were there for a "Disabled Women in Development Seminar" sponsored by the North American and Caribbean Region of Disabled Peoples' International.

The 65 disabled women and 20 disabled men discussed employment, sexuality, parenting, independent living and leadership skills. At the end of the conference, the participants made recommendations which they will take back to their Governments for action. Among these were calls for Governments to provide daycare for children with disabilities and to enforce existing legislation for non-supportive fathers to support their children. Indeed, through the seminar discussions it became apparent that many women with disabilities in the Caribbean are single parents whose partners are not supporting their children. Non-disabled Caribbean women also share in the same difficulty. Often men are not interested in having disabled women as their wives, but are willing to have children with them. Disabled women are often viewed as damaged goods.

In addition, the seminar participants called on governments to introduce legislation, prohibiting discrimination against disabled people in employment, which is around 99 percent in the Caribbean and about 61 percent in North America. Disabled persons at present know that they must also start their own businesses. Already, some of the disabled women have their own ventures in areas such as dressmaking and vending.

The participants also called for governments to ensure accessible education for children with disabilities. In the Caribbean disabled persons are often unable to attend school, because there is no transportation for them to attend. Generally, disabled people in the Caribbean are not well-educated and literacy levels are low.

Time and time again, the seminar discussions revealed that the most pressing issue for disabled people in the Caribbean is to come out of hiding from their homes into the community. Ways to encourage disabled persons to move out were discussed, such as self-help organizations holding events or visiting disabled persons in their homes and encouraging them to attend meetings. Disabled people's reluctance to move out is a result of social attitudes--disabled persons are generally ridiculed and stared at. In fact, their presence in a family is sometimes viewed by the community as a punishment from God.

The seminar's greatest impact was in creating solidarity among disabled women to face

social barriers. As Marie McQueen, a mobility-impaired woman from Guyana explained:

"It [the seminar] has helped me and others gain a feeling of unity with other people with disabilities. Sometimes it feels like it's only me, but there are disabled people all over the world... You tend to draw strength from each other."

The seminar also encouraged disabled women to go home and influence their Governments, women's organizations and societies for changes for disabled people. As Joyce Joseph, a crutch-user from Trinidad and Tobago explained:

"We need disabled persons to be in places where they can make decisions for themselves. I see Disabled Peoples' International having a real place within the disabled community."

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Conflict Situations and Disabled Persons

"In spite of the often difficult situations, disabled people are not giving up the struggle for freedom."

Henry Enns, Executive Director, Disabled Peoples' International

Disabled Refugees

by Henry Enns

According to the United Nations High Commissioner for Refugee (UNHCR), there were some 10 million refugees in the world in 1984. They were spread out in refugee camps in every continent except North America and Australia. The situation has not improved since then.

According to the UNHCR, a refugee is defined as "any person who, owing to well-founded fear of being persecuted for reasons of race, religion or nationality, is unable... to avail himself of the protection of that country." Each and every refugee is a person--a mother, father, child--with much the same hopes, cares and fears that we all have. Will I eat today? Will I live till tomorrow? Refugees cannot be sure of anything.

Among these refugees, several thousand have been classified as disabled by asylum countries, according to the UNHCR. They are physically, mentally or sensory disabled. According to the World Program of Action Concerning Disabled Persons, 10 percent of the population has a disability, and it is as high as 20 percent in some developing countries. Thus out of 10 million refugees, one might expect to find some 2 million disabled refugees. Yet only several thousand seem to exist among them.

The question might well be asked where are the others? What became of the disabled persons before or when the refugees fled to neighbouring countries? Were they left behind? If they were, where are they now? Did they die enroute to the camp? No one really knows or admits to knowing. It seems as though they never existed in the first place. Yet we know that they did!

Since 1981, the UN High Commissioner for Refugees has had a section for disabled refugees. Its purpose is to encourage countries to take more disabled refugees. It does this through a special plan called 10 Plus. Countries are encouraged to take at least 20 disabled persons and their families each year. This allows for long range planning. A number of countries have committed themselves to this plan--Sweden, The Netherlands, Switzerland, Finland, France, Belgium, Norway, New Zealand and recently, the U.K. and Canada.

Refugees are considered for resettlement using a number of criteria designed to predict prospects for successful integration, such as education, linguistic ability and family ties in proposed countries. Family ties are seen as especially important because they are directly correlated with successful integration. Sponsorship expedites a refugee's chance of resettlement, but everyone must still pass a medical examination. A whole family accepted for resettlement can be rejected at this stage if one family member is identified as being handicapped and thus a potential "burden" on society.

On the whole, immigration policies in most countries discriminate against disabled refugees. Countries only want the cream of the crop, the best trained and educated refugees and those who are physically and mentally "perfect".

Mentally ill persons are particularly difficult to resettle because countries claim they have no facilities to deal with cross-cultural mental illness. However, once diagnosed it is almost impossible to change the assessment.

In the camps the refugees are well aware of criteria for acceptance in each country. They are handed these as they enter. Rumors travel around camps regarding who is strict and which official is lenient. Because most doctors and officials are over zealous and often prejudiced, they label people falsely.

As a result of the strict immigration policies and the inadequate assessment process, tragic situations have occurred. Stories are told about families leaving disabled children behind in order that the rest of the family may be resettled. There are even reports of disabled children having to be killed. In other cases disabled persons have taken their own lives to save the rest of the family. What horrible guilt to burden a family with.

Clearly the plight of disabled refugees is a human rights issue that needs to be addressed by the UN and member states. Policies and procedures are based on a prejudicial perception of the abilities of disability as a "burden" on society. Yet it has been demonstrated over and over again that disabled persons make significant contributions to society. Surely the treatment of disabled refugees is in flagrant violation of the United Nations Declaration of Human Rights.

Henry Enns is Executive Director of Disabled Peoples' International.
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[Visit To Angola:](#)

Where Civilians are Disabled As a Strategy of LIC

by David Werner

Dr. David Werner, Director of Hesperian Foundation of California and author of *Where There is no Doctor* and *The Disabled Village Children*, visited Angola in September of 1989. The following is a summary of his article "Visit to Angola".

A visitor to the capital of Luanda is immediately struck by the many disabled men, women, and children hobbling along with the help of wooden poles or crutches. Most of the disabilities are due to amputation or polio, both the result--directly or indirectly--of the "Low Intensity Conflict" (LIC) to which the Angolan people have been subjected since independence. The incidence of polio is due to the breakdown of health services in a land where access to rural areas has been cut off by random but persistent terrorist attacks along roads.

This war against the Angolan people is largely due to the intervention of foreign governments. The US government, for example, has poured millions of dollars of assistance--much of it in the form of military hardware and training in the tactics of LIC--to UNITA (National Union for the Total Independence of Angola) the "Rebel", partly mercenary guerrilla troops sustained by South Africa.

The large number of disabled people is part of the strategy of LIC. Leaving people seriously disabled puts a greater economic burden on families and on the nation than does killing people. It also takes a bigger toll psychologically: disabled people remain far more visible than the dead.

I was invited to Angola to serve as a resource person at a training workshop on vocational rehabilitation of disabled persons. After a discussion of possibilities, we decided to actually try to make a variety of aids and appliances. For if disabled persons could master these skills, they would not only help to answer the mobility needs of the vast (and growing) numbers of disabled people, but would also have important work to do.

We scrounged bits of wire, old broken plastic buckets, blown-out car tires and inner tubes, bits of metal, old packing crates, and branches from ornamental trees. From these items, the groups managed to create a wide range of devices, including: a log scooter-board with wooden wheels; a folding sitting frame for a disabled child; a special seat and toys for a cerebral palsied child; a tray suspended by cord for one-handed transport; parallel bars for learning to walk; an enclosed swing made from a tire turned inside out; underarm and Canadian crutches made from tree branches; hand "shoes" soled with pieces of car tire, for crawlers; an arm rocker permitting a person with paralyzed arms to feed self; ramps for wheelchair access and for exercise; an orthopedic lift for a sandal, made from old rubber sandal; a pair of leg braces, made from a plastic bucket, designed for a little girl with a severe, progressive bowing of the knees; a large wood wheel with flat wooden spokes, lined with car tire (the design was later adapted for the wheelchair); an all wooden wheelchair, made from old packing crates.

Perhaps the most worthwhile part of the workshop was the growth of understanding and mutual respect that took place among the participants. We learned from each other, and a new sense of appreciation, camaraderie and self-confidence developed.

The disabled persons also talked about forming a network or association--which would be

a first for disabled people in Angola.

Our most sobering thought, however, was the realization that for every artificial limb or wheelchair or pair of crutches the members of our workshop produce once they return to their provinces, dozens of additional people will become disabled by the continuing war. We agreed that our rehabilitation efforts for and by disabled people--although important--do little to resolve the root problem. The root problem lies in a global power structure based on greed and unlimited acquisition for the few at the expense of the many, a power structure that strategically misinforms the public, while using illegal and immoral terrorist tactics to pursue its ends.

I returned from Angola convinced that the biggest changes regarding the disabled community in Angola need to be made in South Africa and in the USA. The US government must stop supporting terrorists who strategically disable individuals, communities and nations. The people of the United States must learn what their government is doing. They must know that it is violating international law and every code of human decency. They must know that such violence is causing untold death, disability, disease, displacement, and suffering.

They must see--and help their government to see--that in the long run there will be no winners.

NOTE: Since David Werner wrote this article, Namibia has become an independent state. Angola thus no longer borders on South Africa, and is therefore no longer a "security threat" to South Africa. We can only hope that this will result in the situation in Angola becoming more stable and less violent.

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Journey To The Middle East

by Henry Enns

In March, Marion Stroud, a member of the International Committee on the Mennonite Central Committee (MCC), and myself visited five countries in the Middle East to explore ways that MCC could support the grassroots development of disabled people. MCC is already involved in funding a community-based rehabilitation program in Husan Refugee Camp and in providing support to organizations of disabled people in Lebanon. We arrived in Jordan Thursday evening, March 3rd. In less than a month we had the opportunity to visit the Roman ruins in Palmyra, the pyramids in Egypt, the Dead Sea in Israel and Jericho, supposedly the oldest city in the world.

Spending some time in the area one can easily realize why tensions are so high. Distances are small, cultural perspectives diverse, historical and political systems vary greatly. In every country one is faced with the situation of the Palestinian people. Many of them live in refugee camps and all of them are treated as second class citizens in the countries they live in.

The Middle East is an interesting and beautiful region. From the snow-capped mountains of Lebanon to the desert sands of the Sahara, it has a diversity that entralls people. The people are friendly and curious as in any other corner of the world. Yet one senses a

difference due to the tight security measures in evidence everywhere.

It is a region where disabled people have only started to organize themselves recently. In the five countries that we visited, we met organizations of disabled people at various levels of development. In Jordan, the Futures Club organized itself only last year. In Lebanon, the country where ironically disabled people are the best organized, we had the opportunity to attend a symposium organized by Friends of the Disabled, OXFAM and MCC. As a result of this symposium, a national assembly has now been formed in Lebanon. In Egypt, a group of approximately 20 disabled people have started to meet together in an effort to organize themselves and form a national assembly.

The sense of powerlessness among disabled people was perhaps the most evident in Damascus. Even the war veterans felt it was impossible to change their situation in any way. Nevertheless, even in Damascus there is an emerging disabled movement. A small group has formed their own theater company and were performing plays in the local cultural centre. Their presentation, written by disabled persons, was one of the most powerful and moving presentations that I have ever had the opportunity to attend.

Palestinian disabled people probably face the most oppression of any group in the area. The United Nations Relief and Work Agency (UNRWA), is supposed to provide social services and health care for people in the refugee camps. On the whole, they have neglected their responsibility to disabled people. Only small projects exist that assist disabled people and they are usually funded by outside agencies. Palestinians are not allowed to join organizations in most countries, and it is thus difficult for disabled people to organize. The Intifada or uprising has caused a considerable escalation in the number of disabled people in the region. While there are no statistics on those permanently disabled, it is estimated that some 30,000 people have been injured. This figure does not include those who have been killed.

In spite of the often difficult situations, disabled people are not giving up the struggle for freedom. In Lebanon, the Friends of the Disabled, under the capable leadership of M. Kabura, have developed a unique independent living approach. Their peace efforts have gained them international recognition. Dr. Masad from Cairo is providing leadership to the development of the disability movement in Egypt. In Jordan, disabled people are working with the government to develop a new piece of legislation focused on the equalization of opportunity. During our visit in Damascus, a group of disabled people decided that they would attend a training seminar in May of 1991 to assist them in forming a grassroots organization.

Though the movement of disabled people in the Middle East is only beginning, there is a sense that it may develop very rapidly. It may well be that a new Disabled Peoples' International (DPI) region will emerge as disabled people continue to organize themselves in the Middle East.

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What Kind of Development?

"Disabled persons are rarely consulted about plans for their own welfare, for to

do so would imply their near-equality with the planners. Instead, it is common to find rehabilitation professionals and social workers feverishly setting up little empires..."

M. Miles, Pakistan

"We [disabled persons] look at development as a process of liberation--a process that combats domination and segregation."

A.K. Dube, Zimbabwe

What Do We Mean By Development?

by A.K. Dube

A useful definition of development cannot be relevant to us unless it derives from the situation in which we as disabled people find ourselves.

We tend to define under-development fairly easily because we continue to experience it and have become accustomed to it. In our context as disabled people, we assume that development occurs only if we wage a successful war against deprivation, poverty, discrimination, superstition, fear and condescension--all of which characterize our daily lives.

We look at development as a process of liberation--a process that combats domination and segregation. But, we must also be careful to reflect on what we mean when we say we are "dominated" or "oppressed."

The nature of domination is that it is systematic. It is not merely a question of one individual dominating another, but of one segment of society dominating other segments. Domination is dualistic. Each one of us is sometimes a dominator and sometimes we are dominated. We sometimes oppress and sometimes we suffer oppression. When we look at the broad spectrum of society, it is clear that there are those who oppress far more often than they are oppressed. It is essential to understand these features of the development/under-development process, as people can only liberate or develop themselves if they are able to identify the forces that constrain or oppress them.

Over the last few years, a new more uncompromising mood has been growing among disabled people. Increasingly, we are moving away from passively accepting the unfavorable situations that have been imposed upon us by a prejudiced society. We are seeing ourselves as disabled, not by the idiosyncrasies of our bodies, but by a world that is unprepared to respect our needs.

The plight of disabled persons has been aggravated by the role that society has prescribed for us. These roles are characterized by feelings of being powerless; things are just as difficult and impossible as they appear to be and that one simply has to accept them.

This "role conditioning" is central to many, if not all forms of oppression. The common factor is that people are conditioned to play roles that serve the needs of the oppressor.

We are beginning to rid ourselves of these feelings of being powerless and dependent and becoming aware that we can exert a great deal more control over our lives than we have been led to believe.

As we continue to come together in organizations of a human rights nature, we must examine ourselves and look closely at the roles of the oppressor and the oppressed. Our experience, coming as it does from years of domination and oppression, has made us learn certain roles very well. We now have internalized images of what is undesirable and what is desirable.

We should recognize that disabled people who have become models of success are not necessarily the best models because their success has been achieved in a world of domination where the definitions of "success" and "failure" are prescribed by the non-disabled, not by us.

We must ensure that we are learning the skills necessary to liberate humanity from oppression. As we organize ourselves, we must be careful that we are not learning the roles of how to manipulate fellow disabled people, or how to divide disabled people. We have the right to make our own mistakes, which is a characteristic of human beings, and we should not be separated from that.

Our organizations must above all else, be avenues for the personal growth and development of all members. The importance of enabling and empowering members to make decisions about themselves and for themselves cannot be overemphasized. Advice, information and specific programs must be established to reach out to impoverished members.

Our organizations should be open to giving and receiving ideas. They should be democratic in nature and responsive to the needs of the membership.

For further reading:

"Report of Leadership Development Seminar, Francistown, Botswana, August 14-16, 1986," available from the Southern Africa Federation of the Disabled (SAFOD).

"Report on DPI Seminar, Turku, Finland, August 21-24, 1983", available from Disabled Peoples' International (DPI) Secretariat, Winnipeg, Canada.

A.K. Dube, is based in Zimbabwe, is the Southern Africa Federation of the Disabled (SAFOD) Regional Development Officer.

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Why Asia Rejects Western Disability Advice

by M. Miles

Many western disability experts and international organizations now advise Asian governments to base their disability policies on prevention and community-based rehabilitation. This, they believe, will avoid the painful historical mistakes of western rehabilitation services. Most Asian governments are in fact doing exactly the opposite: building prestige "handicap palaces", large residential institutions and imitations of western high-tech specialist facilities. The reasons are not hard to find.

"Asia", which includes two thirds of the world population, can be treated as a unit only by over-simplification. However, I have reason to believe that most of the following applies throughout Asia (and large parts of Africa and South America).

Psycho-Social Factors

Most disabled persons throughout the world now live in communities where life is a daily and often losing struggle to meet physical needs. When the average, able-bodied person can barely satisfy his/her own needs for food and shelter, loving care, purpose and personal recognition, it is unrealistic to expect that much attention should be paid to the needs of disabled persons.

Rural development programs try to foster community decision-making and implementation. All families benefit when by their own labor or participation they get clean water on tap, roads, electricity, improved crops. But the average person with the minimal standard of living cannot be expected to be too enthusiastic about participating in the rehabilitation of disabled people, a weak, low-status and practically voiceless minority. Its uplift would bring little visible general benefit, and no immediate gain to any family without a disabled member.

For millions of families in absolute poverty, the birth of a disabled child (or an illness or accident producing serious impairment) places them in a slightly worse position than their neighbours. It may affect adversely the marriage opportunities of the rest of the family. There will be additional expenses. There is no hope that this new child will bring any upswing in the family's fortunes. Therefore, even the best-planned and -executed rehabilitation program will do little more than restore them to a position between hunger and starvation, with chronic illness, depression and debt their normal condition. Participation in a rehabilitation program will have only one certain effect: the rest of the village or neighborhood will know for sure that this family has a disabled member, a fact which they may have been at great pains to conceal.

Religious Factors

Religions of the world exhort their followers to act for the benefit of the weak and needy, sick and disabled. Exhortations to do good are rarely heeded unless the circumstances are conducive. But building credit towards an after-life is an inducement. Dropping coins into the blind beggar's bowl may lead to avoidance of punishment in the after life. Disabled beggars in Asia do not hesitate to remind the public of this possibility, nor do they thank the donor since they are aware that the intention is merely to acquire credit.

The disabled beggar asks for "justice". Since fate, karma or deity has deprived him, begging becomes his rightful duty and occupation: justice demands that his bowl be filled. If the unseen forces present a poor family with a deformed baby, it is the family's duty to exploit the deformity for financial gain. To straighten and untwist the limbs of the disabled child would be to fly in the face of providence.

Prestige and Visibility

The prestige disability project is a highly visible demonstration of compassion and charity. A huge building filled with gleaming gadgets is evidence of "something being done about disability". It can be shown to foreign visitors as evidence of good intent, and as a manifestation of the "modernness" of a developing country. It draws public attention to a neglected field. Rehabilitation professionals approve because their status is related directly to the amount of money splashed about. It is also more newsworthy to report that a 10 million dollar "handicap palace" has been inaugurated by the President than that 10

thousand disabled children have begun attending normal schools at no cost other than change of attitude on the part of the teachers.

Empire and Ego Building

Disabled persons are rarely consulted about plans for their own welfare, for to do so would imply their near-equality with the planners. Instead, it is common to find rehabilitation professionals and social workers feverishly setting up little empires, cornering a part of the rehabilitation market and defending it against all comers, regardless of the welfare of their clients.

Not everyone aspires to rule, but many desire the status of the ruler's court. Rehabilitation professionals may have a choice between working in a large city-based "handicap palace", visibly earning merit by benevolence, or slogging away at polyimmunization and home-based rehabilitation schemes in obscurity. There is little doubt which alternative the average professional will find more gratifying to his/her ego.

Political Inequalities

The rich and powerful in every country ensure that high-quality facilities are built for their own use, before anything is done about inexpensive and widespread facilities for the masses. The once-favoured practice of going abroad for treatment is becoming increasingly expensive. If governments propose to put resources into rehabilitation facilities at home, the rich and powerful require a good imitation of what they would find in western capitals. Unfortunately, the new facilities will be available only to a privileged few. The same resources could perhaps have created a national network of modest local rehabilitation centres.

Prevention Wins No Votes

The politician who provides an institution for 30 disabled children boosts his public image more than the one who immunizes 30,000 against polio. The benefit of the first activity is immediate and recordable on film; that of the second can be proved only years later and depends on accurate recording of statistics and a groundwork of epidemiology which are absent in most of Asia. An institution is relatively uncomplicated to provide and run. An immunization campaign may cost less and potentially bring far greater benefit, but it involves many people and complicated factors.

The very concept of prevention by immunization assumes a worldview of a logical, causal Universe. It assumes a degree of control over one's destiny and health, an ability to predict the future and to present statistical evidence of likely outcomes. However, this is not the worldview of the majority of Asians who live in rural areas at the mercy of natural elements and who have little education.

Inappropriate Training

Shortage of appropriate rehabilitation skills is the greatest single problem in developing facilities for disabled persons, and it will take many years to overcome. Two remedies have typically been tried and found wanting: (a) nationals are sent abroad for training (often they do not return or are unable to relate new skills to the local situation); and (b) expatriates are recruited to give training courses within the country (problems include inappropriate course material, inappropriate trainees, and assumption of either administrative or ex-patriate posts by trainees).

A sharp division is maintained between locally-trained professionals with theoretical

knowledge and academic qualifications who devise programs and the hands-on workers. The latter are few and poorly paid, and likely to remain so.

A third group, rehabilitation professionals who have trained and worked abroad for some time and decide to return to their country, may ultimately be the ones who make the system run. They suffer from the disadvantage of being geared to sophisticated systems, and many will naturally prefer to work in western-style "handicap palaces."

Lack of Credible Schemes

Many advisors urge the adoption of low-cost rural community-based schemes at a very modest level of professional skill. The difficulties into which low-cost, community-based schemes will certainly run are illustrated by the problems of providing primary health care. These include: (a) opposition from professionals and inertia of the status quo; (b) opposition from local communities, who know that if they accept the low-cost scheme they will never get a hospital; (c) difficulty of finding and retaining suitable front-line personnel, maintaining enthusiasm, providing adequate support and supervision, encouragement and some sort of career structure; (d) transport and communication problems; and (e) preference for curative medicine to the near-exclusion of preventive and education measures.

There will be other problems in the disability field. A greater stigma is attached to disability as compared with illness. The modest level of skills being disseminated means that positive results will be slow and the drop-out rate higher than in curative medicine. Even the West has little experience involving the community and the family of the disabled person in rehabilitation (the lack of information and expertise puts community rehabilitation further behind primary health care). Misinformation from qualified doctors is quite common in the disability field, and will be believed in preference to any other opinion.

A Tentative Alternative

It appears that what is needed is a via media between the big-city institution and the rural primary-level scheme. In order to achieve some visible results over a wide area in the shortest time using local resources, we have adopted certain priorities in the Community Rehabilitation Development Project recently started on the North-West Frontier of Pakistan; (1) towns before villages; (2) children before adults; (3) locally perceived needs before theoretical strategy; (4) small-scale before large-scale; (5) visible centers before invisible periphery; (6) well-motivated parents before indifferent ones; and (7) day-centres before residential work.

The plan is to discover well-motivated parents of disabled children living in towns (starting with population of 50,000 and above), to learn how they perceive their problems and what they would like to do about them, and to steer the action towards small, local day-centres, run by committees of parents and local professionals. All over the world the evidence is that, once mobilized, parents or close relatives of disabled children have the greatest motivation and stamina for the battle to establish and monitor appropriate services. This is a resource at present virtually untapped in Asia.

1990 Update

With the above-listed principles, the development movement in Pakistan's North West Frontier produced ten locally autonomous rehabilitation centres for children with disabilities, run by associations of parents and other interested people. Some of these small-town centres reached out to the surrounding rural populations. Several have acted as

resource centres, disseminating the Urdu-language information and advice publications of the Mental Health Centre (MHC). The MHC gave training in community-directed rehabilitation techniques to over 90 people, including some working with disabled Afghan refugees.

While thus acting as a regional resource base, MHC staff discovered the importance of reconceptualizing rehabilitation development efforts as described in: "Resource Centre Developing Information Based Rehabilitation." In Thorburn M., Marfo K. et. al (1990), Practical Approaches to Childhood Disability in Developing Countries: Insights from Experience and Research. St. John's, Canada: Project SEREDEC, Memorial University of Newfoundland, pp. 261-275.

M. Miles was Administrator at Mental Health Centre, Mission Hospital Peshawar, Pakistan from 1978-1990. He is currently Commissary for the Centre.

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Disabled People's Development Projects

"In practice the Self-Help Factory does address the issues of powerlessness and isolation. This is because it is entirely run by disabled people who get access to managerial experience and who develop their negotiating skills in the course of running the business."

Friday Mavuso, Soweto

Project Projimo: A Program For and By Disabled People

by David Werner

My main interest is in innovative community program where disabled persons themselves or members of their families take the lead in management, provision of services and decision making. My interest in program that are run by and help empower disabled persons comes from my own personal bias, for I, myself, have a physical disability.

PROJIMO is a Spanish word for 'neighbour'. But it also stands for Program of Rehabilitation Organized by Disabled Youth of Western Mexico. PROJIMO is a rural program run by disabled villagers to serve disabled children and their families. It was started in 1982 by disabled village health workers from an older community-based health program, Project Piaxtla, now in its 23rd year. In the early years of Piaxtla some of the health workers selected by their villagers happened to be disabled. As the years passed, some of these disabled persons proved to be among the best health workers. Perhaps this was because participation in the health work had brought them from a marginal to a central position in their community. For whatever reasons, they tended to work with

greater compassion and commitment than most of the able-bodied workers. In time, some of the disabled health workers became leaders in the primary care program.

The disabled health workers became increasingly concerned that they knew very little about meeting the needs of disabled people, especially children. Adding to their problem, the prices in the cities for braces or calipers, wheelchairs, therapy and other necessities for disabled persons, were often too high for the villagers to afford. The cost to get a child with polio walking could economically ruin the child's extended family. The orthopedic devices made by specialists in the cities also tended to be elaborate and heavy. They were usually fitted onto big boots that made the child feel out of place in her village. Surely, thought the health workers, there must be more simple, low-cost alternatives. Five years ago the health workers met with the other villagers of Ajoya to ask for community support to start a rural program for disabled children. The villagers responded enthusiastically and PROJIMO began.

Over the next few years, adventurous rehabilitation specialists with a sense of innovation and community commitment—including physical and occupational therapists, brace makers, limb makers, wheelchair makers and special educators—made short volunteer visits to the program to help teach their skills to the village health workers. As appropriate methods and skills were tried, they were drafted into a series of simple and clear guidelines, experimental instruction sheets, and handouts for families. These were tested and corrected over and over again, until finally they were put together to form the reference manual, *Disabled Village Children*. Today, among a wide range of rehabilitation services including physical therapy and correcting club feet and contractures, the disabled team makes low-cost lightweight braces, wheelchairs and artificial limbs at about one-tenth the cost of less appropriate models made in the cities. Word of the village program has spread and disabled children have been brought to the program from 10 states in Mexico. More than half come from the slums of the cities. In a village of 850 people, PROJIMO has helped meet needs of over 1,500 disabled persons, mostly children and their families.

PROJIMO differs from many rehabilitation programs in a number of ways:

- Community control. Unlike many "community-based" programs, which are designed and run by outsiders, PROJIMO is run and controlled by local disabled villagers.
- De-professionalization. The village team, although they have mastered many "professions" skills, is made up of disabled persons with an average education of only three years of primary school. Their training has been mostly of the non-formal, learn-by-doing type. There are no titled professionals on the PROJIMO staff. Rehabilitation professionals are invited for short visits to teach rather than to practice their skills.
- Equality between service providers and receivers. When asked how many "workers" they have, the PROJIMO team has no easy answer. This is because there is no clear line between those who provide services and those who receive them. Visiting disabled young persons and their families are invited to help in whatever way then can. Most of the PROJIMO workers first came for rehabilitation themselves. They began to help in different ways, decided to stay and gradually became team members and leaders.
- Self-government through group process. The PROJIMO team has been trying to develop an approach to planning, organization, and decision-making in which all participants take part. They are trying to free themselves from the typical "boss-servant" work relationship and form more of a "work partnership". The group elects its co-ordinators on a one-month rotating basis so that everyone has a turn. This leads to a lot of inefficiency and confusion, but to a much more democratic group process.
- Modest earnings. The PROJIMO team believes that they should work for the same low pay as that of the farming and laboring families they serve. They can see that the high pay

demanded by professionals and technicians is one reason that the children of the poor often cannot get the therapy and aids they need.

- Grassroots multiplying effect. The PROJIMO approach has been spreading in various ways. Locally, families of disabled children in a number of towns and villages have begun to organize, build playgrounds, and form their own special education programs in other parts of Mexico and Latin America to visit and take ideas back to them. Some programs have sent disabled representatives to work and learn at PROJIMO for several months so they can start similar programs in their own area.
- Unity with all who are marginalized. The PROJIMO team sees society's unfair attitudes towards disabled people as only one aspect of an unjust social structure. They feel that disabled persons should join in solidarity with all who are rejected, misjudged, exploited or not treated as equals. This feeling has led the team to become more self-critical and to seek greater equality for women within their own group.
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David Werner is Director of the Hesperian Foundation.

This article is reprinted from Community Based Rehabilitation News, April 1990.

Multi-Million Dollar Hatchery For Guyana

by Julie Lewis

Disabled people of Guyana have placed their feet on yet another rung of the ladder which leads to ultimate attainment of economic, social and psychological independence, development, and well-being.

This has happened with the commissioning recently of a multi-million dollar hatchery undertaken by the Guyana Coalition of Citizens with Disability (GCCD), with assistance from several funding agencies and organizations.

The hatchery project aims to provide honest employment for disabled persons by producing baby chicks and selling them to persons with disabilities to rear, thus enabling them to earn a living for themselves and their families in the first instance, and secondly to make a tangible contribution to the society as a whole.

The project is being managed by Diverse Industries for Citizens with Disabilities (DICD), the business arm of the GCCD. The board of directors of the company comprises four Rotarians and three members of the GCCD, two of whom are disabled. It is expected that gradually, more disabled persons will be appointed to the board.

Funding

Funding for the project came from two Rotary Clubs in Georgetown, Guyana through their affiliates in North America; the Manitoba League of the Physically Handicapped, with which organization GCCD is twinned; the British High Commission in Guyana, Action on Development for the Disabled (ADD) in England; Disabled Peoples' International and others.

Julie Lewis is a member of the Guyana Coalition of Citizens with Disability (GCCD).

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Soweto's Self-Help Factory: An Empowerment Lesson

by April D'Aubin

The majority of disabled South Africans face double discrimination: disability-based discrimination and racism.

"As a result of the combined affects of these two sources of discrimination, black disabled people in South Africa know only poverty and powerlessness. They are truly the poorest of the poor," explained Friday Mavuso of the Self-Help Association of Paraplegics, Soweto, (SHAP) at a Disabled Peoples' International (DPI) Independent Living Symposium which took place in Finland in 1990.

Mavuso and other disabled activists, under the auspices of SHAP, established Soweto's Self-Help Factory in 1983 to address the dual problems of poverty and powerlessness experienced by people with disabilities. The Self-Help Factory, a business development project managed and staffed by disabled people, combines the principles of self-help and business development.

A SHAP needs survey indicated that disabled people were living difficult lives, exacerbated by the lack of access to wheelchairs, transport, housing, employment, and income security. "The members told us that if they had access to work and money, then this would help them to solve other problems in their lives," reported Mavuso.

Originally SHAP attempted to find employment for its members in Johannesburg. "We did not want to further isolate disabled people from the general community," explained Mavuso. The lack of accessible transportation made this option unworkable. It became obvious that employment for disabled people in the Soweto township was what was needed.

In 1989 a second factory opened, and now 150 disabled people are employed, doing various tasks ranging from simple packaging to sophisticated electronic repairs. The Self-Help Factory's clients include: Gold Fields of South Africa, Carlton Paper, Hewlett Packard, various camera importers.

The Factory pays its workers wages commensurate to those of other employers, so those disabled people employed by the Self-Help Factory do not have to subsist on meagre government pensions. The Self-Help Factory stands in sharp contrast to North America's sheltered workshop system, which exploits disabled people's labour and maintains their poverty with a continued reliance upon welfare.

"In practice, the Self-Help Factory does address the issues of powerlessness and isolation. This is because it is entirely run by disabled people who get access to managerial experience and who develop their negotiating skills in the course of running the business," explained Mavuso.

Consumer goods are not the only product generated by the Self-Help Factory. Activists for the disability rights movement are an important by-product of SHAP's business initiative. Mavuso explained, "People who travel and work together also start discussing issues of mutual concern. In this way, disabled people in the project become conscientized

in disability issues. By being in control of our project, this also gives us access to telephones and typewriters. In this way we are able to become spokespeople on disability issues."

SHAP and the Self-Help Factory have received extensive media attention in South Africa. This has inspired other disabled people to develop similar self-help projects and to organize Disabled People South Africa, which has a membership of about 10,000.

Disabled People South Africa is working to ensure that disability is on the political agenda as South Africa draws closer to ending apartheid.

SHAP's self-help and development philosophy is having an impact at the political level, as well as the personal level: individuals are being empowered and society is being affected by disabled people's advocacy.

For more information on SHAP [click here](#).

International Solidarity

"Our people can be found
In every class and race
Of every age and nation
Our people are awakening.
We will not beg
We will not hide
We'll come together
To regain our pride."

Micheline Mason, United Kingdom

COPOH's International Involvements

by Diane Driedger

Disabled people are the poorest of the poor around the world. And 80 percent of the World's disabled persons live in the developing regions. There are also organizations of disabled people in over 70 countries. In recognition of these realities, the Coalition of Provincial Organizations of the Handicapped (COPOH) embarked upon its international program in 1985.

COPOH has been involved internationally through Disabled Peoples' International (DPI) since 1980. COPOH was one of the founders of the international coalition and one of its members, Henry Enns has served as Deputy Chair and Chair over the last decade. Thus, COPOH has its interest in international solidarity and it established an international committee for this work. COPOH decided to formalize its solidarity through twinning

projects, international exchanges and development education about disability issues.

Twinning

Since 1985, three COPOH affiliates have twinned, or formed partnerships, with organizations of disabled persons in other countries. Kingston, Ontario is twinned with Kingston, Jamaica; Manitoba is twinned with Guyana; and Saskatchewan is twinned with Nicaragua. These organizations have had exchanges, and provided expertise to each other in areas such as income generating and independent living. Both the partner in Canada and in the developing country have found the exchange of information and solidarity for disabled persons valuable. Indeed, COPOH has discovered that disability is a unifying force; there exist attitudinal and physical barriers to disabled persons' participation world over.

International Projects

In 1987, COPOH initiated projects with disabled persons' organizations overseas, through the Institutional Cooperation and Development Division (ICDS) of the Canadian International Development Agency (CIDA). To date, COPOH has carried out projects in El Salvador, Guyana, Jamaica, Nicaragua, Trinidad and Tobago, and Dominica. In all of these projects, COPOH consultants (disabled persons) travelled to the countries during the implementation of the project. These projects have centered around independent living as was the case in Jamaica, organization-building as was done in Guyana, Women's Literacy as was the case in El Salvador, and public awareness as has been carried out in Nicaragua.

In all cases, the projects were designed by the local organization and COPOH applied for funds and offered its expertise and moral support. COPOH sees itself as being in solidarity with its partners.

Development Education

COPOH started its development education program in 1985 with grants from the CIDA Public Participation Program. Initially, COPOH focused on educating the disabled persons' community about the issues facing developing world disabled people. This effort was successful in three twinning relationships being established. These initial efforts expanded into educating the NGO international community as well about the needs and concerns of disabled persons in the developing regions. COPOH hopes to have increasing contact with other NGO's to discuss disability issues and possible collaboration. If your organization has projects with disabled people, COPOH would appreciate hearing about them. Or, if you would like to discuss your organization's potential projects with disabled persons, COPOH is open to hearing about them. COPOH's address is: 926-294 Portage Ave., Winnipeg, MB, R3C 0B9 Tel: (204) 947-0303, FAX: (204) 942-4625.

Disabled Peoples' International

by Diane Driedger

"Disabled people of the world--join us in our struggle. Join us in our struggle for full participation and equalization of opportunity". (DPI Singapore Declaration, 1981). Indeed,

Disabled Peoples' International (DPI), an organization of people with physical, mental, and emotional disabilities, wants justice, not charity.

DPI has obtained consultative status with the United Nations, International Labor Organization, and UNESCO. It has been successful in airing human rights violations against disabled people at the United Nations Human Rights Commission. Perhaps most important, DPI has shown the world that people with disabilities are able to represent themselves effectively at the international level. DPI has been the catalyst for the building of organizations of disabled people in 100 countries around the world in the last 5 years.

DPI was officially born in December 1981 in Singapore. Four hundred disabled people from 51 countries attended the first DPI Congress.

The Constitution and Manifesto accepted in Singapore asserted the basic rights of disabled people as participants in society like everyone else: the right to education, rehabilitation, employment, independent living, and income security. The Manifesto also declared that disabled persons have the right to influence governments and decision-making processes through their own organizations. By the end of the Congress a new World Council was elected for DPI with 25 people, five from each of five regions of the world. This governing body would meet once a year in the next 5 years. To be a full member of DPI, an organization must be national, and the majority of decision-making positions must be filled with disabled persons.

National organizations are involved in a variety of issues. They lobby their governments for increased access to public buildings, employment opportunities, public schools, and transportation. Although all these issues are important, perhaps transportation is most fundamental. The ability to live independently depends on whether one can leave home for work and recreation. If there is no affordable or accessible transportation for many people who are mobility-impaired, they will have difficulty finding and holding a job. In many North American and European countries, governments fund public transportation, such as bus travel, for disabled passengers. In these systems disabled people usually pay the same fare as non-disabled bus riders.

In developing nations in Africa, Asia, Latin America and the Caribbean, a pressing issue for mobility-impaired people is the lack of wheelchairs, crutches, and prostheses. Without these aids, people with a physical disability crawl, scoot on leather or bamboo mats, or remain bedridden in parental homes. Because of this, many disabled peoples' self-help organizations are initiating wheelchair factories operated by people with disabilities themselves, with local materials used to produce wheelchairs designed for the local terrain.

Not only have these organizations addressed the wheelchair shortage, they have started self-employment projects. In Jamaica the Combined Disabilities Association has run a wood products factory since 1983. It is an integrated factory in which half of the employees are disabled and the other half are non-disabled. In Zimbabwe, the National Council of Disabled Persons has started small animal and vegetable farming cooperatives.

DPI's "Self-Help Leadership Training" seminars enable disabled people who are experienced leaders and organizers in their countries to share their expertise in forming disabled peoples' groups and in lobbying governments for changes. Self-help organizations are a vehicle for disabled persons to speak collectively to governments, society, and service providers for improved job opportunities, accessible public buildings and transportation, and education. After a 2-week seminar, newly-trained leaders return to their countries equipped with tools to organize and build their own groups.

In addition to conducting a development program, DPI has addressed international issues. DPI helped shape the United Nations World Program of Action Concerning Disabled Persons and the International Labor Organization's Vocational Rehabilitation Convention. In both cases, DPI was successful in incorporating key elements of DPI philosophy into these documents. Most important, the documents assert that disabled peoples' organizations should be consulted on policies that relate to disabled persons.

DPI was successful as well in bringing human rights violations against disabled people to the attention of the UN Subcommission on Prevention of Discrimination and Protection of Minorities. DPI was successful in appointing a Special Rapporteur, or reporter, on the status of disabled peoples' rights.

Disabled persons' rights as human beings are violated in wars and armed conflict every day around the globe. Thus, peace is a disability issue for DPI. It called for peace in its International Peace Declaration, issued after the DPI World Council visited Hiroshima, Japan, the site of the first atom bomb blast: "The creation of disability and the ending of life by the waging of war gains pace... Let us insist that the \$600 billion now spent on armaments is diverted to socially useful projects."

DPI, as an organization purporting to represent all the world's disabled people, recognizes the need to increase the representation of certain disability groups. Persons who are deaf and mentally handicapped must be represented more equally. In 1985, DPI resolved to involve more women in its leadership. DPI's goal is to increase the participation and representation of women to 50 percent at all levels of the organization in the coming years.

The participation of all disabled people will strengthen self-help organizations worldwide. All over the world disabled people are organizing to speak for themselves with, in the words of DPI's motto, "A Voice of Our Own."

This article originally appeared in *Rehabilitation Gazette* 28 (1987), pp. 13-14.

Additional Resources

- Community Based Rehabilitation News, AHRTAG, 1 London Bridge Street, London SE1 9SG, UK.
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