

Disability in the Developing World

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BENEDICTE INGSTAD

During the past two decades, there has been a considerable increase in professional interest concerning disability and rehabilitation in what may be called the developing world—most countries outside Europe and North America. The International Year of Disabled Persons (IYDP) in 1981 played an important role in promoting such awareness, locally as well as internationally. The increased interest in programs related to disability is also due to the strengthened position of organizations of people with disabilities in the rich countries and their lobbying and influence on general aid programs. It is now becoming more acceptable to include people with disabilities as a target group for aid to developing countries.

In 1983, the United Nations General Assembly signed a *World Programme of Action Concerning Disabled Persons*, which was followed by the Decade for Disabled Persons 1983-1992. The overall objectives of the *World Programme of Action* were to “promote effective measures for prevention of disability, rehabilitation and the realization of the goals of ‘full participation’ of disabled persons in social life and development, and of ‘equality’ ” (United Nations 1983:1). The program has developed 22 *Standard Rules on the Equalization of Opportunities for Persons with Disabilities* (United Nations 1994) that do not bind but rather serve as recommendations for the member states.

During the IYDP and the following decade, a large number of countries in the developing world developed official policies, laws, and action plans to ensure the rights of persons with special needs. Although action has not necessarily followed legislation and much still remains to be done, such documents are essential to ensure that services will be provided in the long run (Eleweke 1999).

This chapter will focus mainly on experiences and problems in implementing rehabilitation programs in developing countries. Most often, such programs are based on models developed by United Nations agencies or nongovernmental organizations originating in Europe or North America and need considerable adjustment to local conditions to succeed. However, before we go on to our main topic, we will touch on two issues that have strong bearing on the implementation of such programs: the problem of surveys and the question of attitudes.

Closely linked to this is the issue of *culture*. To what extent is it necessary and possible to take cultural considerations in planning and implementing rehabilitation programs, and to what extent are we able to do so? These questions will be addressed throughout the chapter.

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THE PROBLEM OF SURVEYS

Intentions to do something for persons with disabilities worldwide soon raised new questions, such as “who are they,” “where are they,” “how many,” “what are their needs,” and so on, and it was realized that very little was known. The World Health Organization (WHO), in connection with the launching of its program for community-based rehabilitation (discussed later), stated that about 10 percent of any population could be considered disabled in one way or another. This was meant to serve as a guideline for other countries planning their services. However, it was initially unclear how these figures came about. In later years, these numbers tended to be modified due to lower survey result figures from several member countries. The reason given for the initial relatively high figures was that malnourished children had been included.¹

This illustrates one of the problems with using surveys as a tool for the planning of services for people with disabilities—namely, finding and agreeing on a definition of what is and is not a disability. Which impairments and what degrees of severity should be included? The inclusion criteria have tended to vary in the extent to which surveys of people with disabilities from various developing countries have elaborated on these points (which they often have not), thus making global or regional comparisons very difficult.

Attempts have been made to classify disabilities through the *International Classification of Impairments, Disabilities, and Handicaps (ICIDH)* (developed by WHO 1980) and to estimate the costs involved through the disability-adjusted life years (DALY), launched by the World Bank (1993) in its *World Development Report*. *ICIDH* was developed in response to the need for a framework to describe the consequences of what we usually understand as chronic and nonfatal outcomes of disease. It describes three dimensions of consequences such as *impairment*, *disability* and *handicap*. *ICIDH* has served as a guide for community assessment and planning of (re)habilitation² programs and has underpinned national-level policies and practices that affect equal opportunities and social integration of people with disabilities (Goerdts et al. 1996). DALY aims at measuring the economic burden of both disability and mortality from more than 100 diseases in all regions of the world for the purpose of health care planning and policymaking.

According to the *ICIDH*, the statistical division of the United Nations Department of Social and Economic Development has established a disability statistics database that includes information on the prevalence of impairments and disabilities in more than 90 countries. A *Disability Statistics Compendium* (United Nations 1990) presented these data from 55 countries. It is interesting to note from this compendium that census questions that identify impairments produce lower reported rates than questions that identify disabilities. Among the 55 countries, impairment rates varied from 0.2 percent to around 6 percent, while disability rates varied from approximately 7 percent to 20.9 percent (Goerdts et al. 1996).

ICIDH and DALY, however, have been met with criticism from disabled people and their organizations as well as from social scientists concerned with the issue of culture and the problem of cross-cultural comparison. Pfeiffer (1998) argues that disability is not necessarily a burden and that time spent as a person with a disability is not time lost. Thus, he claims that classifications and measurements of the impact of disability are a treat to communities of people with disabilities. He points out that disability is not a health question but a political one.

By making disability a health question or associating it with health problems, the WHO contributes to the oppression of persons with disabilities. It contributes to the oppression when people with disabilities are actually the victims of class-based standards and barriers. (Pfeiffer 1998:519)

Bickenbach et al. (1999), however, argue against what they call the disability group approach to models for the classification of disabilities on the basis of constraints caused by physical, social, and political barriers. They claim that such a model is provocative but blurs the facts that some

barriers to functioning are also inherent in the impairment as such, and some barriers are not necessarily discriminatory in their intentions.

Keck (1999), in a study of the Yupno people of Papua New Guinea, demonstrates the problem of applying *ICIDH-1* and definitions of impairment, disability, and handicap to a society in which the explanation of illness and its consequences is totally different from that of biomedicine. She challenges the assumed objectivity and culture-independence of biomedical concepts by showing how Yupno ideas of “being different” are “closely tied up with, and only understandable, against the background of their theory of personhood and their medical system” (Keck 1999:275).

Kleinman and Kleinman (1996) criticize DALY for not giving a real picture of human suffering. They advocate that such an approach should be complemented by “narratives, ethnographies and social histories that speak to the complex, even contradictory human side of suffering. Absent this other side, the economic measurement of suffering leaves out most of what is at stake for peoples globally” (p. 15). Bickenbach et al. (1999), however, argue in favor of the revised *ICIDH-2*, which they claim takes into account many of the complaints to the earlier version made by groups of people with disabilities. The *ICIDH-2* version also tries to meet the anthropological critiques in that it is developed by means of a process of consensus involving both developed and developing countries. The WHO has conducted at each of the steps an extensive social-anthropological exercise called cultural applicability research (CAR), designed by an anthropologist specializing in the applicability of epidemiological instruments cross-culturally.³ Whether this meets the arguments made by Keck (1999) and Kleinman and Kleinman (1996), as discussed above, remains to be seen.

Despite the problems of definitions and criteria for inclusion, or perhaps because these problems have not often been raised locally, surveys are highly cherished tools by planners and politicians who usually see this type of information as mandatory before any discussion about action can be initiated. Thus, inclusion criteria become essential for political and economic reasons because results of a survey may indicate the standard of living or level of health care in a country as well as commit that country to future rehabilitation costs.

On the individual level, another more serious impact of surveys is that they raise expectations that often cannot be fulfilled. Clearly, a disabled person or family visited for the purpose of a survey will easily come to expect that something will be done to help them. However, only rarely will a rehabilitation program be able to help all those who are surveyed. A survey often exhausts most of the available donor money so that once the figures are completed, there is little more that can be done. For this reason, voices have been raised, especially from the organizations of people with disabilities themselves, to limit (or drop) the surveys and start to give help, on a small scale, to those in need and to expand help as needs arise. This has been a viable policy for many nongovernmental organizations (NGOs) but clearly not sufficient for government policymaking.

THE ISSUE OF ATTITUDES

In the field of cross-cultural disability and rehabilitation studies, a powerful “myth” stands out and influences much of what has been said and done, especially in connection with the IYDP. This is the myth that people in non-Western societies hide, abuse, and even kill their disabled family members. We saw this myth strongly emerging in connection with fund-raising during IYDP,⁴ underlying the design and consequently often the conclusions of many knowledge, attitude, and practice (KAP) studies and appearing in official documents from the WHO:

The survival of disabled people is even today threatened by attitudes, prejudices and beliefs common among non-disabled people. The resulting behavior has led to, and still leads to premature death caused by negligence. . . . Moral trespasses or “sins” and “evil thoughts” may remain hidden, but the appearance of disability in a family will make the

“sin” visible to all. In a close knit society, this may lead to rid oneself or one’s family of such obvious proof of evil-doing. (Helander 1984:34-35)

Elsewhere, I have argued (Ingstad 1995, 1997) that there are several problems attached to such a “myth.” First, it wrongly assumes that there is a direct link between what people say about their attitudes and beliefs and what they actually do. Second, such a “myth” breeds arrogance in the modern rehabilitation workers and blurs their vision to the fact that most families with disabled members try their best to care for their disabled family members; by underestimating their motivation for care, they may lose a valuable resource in rehabilitation. Third, it may also serve as an excuse for governments and hide the fact that premature deaths of disabled persons are more likely to be the result of general poverty and poor health care than the family’s lack of will to care. I am *not* saying that abuse and neglect never take place. However, we do not make single cases of child abuse to be typical examples of child care in industrialized countries. So why should we do so when it comes to the developing part of the world? Instead of making assumptions about developing countries in general, we should base our actions on actual knowledge, not the least of the numerous other factors besides “beliefs” and “attitudes” that determine the quality of care.

*What We Know About Beliefs, Attitudes, and Behavior*⁵

If we turn to the past, our knowledge of beliefs, attitudes, and behavior toward people with disabilities is scarce indeed and originates mainly from legends, folktales, and scattered historical sources that only scratch the surface of the topic.

We find statements in the Bible about disabilities being negatively stigmatized when people with psychiatric symptoms are seen as possessed by unclean spirits and physical impairment seen as the consequence of sins. We also find many such statements in the classical literature of Hinduism, some of which advocates concern and care for persons with impairment, while others state the contrary (Miles 1999). From studying Old Irish and Icelandic manuscripts, Bragg (1997) concludes that these sources show a very different picture, where aberrancy is seen as the mark of an outstanding person, a hero, a seer, or a god. In the old Norwegian fairytales, we find stories of children born with impairment who were seen as the offspring of the small people living underground, exchanged at night for the normal human child. Such children should be beaten or in other ways abused so that the original parents would feel sorry for the child, take it back, and thus bring the human child back to its parents. On the other hand, these same folktales also include stories about people with “strange behavior” or mild mental retardation who went from farm to farm doing odd jobs and being what we today call “integrated” in the community. In a Tswana folktale from Southern Africa, we hear about an albino girl who was initially kept out of the family because of her deviant looks. But when she managed to show her capacity as a hard worker and contributor to her household, she was accepted and loved even more than her lazy sister who was not albino.

The interpretation of such fragments of history and folktales, of which there are many more examples, must take into account that they are just as much mythical and symbolic in their message as an account of what actually took place in the old days. Still, they may tell us something about what people valued most and what was needed to be accepted and “integrated,” as in the story about the hardworking albino girl.

One of the first modern scientists to take an interest in the topic of disabilities cross-culturally was the anthropologist Robert Edgerton. With a special focus on mental retardation, he based his analysis on the anthropological database Human Relations Area File (HRAF), as well as fieldwork among American Indians and four different tribes in East Africa. He found large variations in both culturally prescribed attitudes as well as actual behavior. As an example, he mentions that among the Chagga of East Africa, where customs prescribed that even severely retarded people should be well treated, some fathers risked punishment by killing their severely

retarded infants. In contrast, in societies where such killings were accepted and recommended, many severely retarded survived and were well cared for and loved by their families. Thus, Edgerton (1970) draws the following conclusion:

So extreme is the dearth of existing data that most conclusions about the nature of mental retardation in these societies may remain quite speculative. Still, however inadequate these existing data may be, they are sufficient to call into question any notion that what is said or done about mental retardation in non-western societies is highly uniform from society to society. Quite the contrary is true. What is said and done is highly variable, so much that given the inadequacy of the present available data, it is difficult to generalize about this world at all . . . we must declare a moratorium upon facile assumptions, and upon programmatic polemics, and must engage in the collection of data that will answer our perennial and essential questions about mental retardation. (P. 555)

Whyte (1991a, 1991b) did a study of attitudes toward and management of a mental health program in two regions of Tanzania in connection with a baseline evaluation of a WHO/DANIDA program for mental health. She found that respondents showed a marked complexity in their attitudes toward different conditions. Different individuals had different feelings toward the same condition, and single individuals could show marked differences in attitudes toward various conditions. One of the most commonly expressed concerns was the inability to support oneself and to contribute to the family and the village. The practical burdens of care were seen to lie with the family and not with other members of the community, and large families were expected to be supportive and kind to their disabled members.

Goerdt (1984) studied persons with physical disabilities in Barbados. She found that they were not expected by others to fulfill normal adult roles, partly due to beliefs and concepts about disability and partly by their observations of what persons with a physical disability were actually able to do in that society.

From Nigeria, two different studies on attitudes of parents toward their disabled children show quite different results. Okunda (1981) found that among Yoruba parents of visually, auditory, and physically disabled children, the Western-educated elite were less favorably disposed to handicaps in children than those in traditional settings. Enwemeka and Adeghe (1982) found in their study that most fathers with physically disabled children were rather indifferent to their children. There were, however, highly significant differences between fathers with higher and low education; the fathers with high education were the most interested in their children. From Zimbabwe, a study by Jackson and Mupedziswa (1988) found that beliefs and attitudes expressed by informants toward persons with a disability often seemed to be in contradiction with how they acted toward them.

A collection of articles in *Culture and Disability* (Ingstad and Whyte 1995) discusses the concept of personhood as a central theme in understanding how impairments are perceived in a society and to what extent and on which conditions disabled people are included as full members of a society. From societies as different as the Maasai of Kenya, the Punan Ba of Sarawak, and those from Somalia, Botswana, Uganda, and Nicaragua, we are told how the acceptance of a person with a disability is not mainly a question of physical or mental condition but more of conforming to the defining characteristics of full personhood in the particular society. Such defining characteristics may be sociability or living together with other people and having a socially recognized father and thus rank and kinship identity, marriage, and children and the ability to contribute to the household economy. People with impairment may find it difficult to live up to such characteristics, but it is often seen as the responsibility of the family to make it possible. Thus, in many developing countries, personhood depends more on social identity and the fulfillment of family obligations than on individual ability.

The issue of personhood is followed up further in a collection on culture and intellectual disability (Jenkins 1998). In the introduction, Jenkins points out how capacities, potentials, and adequacies must be understood as socially constructed and ascribed and will thus vary between different local and cultural settings. The competence of a person is usually not doubted until it is

in doubt. However, in all local settings, there are persons to whom the presumption of competence is not extended or has been withdrawn. Thus, assumptions of incompetence may be based on various types of otherness such as race, appearance, mental capacity, or any deviance from local perceptions of “fitness.” Interestingly, though, childhood and old-age senility are not usually perceived as incompetence but rather as aspects of natural development and adequate humanness. Whyte (1998), in a case from eastern Uganda, demonstrates how in a society that values relatedness and mutual family support, the incompetence of mentally disabled persons lies primarily in their inability to extend and strengthen their families through social activities and relationships. As a result, a mental impairment may not be considered a problem if the person is able to behave in a socially acceptable manner and contribute somehow to his or her family. The modern school system, with a heavy emphasis on grading of children’s performance, brings in something new by seeing intellectual capacity as the main criterion for competence and thereby risks labeling children as dull who might otherwise be considered competent. Nuttal (1998), in a case from western Greenland, shows how disabled children from remote villages are taken far away from their families to get special education in boarding schools, while the teachers and authorities keep alive a myth that they are “dumped” and neglected by their families. He tells a touching story about a boy, Nils, with a hearing impairment, who was being trained by his father to be a fully competent hunter until taken away by the school authorities and sent to boarding school far away. Nuttal concludes that “not only was Nils categorized as incompetent, but his family were also left feeling a sense of inadequacy and incompetence at being deprived of caring for him” (p. 192).

Few studies have seriously tried to document the issue of “hiding” and “abuse” of people with disabilities beyond mere statements. Weiss (1998) is one exception. In a study of families with what she calls “appearance-impaired” children, she found that nearly 50 percent of all families in Israel that gave birth to children with major physical or medical defects chose to leave them behind at the hospital. Going in-depth into four families that eventually brought their disabled children home, she reveals a picture of hiding, shame, and despair but does not give the deeper insight into their life situation that enables us to understand how such situations are generated. She largely blames it on parental “attitudes.” Neither do we get an insight into characteristics of Israeli culture, society, and health care that may create a picture of abandonment that we recognize from European history but that fortunately seems to be exceptional these days.

This brief review of some studies on beliefs, attitudes, and behavior concerning disabilities and toward disabled persons shows us some of the global variety and the danger involved in drawing conclusions as in the WHO quotation that opened this section. It also shows us the need to understand the sociocultural context in which “attitudes” are acted out. Most of all, it shows us that we do not know enough, and more studies are needed on the life situation of people with disabilities in non-Western societies as a foundation for providing adequate rehabilitation services in developing countries.

REHABILITATION IN DEVELOPING COUNTRIES

We shall now turn to look at the development and implementation of programs for rehabilitation in developing countries. In doing so, I have chosen examples from Botswana, Zimbabwe, Palestine, and Eritrea, well aware that there are numerous other examples that could equally have represented the topic. Much-needed thorough analysis of rehabilitation experiences from (a large number of) developing countries remains (to my knowledge) yet to be written. In the meantime, I will use this chapter to give a contribution from the examples that I know best. What happens today, however, cannot be seen in isolation but must be understood on the background of a history, which, especially for the previously colonized countries, has strong links to the history of rehabilitation in Europe.

The Missionaries and the Colonial Powers

The first contact that people in developing countries had with what we today call rehabilitation came through missionaries and representatives of the colonial powers. These agencies, although seemingly quite different in their intentions, often walked hand in hand, and medical services, especially in the rural areas, were more often run by missionaries than by the colonial powers (Comaroff and Comaroff 1991; Vaughan 1991).

This was also the case for medical care regarding rehabilitation. Linked to education, also from the start a missionary concern, biomedical knowledge provided new options for treatment of conditions that previously seemed unchangeable. For missionaries preaching the gospel of love and mercy, the seemingly most disadvantaged members of a society would often become the focus of attention. Thus, many youngsters with physical or sensory impairment got their chance to health care and education by becoming the protégés of missionaries. Some missions would focus their activities only on people with a disability (e.g., the German-based Cristoffel Blinden mission, which for years has been running training facilities for people with hearing impairments in Africa). Another example is the Mission of Cyrene in Zimbabwe, where persons with a physical disability were taught to become artists (Devlieger 1998). Yet, for the most part, the mission's activities for people with disabilities have been part of their general setup of church, hospital, and educational services.

While missionaries were relatively few and often lived scattered throughout rural areas, the colonial powers brought a larger number of administrative personnel, often accompanied by family members. Settlers claiming land was a third category. These people brought with them their European standards and habits, and when some of their own children needed special medical care or special education, special schools and institutions were created after the model from the "mother country" at the time. These early services for people (mostly children) with disabilities were usually located in the capital or larger centers and catered to children of the newcomers and sometimes to the children of the local educated elite. While late eighteenth-century Europe recognized the benefits of special education for children with sensory impairments, those with a mental disability were usually sent away to large institutions or mental hospitals. This pattern, to some extent, has prevailed in developing countries. Lucky were those children with mental retardation whose parents could not afford or had not heard about such "help." In countries that developed a system based on (more or less official) segregation of races (e.g., South Africa and South Rhodesia, which is now Zimbabwe), the services developed for the "whites" clearly had much higher standards than those (if any) developed for the local non-whites.

The colonial powers brought with them the principle that assistance to people with disabilities should be financed through fund-raising and private donations and organized by specially committed groups or private persons. This coincided with traditions of almsgiving in religions such as Islam and Hinduism (Miles 1999), as well as with tribal traditions of the rich sharing wealth with poorer segments of the population. Until today, such principles, which we may call the "spirit of charity," have stuck to the services for disabled persons in many developing countries and may have served as a reason for the failure of governments to commit to full responsibility for disabled citizens.

The Role of Wars

Wars have always been a major "producer" of impairment, and war victims have always held a highly regarded position—provided they were on the "right" side. Bruun (1995) has shown how both sides in the Nicaraguan conflicts used war victims for their propaganda purposes. The Sandinistas depicted them as "heroes" and "martyrs" of the revolution and thus brought together connotations of religion and machismo, two important values in Nicaragua, with the values of the revolution. The political opposition, on the other hand, presented the martyr as-

pect but not the heroism. As victims of the wrong policy, those who suffered for a lost case therefore were liable to pity and provided for charity (Bruun 1995:202).

Following the two world wars, the building of rehabilitation centers and the introduction of disability pensions for war victims took place in many European countries. For instance, in Norway, a war disability pension was introduced after World War II, and it is interesting to note that the payment from this source is higher than that from an ordinary disability pension, thus marking the special honored status of a war victim. The Norwegians who joined the Nazis and were impaired fighting on the East Front would not be considered for such a pension. Rehabilitation centers and pensions for wounded soldiers have also been introduced in a number of developing countries following their wars for independence (see the case of Zimbabwe below).

In recent wars, we have seen how the plight of land mine victims has come up as a new agenda, attracting considerable funds and new attention. This has occurred despite the fact that land mines have been around for a long time and are probably accountable for a relatively small proportion of physical impairment in the world.

The United Nations and Community-Based Rehabilitation

As mentioned in the introduction, the United Nations General Assembly in 1971 adopted a *Declaration on the Rights of Mentally Retarded Persons*⁶ and a *Declaration on the Rights of Disabled Persons* in 1975.⁷ Both these declarations established the same civil and political rights for a person with a disability as for other people.

In a resolution adopted on December 16, 1976, the United Nations General Assembly proclaimed 1981 to be the International Year of Disabled Persons (IYDP) with the theme “full participation” and “equality.” In 1979, the Decade for Disabled Persons was proclaimed to be from 1983 to 1992⁸ and later prolonged for another 10 years to 2002, with the objective of achieving “a society for all” by 2010.

In 1982, a *World Programme of Action Concerning Disabled Persons* was adopted by the General Assembly to provide for effective international and national measures to ensure the full participation of disabled persons in social life and the development of their societies.⁹ It emphasizes prevention, rehabilitation, and the equalization of opportunities, and it encourages disabled persons to organize to make themselves heard. The coordination, implementation, and evaluation of this program are to be done by the United Nations Center for Social Development and Humanitarian Affairs in Vienna (International Labor Organization [ILO] 1998). A set of standard rules to be used as recommendations for member countries was developed on the basis of the *World Programme of Action* and adopted by the General Assembly in 1993.¹⁰

The IYDP in 1981 and the following decade, for the same purpose, were probably among the more successful ventures of this kind. Awareness was created globally about the needs of people with a disability and the promotion of *integration*, meaning that disabled people should participate in society on their own premises, and *normalization*, meaning that the various sectors of society should take part of the responsibility to see this happen.¹¹ Much of this discourse was strongly influenced by a debate that had been going on in the Scandinavian countries since the early 1960s, closely linked to the ideology of the welfare state and its concept of “equal rights” (Ingstad 1995).

The WHO had for some time been preparing itself for the IYDP. The idea of launching a program for community-based rehabilitation (CBR) was introduced in 1976 and was adopted by the World Health Assembly later that same year. The program was seen as part of the strategy toward “Health for All by the Year 2000.” It was no coincidence that the CBR program that was consequently launched by the WHO had many similarities to the debate that had been going on in Scandinavia during the previous decade, launching concepts such as *integration* and *normalization*. The head of the WHO rehabilitation department, one of three coauthors of the first CBR manual, was a Swede (a medical doctor),¹² and so was one of the other authors (a physio-

therapist). The program was planned especially for the developing countries and represented a first attempt to create a worldwide model that could be used cross-culturally. After field testing in nine different countries (1979-1982), it was recommended that governments should take urgent steps, in cooperation with the WHO and NGOs, to plan for an implementation of CBR within the context of primary health care (WHO 1982).

The WHO claimed that CBR represented a *new* approach, which in a sense was both right and wrong. As pointed out by one of its main critics (Miles 1985), it was wrong because the awareness for the need of decentralized rehabilitation measures building on local resources existed prior to 1976, and there had been scattered attempts at doing this in several developing countries. However, it was true in the sense that the CBR program was the first attempt at creating a rehabilitation model to be implemented on a worldwide scale.

The *model* of community-based rehabilitation, as seen by the WHO, is a low-cost way to reach out to persons with a disability by integrating rehabilitation services in already existing infrastructures. Four different levels of services have been identified, which correspond well to the organization of primary health care and its system of referral in most countries:

1. At the community level, the household is the main area for rehabilitation work and family and community members the important actors.
2. The county level is the first level of referral for rehabilitation problems that cannot be handled sufficiently at the community level. The person mainly responsible for CBR at this level should be the rehabilitation assistant, which corresponds to the village health worker found in many developing countries.
3. The provincial level is the second level of referral. Here we may find a provincial hospital with specialized health personnel (e.g., physiotherapist) as well as other rehabilitation facilities.
4. The national level is the third level of referral for rehabilitation problems that cannot be solved at lower levels. Here we find specialists such as orthopedic surgeon, cardiologist, and so on, as well as special institutions for rehabilitation. At this level, it is suggested that there should be a national coordinator of the CBR program who would often (but not necessarily) be located under the Ministry of Health (Helander 1993; Ingstad 1997).

The main *tool* of this CBR approach is a manual consisting of several different booklets with simple drawings and instructions to be used by family members and local supervisors in the training of persons with various types of disabilities. Thus, we recognize in the WHO-CBR approach the principles of *low-cost*, *community participation* and *simple technology* that were commonly found in discourses about “development” at the time.

The WHO’s initiative in CBR was closely followed by the ILO with a CBR program for community-based vocational training. Actually, the initiative of the ILO in the field of vocational rehabilitation dates back as far as 1921, when it explored how the obligation to employ disabled ex-servicemen, as well as methods of placing disabled persons in employment, might be introduced in national legislation. As a result of the conclusions adopted by the experts consulted and the legislative measures that were proposed, the vocational needs of disabled workers gained international recognition for the first time in 1925 (ILO 1998). The ILO continued to play an active role in the process leading up to the *World Programme of Action Concerning Disabled Persons* and passed its own convention and recommendation concerning vocational rehabilitation and employment at an ILO conference in 1983.

The ILO-CBR involvement differs from the one by the WHO in that it seems to be more concerned with advocacy and policymaking than with implementing a particular model for how vocational rehabilitation should be done at the local level. While the ILO had previously given technical assistance to the establishment of vocational training centers and sheltered workshops, it now turned to establishing programs aimed at giving assistance for disabled individuals to start informal-sector, income-generating activities. The ILO also emphasizes the mainstreaming of training and employment opportunities for vocational skills. Thus, ministries

have been assisted in adapting training facilities, curricula, and equipment for the inclusion of trainees with disabilities (ILO 1998).

The third United Nations organization directly involved in CBR is the United Nations Educational, Scientific, and Cultural Organization (UNESCO), with an emphasis on “education for all.” It states that special-needs education should not be developed in isolation but be made to form part of an overall educational strategy and of new social and economic policies. This implies a shift in emphasis from special schools and institutions to the integration of children with disabilities in mainstream schools and classes. This clearly implies great challenges to all involved parties, especially when it comes to the integration of children with mental or sensory impairment. A World Conference on Special Needs Education in Salamanca, Spain, in 1994 (attended by 300 participants representing 92 governments and 25 international organizations) put down a statement and framework for action on special-needs education (UNESCO 1994). Judging from a collection of “success stories” published by UNESCO, it seems that the principle of CBR has been used quite differently in projects in different countries. While some countries have put the main emphasis on enabling teachers to integrate disabled pupils in local schools, others have used the WHO-CBR model as a starting point for early stimulation and school integration (UNESCO n.d.).

In the early days of CBR efforts, the communication between the WHO, the ILO, and UNESCO seems to have been rather limited, sometimes more of a competition. One of the problems seems to have been that the various United Nations organizations tended to have their separate projects in various developing countries, attached to different ministries (Ministry of Education, Ministry of Health, etc.). Consequently, instead of joining forces, they tended to compete for government funds and public attention.¹³

Realizing this problem, the three organizations held a meeting in 1994 and came up with a joint position paper. The purpose of their joint position was “to clarify for policy makers and program managers the objective of CBR and the methods for implementing it” (ILO/UNESCO/WHO 1994).

Thus, they also managed to agree on a definition:

Community-based rehabilitation is a strategy within community developed for the rehabilitation, equalization of opportunities and social integration of all people with disabilities. CBR implemented through the combined efforts of disabled people themselves, their families and communities, and the appropriate health, education and social services. (ILO/UNESCO/WHO 1994:2)

What is new in this definition is defining CBR as a *strategy within community development*. This opens various ways of applying the concept that are sensitive to local cultural, political, and socioeconomic conditions, not just the implementation of one model.

The Role of Nongovernmental Organizations

With all its good intentions of implementing CBR, the United Nations system was faced with one big problem: its shortage of funds. This was also the problem of most countries involved in implementation. Thus, help was sought in international NGOs (e.g., the Red Cross) and in NGOs based in the more developed countries.

NGOs from more developed countries had long been involved in rehabilitation in developing countries, implementing their own ideal models and according to their own definitions of need. Such models tended to be isolated islands of local projects, mostly small scale, and sometimes in collaboration with local NGOs. Sometimes the support took the form of large buildings intended to be rehabilitation centers. These easily ended up as so-called white elephants—nice for a government to show off to visitors as a proof of engagement in the cause of rehabilitation but difficult to sustain when donor money came to an end. The new challenge for the

NGOs was to become partners in a development process that involved local government, local NGO(s), and a United Nations organization providing morale and sometimes short-term technical support.

Other types of NGOs are the international organizations formed by the disabled people themselves (e.g., Disabled Peoples' International, International League of Societies for the Mentally Handicapped, etc.). These have come to play a vital role as partners of dialogue in the United Nations developments outlined above and in disseminating information about human rights issues to sister organizations in developing countries. We often see that organizations started by disabled persons come into being in developing countries when a close family member of a prominent person in society becomes disabled. We have seen this happen in China, Nicaragua, and Kenya, to name a few countries. The problem with such organizations in developing countries seems to be that they easily become a city or elite activity advocating for specialized and centralized services for their particular group. Also, in a situation when there is a shortage of funds and positions for persons with a disability, they easily end up in internal struggle and eventually may split instead of joining forces. This was the case in Botswana, where for many years, two organizations by the blind and physically handicapped went into what seemed like an endless power struggle, which kept them from presenting joint demands to the government.

The idea that disabled people should be active in creating and running a CBR program is a central theme in the book *Disabled Village Children: A Guide for Community Health Workers* by David Werner (1987)¹⁴ and later in *Nothing about Us without Us: Developing Innovative Technologies for, by, and with Disabled Persons* (Werner 1998). The main difference between this model and the WHO-CBR approach is that it centers on the idea that the persons with disability should generate and sustain the activities that they perceive as necessary. Thus, this model is less than the one by the WHO, which is concerned with replicability but visualizes different forms of rehabilitation activities emerging from different sociocultural circumstances.

We can sum up a few of the main problems facing CBR in an early phase:

- There are unclear definitions of what a “community” is and its potential for mobilization, and the potential of a “community” for volunteering is overestimated. Is community participation often lacking?
- There is a lack of sufficiently trained people, which in combination with insufficient community mobilization, may lead to the program becoming an outreach program instead of community based.
- CBR (especially by the WHO) is presented to governments in developing countries as “cheap,” thus not sufficiently preparing them for the needs of future investment in training and infrastructure.
- The attachment of CBR to one particular sector or one particular United Nations organization may easily become a barrier for collaboration with other sectors.

The Present

The outline of the development of modern rehabilitation services in developing countries given above reveals a dilemma that gradually emerges in most countries. Should one aim at giving community-based services for all people with a disability, or should high-quality specialized services that invariably reach only a limited number of those in need be the first priority?

Outreaching services combining the expertise of, for instance, a physiotherapist or speech therapist based in a center with regular home visits in the district(s) nearby is a middle solution. This is, however, often costly (because of need for transport) and cannot reach everyone in need.

In most countries, however, the developments are not steered by government decision making alone but are the result of complex processes in which history, influences from foreign agen-

cies, and general socioeconomic development play important roles. We can illustrate this with two examples from the neighboring African countries Botswana and Zimbabwe.

The Case of Botswana

Botswana achieved its independence in 1965 as a result of political negotiations and without having to fight a war of independence. Being previously a British protectorate, the country had been seen mainly as a source of labor reserve to the mines of South Africa. This meant that few investments had been made, and few Europeans had come to stay for longer periods of time. The few activities that had taken place in rehabilitation had been mainly in terms of scattered and very limited NGO efforts. Since independence, as a result of large diamond finds, Botswana has had a blooming economy and is today one of the richest countries in Africa. It has also been blessed with political stability and a multiparty democracy.

In the launching of the WHO's CBR program, Botswana was chosen in 1979 as one of nine pilot countries for field testing and thus already had some experience by the start of IYDP in 1981. After holding several workshops with people from the WHO, it was decided to make the program nationwide from the start. One reason for this choice was the relatively small population.¹⁵ What was forgotten was the long distances that field-workers had to cover between settlements. A pyramidal structure was created with a Commissioner for the Handicapped at the top, located in the Ministry of Health. Social welfare officers (SWO) for rehabilitation are located in each of the district health teams, which are part of the primary health care (PHC) structure. At the local level, the SWOs are supposed to refer to the family welfare educator (FWE), which is the Botswana version of the village health worker. However, this collaboration has never been much of a success. The FWEs have always felt that they have had enough other things to do in PHC and that they have not received sufficient training to carry out CBR. They also feel that their superiors, the clinic nurses, have resented the interference of the SWOs in clinic routines. The onset of HIV/AIDS, causing more than 40 percent of all pregnant women to be HIV positive in some places and adults and children to be dying from the epidemic, has in recent years pushed rehabilitation of disabled people even further down the list of priorities. Without the FWEs to rely on, the task of community mobilization for CBR has become impossible for the SWOs, and their activities have become mainly outreaching and, to a large extent, transporting disabled people who need referral to hospital or rehabilitation centers. The SWOs have been mostly social workers with little or no previous training in rehabilitation. With a low salary and a feeling of insufficiency, the turnover rates have been high and the vacancies many. The CBR manual is not regularly used, and local participation and mobilization have been minimal.

Another problem impairing the national CBR program from the beginning was the launching of a parallel CBR program by the Botswana Red Cross, which was heavily supported by a foreign donor. Instead of collaborating to make the government program more successful, these two programs soon became competitive, leaving the SWOs with a feeling of insufficiency because they were not as well equipped with cars and funds for workshops as were their Red Cross counterparts. However, as the mobilization of Red Cross volunteers for CBR failed and the donor money eventually came to an end, the Red Cross chose to withdraw from CBR and is now concentrating its efforts on running a rehabilitation center.

With the nationwide CBR program being largely a failure or at least having become a structure with very little content, the field has been left wide open for various NGOs to take over. Some of these were established shortly after independence, catering to special groups of impairments (the blind, the deaf, the mentally retarded), while others, which have come more recently, aim somewhat broader (the multihandicapped, various types of physical disabilities). Two large centers, one in the north and one in the south, run some outreach CBR services in addition to their institution-based activities. There are also special schools for deaf and blind children, respectively. The various activities of the centers remain largely uncoordinated. This has occurred despite the establishment of a Botswana Council for the Disabled (BCD), which is supposed to function as an umbrella organization and allocate government funding for rehabil-

itation. However, for long periods of time, the BCD has been paralyzed by weak leadership or internal disagreements between its member NGOs.

Following the launching of a long-awaited National Plan for Rehabilitation in 1996,¹⁶ the Ministry of Health has allocated a fairly large sum of money to the BCD to distribute according to needs of its member organizations. Also, the Ministry of Education has provided funds for teachers' salaries at some of the special schools. Despite this, most special schools and centers still rely heavily on donor money and fund-raising through "charity walks" and private donations to sustain their activities (see Ingstad 1995, 1997, 1999 for further discussion of CBR in Botswana).

The Case of Zimbabwe

Zimbabwe, the former South Rhodesia, obtained its independence in 1980 after a civil war in which the black majority population succeeded in freeing itself from an apartheid system imposed by a white minority of settlers whose ancestors arrived from Europe around the turn of the century. Followed by some years of tribal power struggle, the political situation has, during the past decade, been seemingly calm (but increasingly tense) under the surface of a socialist one-party system. Although the reconciliation between the previous main opponents seems to have succeeded, one of the major political controversies has been the (still unresolved) issue of allocation of agricultural land from white farmers to the poor rural black majority. Despite being rich in agricultural and other natural resources, the economy of Zimbabwe has been deteriorating in recent years.

Although the white Rhodesians had established special schools and rehabilitation services according to European models for their own disabled children, very little had been done for those of the black majority. Following independence, these previously "white-only" schools were also opened for black children but were far from enough to meet the needs of the majority. However, these centers, with their well-trained staff, have become valuable resource and referral centers for more decentralized rehabilitation activities.

The civil war left Zimbabwe with many disabled war veterans, and one of the first rehabilitation activities of the new government was (with the help of donor money) to build a large rehabilitation center for people with a physical impairment, mainly war injuries. However, this center turned out to be exactly the "white elephant" that many people had feared and is today used more for multipurpose training activities.¹⁷ A pension scheme was also introduced for disabled war veterans.

CBR was introduced to Zimbabwe in 1982 by the local Red Cross Society and supported by a foreign donor, the same as the one supporting the Red Cross program in Botswana.¹⁸ However, contrary to Botswana's ambition of reaching the whole country right away, Zimbabwe decided to start small, in only one district. After three years of gaining experience and following a favorable evaluation, the Red Cross allowed the CBR activities in the first district to be run by government services and went into a second district, eventually to follow the same procedure there. After having gained experience from the Red Cross in these first two districts, the government felt secure enough to go on alone. In 1988, a policy was made giving the Ministry of Health and Child Welfare the responsibility for introducing CBR on a national scale (Chidyausiku et al. 1998). The process, however, has purposely been gradual, not only due to lack of funds but also because the danger of expanding too fast has been realized. Thus, by February 1999, about 55 percent of the country had been covered by CBR. Although the content and quality of the services vary somewhat between districts according to an evaluation report (Chidyausiku et al. 1998), the experience so far has been good. There has been a considerable amount of enthusiasm and participation locally, and the CBR manuals are regularly used and have been translated into the main local languages.¹⁹

Around the same time that CBR was introduced, the government of Zimbabwe²⁰ started a process of upgrading a large number of the district hospitals. Included in this upgrading were rehabilitation wards that were staffed with physiotherapists or occupational therapists. These have come to serve as important support and referral centers for the rehabilitation technicians

responsible for CBR at the district level. As part of the decentralization and expansion of rehabilitation services, the government, in collaboration with the WHO and the Red Cross, opened a school for rehabilitation technicians in 1981. This new cadre of health workers is given a two-year course covering relevant fields of knowledge for the dissemination of CBR to persons with various types of impairment. In addition to this, the University of Zimbabwe has commenced occupational and physiotherapy training. Thus, we see that CBR in Zimbabwe is part of a comprehensive government program at all levels (institution based, outreach, and community based) that aims at giving “rehabilitation for all.”

How is it then that Zimbabwe, despite a more difficult political and economic situation, seems to have been much more successful in its attempt at introducing CBR than Botswana? In Botswana, the dream of “rehabilitation for all” through CBR has been largely (although not officially) abandoned in favor of a model based on private initiatives, which may provide higher-quality services for some but can hardly reach persons with a disability living in the more remote areas. To the extent that these rural-based individuals are involved, it implies leaving their families to go far away to rehabilitation centers and special schools for a large part of the year. They may have problems maintaining contact with their family and home community, and when they return home, they often have a problem finding employment suitable to the training they have been given. One example is a primary school with boarding facilities for deaf children in Francistown in northern Botswana. Many of the children there come from remote villages and are transported to school by social workers. The children are taught sign language, but since the teachers hardly ever see the parents, the advantages of this type of communication are rather limited when they return home. Another example is that of two blind sisters I encountered in a very remote village in the Kalahari. One had been trained for two years at a craft center for the blind. The other sister had finished secondary school for the blind in one of the larger towns. She wanted to become a switchboard operator but had no options for further training. On her return to the home village, the first sister found that the material she had been trained to work with was not locally available. The other sister had but a few books in Braille on which to practice her skills. She became very depressed and eventually committed suicide. Fortunately, few stories end this sadly, but it clearly demonstrates the dilemma involved in choosing between the principles of giving less ambitious but perhaps more applicable training locally and more specialized higher-quality services. Ideally, one should not have to choose. Both options should be freely available for those in need. However, in developing countries, with limited economic resources and a shortage of trained manpower, options are very difficult to achieve.

In comparing the development of rehabilitation services in Botswana and Zimbabwe, we find that Zimbabwe has had certain advantages that are grounded partly in historical conditions and partly in political choices that have been made along the way.

- ❖ The need and motivation to do something were eminent as a result of the war, not mainly because of an International Year and Decade of Disabled Persons and pressure from the international community to “do something” (as in Botswana).

- ❖ When starting to plan the rehabilitation services at all levels, one could draw on local experts who had been trained by the institutions for the whites in the old South Rhodesia. This knowledge of what was needed must also have played a role in investing in the education of rehabilitation technicians and occupational and physiotherapists. (Botswana has no such training facilities.)

- ❖ The decision in Zimbabwe to start small and expand step by step was enforced by the size of the population as well as by the scarcity of economic resources available.

- ❖ Both countries established, under the Ministry of Health, an office in charge of planning, administration, and coordination of rehabilitation services in the country. Why the one in Zimbabwe seems to have been more efficient than the one in Botswana is difficult to say. It may have been a question of personality factors, most likely the result of differences in economic alloca-

tions and other support from government. It is, however, tempting (but probably controversial) to speculate whether a government based on socialistic principles is more likely to show willingness to promote equal opportunities for disadvantaged groups than one leaning more on ideologies of “private enterprise” and the “spirit of charity.”

Thus, while the main future constraint in Zimbabwe is the economic developments in the country and the nation’s possibility to realize its plans for rehabilitation at all levels, the problem in Botswana is more a lack of a sincere government commitment and a heavy reliance on the spirit of charity. Such commitment does not imply that all activities need to be government run and financed but takes overall planning, implementation, and coordination that demonstrate the willingness to promote equal rights for persons with a disability. Over the years, plenty of good intentions have manifested in Botswana’s National Development Plans but not enough in real action.

The New Role of NGOs²¹

The role and importance of NGOs internationally have radically changed during the past 20 years. While NGOs used to base their finances mainly on their own resources, they are today, to a large extent, supported by donor governments.²² Before, NGOs used to be involved in small-scale activities and only with local NGOs as partners. Today, they may be important actors in general aid policies in donor countries as well as in the policies of the World Bank and other United Nations agencies.

The role of international and local NGOs in rehabilitation has to some extent undergone the same change. Similarly, the concept and content of CBR have also changed. The emphasis is no longer mainly on the implementation of a model but more on a strategy based on community development and the promotion of equal rights. An international NGO may, in partnership with (a) local counterpart(s), serve as adviser to a government and focus on the following:

- integration of projects or programs for persons with disabilities into mainstream development activities;
- strengthening of ongoing rehabilitation activities in governmental and private sectors;
- support in development of governmental, national, and sector policies and guidelines;
- strengthening of interministerial collaborations and multisectorial approaches in rehabilitation.

In addition to financial support, in this new role, the NGOs will have to provide relevant technical input and accept more complex projects and programs with the need for macro-planning. This new role will emphasize the importance of technical and financial sustainability by promoting the development and strengthening of ongoing activities. The NGO has the advantage of being flexible, compared to the United Nations system. It is thus in a position to promote the necessary local collaboration between governmental and private initiatives and implementation, making sure that long-term responsibility will be in the hands of the different local players. This approach will need adaptation to the different local settings and thus will differ from country to country. Two programs by the Norwegian Association of the Disabled (NAD), in collaboration with other countries, may serve as examples.

Palestine

Thirty years of military occupation and being without governmental institutions resulted in a strong local NGO sector in Palestine. Therefore, the CBR program started in 1990 was an initiative of a consortium of 20 NGOs in different parts of the country. The implementation was done by the NGO through the existing structures and networks. The external input from NAD

was financial and technical support for documentation, research, planning, and training. Gradually, the complexity and geographical coverage increased. By 1999, the program covered approximately 60 percent of the population and included most of the relevant sectors (health and medical rehabilitation, social welfare, vocational training and job placement, and general education). Without a government structure, macro-planning and national policies in disability were lacking. After the peace process started in 1993, this became possible through the establishment of the Palestine National Authority. The main challenge for the program was to integrate the different activities into mainstream development policies and establish a functional collaboration between governmental and private sectors. Today, the NGO sector is still mostly responsible for grassroots implementation, while the government is gradually taking over the role of policy development and national planning. The main objective in the program has been social integration of persons with disabilities in their local communities. The program in Palestine was supported by the Norwegian and Swedish organizations, NAD and Diakonia. The two organizations were also to some extent coordinating support for disability programs from other international organizations.

Eritrea

Eritrea, as Palestine, has passed through a long period of conflicts, occupation, and war. By the time the CBR program was established, the new government was in place and responsible for all renovation, rebuilding, and development. The NGO sector was weak or nonexistent, and the government approach was very centralized and politically controlled. This created less space and flexibility in the program design, and the approach had to be different from that in Palestine. Some of the main features and conditions for the CBR program in Eritrea were that it had to be developed at the central governmental level and integrated into governmental policies and institutions. Interministerial collaboration needs political authorization before being implemented, and government employees are the focal point at all levels, from central level to community level. International NGOs thus will have to accept a limited and restricted role.

An important question is whether a centralized regime such as this can develop an environment conducive for the implementation of a CBR program and for the promotion of rights and integration of persons with a disability. As in Palestine, one important factor was the change in awareness that had taken place during the time of conflict and war. Persons with disabilities who had been injured during wartime were considered heroes and martyrs. This had a general positive effect on people and promoted community responsibility and inclusion. In addition, community development is the general government policy. Thus, the use of limited governmental resources focuses on support of community development, promoting local initiatives and responsibilities. From the beginning, the CBR program concentrated on development of national policies and planning documents. Technical training of governmental rehabilitation employees at different levels was also given priority. This bureaucratic approach was necessary for the integration of the program in the government structure, political support to the program, ownership, and development of the necessary technical competence. Compared with a program based on a vital local NGO sector, this takes more time and resources before it can produce results. However, there are advantages when it comes to sustainability and local financial and political support. The CBR program in Eritrea today promotes an inclusive policy in different governmental institutions as education, health, and social welfare. The main focus of the program is to support persons with a disability, their family, and the local community. In the future, the program will need to increase its geographical coverage and include the persons targeted in the decision-making processes.

Some lessons learned by NAD from these experiences are the following:

- Programs for persons with a disability are low on the priority list in all developing countries. Local governmental and NGO partners have to take the main and long-term responsibility for the projects and programs.
- International NGOs should not be involved in implementation of activities.

- Financial and technical sustainability can be maximized by external investments into already ongoing activities and activities with a local priority.
- International NGOs should provide technical support to programs for persons with disabilities according to need defined by the local partners.
- Persons with disabilities, their families, and the local communities should be included in planning and implementing CBR programs.
- International NGOs should be clear in their role and in input to a CBR program and promote cooperation between nontraditional partners in the communities (local NGOs, farmers groups, religious groups, etc.).

THE FUTURE

If we look further into the twenty-first century, some global problems of relevance for persons with disabilities can already be foreseen. Medical science has not only brought about an increased infant survival rate for normal and healthy children but also for those born with impairment. People carrying genetic disorders survive to adult age and may eventually have a wish to bear children, thus contradicting the principle of “survival of the fittest.” New reproductive technologies often lead to multiple and premature births. However, infants with a birth weight of less than 500 grams may survive today, although with increased risk of becoming disabled. Amniocentesis, genetic screening of fetuses, donor eggs and semen, and frozen embryos are not science fiction anymore but open up new possibilities for parents to create the “perfect child.” Thus, medical technology raises numerous ethical questions that we have barely begun to debate but will be even more pressing in the future (Davis-Floyd and Dumit 1998).

What type of society do we want? Should parents in their wish for the perfect child be allowed to use modern technology to achieve this goal? Or should any child, even those who are most severely impaired, have the right to be born? What consequences will prenatal screening have for those who are born with or acquire impairment anyway? Will they be even more marginalized, or will there be more resources to support them? What about prenatal screening and selective abortions to obtain a child of the desired gender, which rumors say is already happening among middle- and upper-class people in some Asian countries? What about the right of parents and unimpaired siblings to choose away a life with a disabled child that will clearly place great strains on family life? What about the right to choose not to identify and abort an impaired fetus (Rapp 1998)? For most of these questions, there are no simple answers.

Wars are not likely to disappear in the future, and modern wars have the capacity to affect even the unborn through radiation, chemical weapons, and the like. Chernobyl, so far, has been the largest atomic disaster during a time of peace but may easily be followed by other manmade disasters, creating not only illness and death but also chronic impairments and disabilities. The victims of land mines are now starting to receive their due attention thanks to the 1997 Nobel Peace Prize, the late Princess Diana, and other less famous but equally dedicated promoters of their case. A special vertical program for land mine survivors has been established in the WHO. Also, the Ottawa Convention for the prohibition and use of land mines was signed by 135 countries in 1997.²³ Although land mines are important as a political issue, they represent a minor cause of disability globally. On the local level, the problems and needs of mine victims are not much different from that of polio victims, victims of traffic accidents, or other physically disabling conditions. There is concern that the sudden increase in interest for their cause and the large sums of money involved may create land mine victims as a category more “deserving” of help than other people with disabilities. We have seen this happen in many countries, with war “heroes” becoming more privileged than others with disabilities.

What then will happen to attitudes and behavior toward persons with disabilities in the future? Will we see integration and increased empowerment, or will demands of the modern, increasingly technological society lead to marginalization and increase the gap between people

with or without the ability to stay on the “carousel” of modern living? We can only make a qualified guess. There is no doubt that the information technology (IT) revolution, with its new communication technology, opens new possibilities for persons with a disability. For instance, voice computers for people with cerebral palsy and access to the World Wide Web may also break the isolation experienced by some disabled persons and make them aware of the rights and activities of people with disabilities worldwide. However, such technology is not a good substitute for human contact and integration and, in a global perspective, will only be available to the economically (and educationally) more privileged in the foreseeable future.

The final but perhaps most important question concerns the family with a disabled member: Will it be able to cope with the demands of the future? We are already starting to see the consequences of demographic transition in the more (or perhaps overly) developed countries, with an increasing aging population and a decreasing or stagnant younger population to take care of them. These are the combined effects of improved health care and family planning, which are increasingly becoming evident in developing countries (Kalache 1994). People no longer die from their first stroke, necessarily, but may live for years with care-demanding handicaps. Longevity also gives rise to increased illnesses such as dementia, cancer, and diabetes. At the same time, families are producing fewer children, and the old family values of caring for the elderly are being challenged by new options for individual careers and consumer goods in the modern society (Ingstad et al. 1992).

New illnesses, such as AIDS, also create new problems in relation to disability, rehabilitation, and care by the family. With the younger generations diminishing in many countries, care for people with disabilities is left to the elderly, who are often also in need of care. The so-called home-based care for AIDS patients that is being introduced in many of the countries that are hit hardest by its effects tend to be little more than sending the dying patient home with a supply of gloves to be used by the caretaker. Faced with such an enormous challenge, the family, as a care unit, will inevitably have to make priorities in their caregiving, and members with a disability are quite likely to be the losers. If science eventually discovers medicines that can harness the HIV virus at a cost affordable to the hardest-hit developing countries, we may, at least for some time, be faced with large population segments that are chronically impaired and even disabled.

Yet AIDS is not the only threat to family care in developing countries. The process of what we call “development” itself causes changes that challenge old values and patterns of family life. The change from a subsistence-based to a money economy contributes to labor migration from rural to urban areas. It is mostly the young people who migrate, leaving the old and frail, persons with a disability, and sometimes also the small children behind. Ideally, the young people will contribute part of their salary to the village family, but sometimes all they find is unemployment. In addition, the salaries are often so low and the costs of living in the city so high that there is little left to contribute to the family.

Education, which is usually seen as having an indisputable positive value in development, also has its unintended consequences that affect people in need of care. The emphasis on personal achievement and career easily comes into conflict with traditional values of family support and caregiving. Young people no longer rate family obligations as their highest priority but are more concerned with achieving consumer goods and personal success (Ingstad et al. 1992). Education may also increase the gap between the able and the not-so-able but at the same time may give persons with a disability new possibilities for competence and a respected place in society.

In summary, the situation of people with a disability and their families in what we call the developing countries is one of both problems and hope. The struggle lies in poverty and the problematic life situations that many families face, whether or not they have a family member with a disability. A person with a disability will rarely fare better than the general standard of living of people around him or her and, in some cases, will fare worse. Thus, to improve the quality of life for people with disabilities does not only imply equalizing individual opportunities but also improving the life conditions of the whole *family* providing care to a disabled member. This again implies implementing rehabilitation programs that take people’s total life situation into consideration—not only the physical, economic, and political constraints for achieving “nor-

malization” and “equal rights” but also their values, knowledge and beliefs, and their perception of personhood—what we often call culture (Ingstad and Whyte 1995; Leavitt 1999; Miles 1996).

Another problem is the often lacking ability of governments at all levels to give priority to a group of the population that cannot normally be expected to contribute much to the national economy. The promises come easily during “International Years” and when donor money is flowing due to a sudden international fad. Sustaining such activities when the international attention turns to other matters is something else.

However, there is much hope. There is hope in the increased awareness of people with disabilities internationally and in the efforts that are being made to improve their quality of life through donor contributions and the continuous development of suitable models for rehabilitation at all levels. There is also hope in the increased global contact between disabled people’s organizations, which increases the awareness of the rights of the disabled and the need for integration and normalization. Only by joining all these positive efforts and thereby empowering the developing countries to help themselves can we hope someday to approach the goal of “rehabilitation for all.”

NOTES

1. Personal communication with Dr. Einar Helander, former head of WHO’s Rehabilitation Department.
2. In medical terminology, a distinction is often made between *habilitation* for those who are born with an impairment and *rehabilitation* for those who have become impaired later in life. For the sake of simplicity, this chapter will use *rehabilitation* for both purposes.
3. I am grateful to an unknown reviewer for making me aware of this point.
4. At least in the Scandinavian countries.
5. Parts of this section are based on an overview of the literature previously given in Ingstad (1997).
6. Resolution No. 2856 adopted by the General Assembly on December 20, 1971.
7. Resolution No. 3447 adopted by the General Assembly on December 9, 1975.
8. Resolution No. 37/53 adopted by the General Assembly on December 3, 1982.
9. Resolution No. 37/52 adopted by the General Assembly on December 3, 1982.
10. Resolution No. 48/96 adopted by the General Assembly on December 20, 1993.
11. The education sector should take responsibility for educating disabled children; the transportation sector should make public transport available and accessible.
12. Dr. Einar Helander.
13. This was the case in Botswana in the mid-1980s.
14. Previously well known for the useful primary health care handbook *Where There Is No Doctor* (Werner 1993).
15. At the time, there were fewer than one million inhabitants.
16. The process of formulating such a policy was started in 1987.
17. Personal communication with Mrs. Chidyausiku, head of Rehabilitation Department, Ministry of Health and Child Welfare, Zimbabwe, December 1999.
18. The Norwegian Red Cross Society.
19. Personal communication with Mrs. Chidyausiku, December 1999.
20. Supported by loans from the World Bank and grants from Norway.
21. I am very grateful to the Norwegian Association of the Disabled, especially Jens Mjaugedal, for a valuable contribution to this section.
22. For instance, in Norway, 30 percent of the government aid budget (NORAD) is earmarked for the NGO sector.
23. Among the countries that did not sign were the United States, Russia, and China.

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