Help for people with disabilities: do cultural differences matter?
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Since the Year of the Disabled (1981) and the Decade for Disabled Persons (1983–1992), many questions have arisen about how to understand and deal with disability in a multi-cultural world. To what extent can programmes developed in one place be successfully implemented elsewhere? What kinds of cultural and social differences matter and how can they be taken into account?

Until the 1980s most people with disabilities did not benefit from special programmes and policies. In the developing countries only a small proportion benefited from charity programmes or special education, mainly in urban areas. Very few people were reached by organizations for the disabled. Organizations run by the disabled were practically unknown. It was common for a blind or deaf person not to know anyone else with the same impairment.

The 1980s saw the globalization of disability programmes. Many developing countries undertook censuses to determine the nature and extent of the problems. Some initiated programmes for disabled people, often based on models taken from the developed world. Community-based rehabilitation programmes were launched in the spirit of primary care. In many developing countries, people with disabilities began to organize themselves in groups so as to promote their rights and interests. Today such groups in developing countries cooperate with similar organizations in Europe and North America.

However, progress has been uneven, and the majority of people with disabilities in developing countries are still not reached by training programmes. The few studies that have been made of community-based rehabilitation programmes suggest that they fail to respond to local realities and are more top-down than grass-roots in orientation (1,2). True community involvement may be difficult to achieve. While improvements in protecting the civil and human rights of persons with disabilities have taken place in some countries, many people feel that their most pressing practical needs remain unmet despite policies that seem progressive. The following questions serve to explore the gap that appears to exist between the assumptions on which programmes are built and the actual situations in which people with disabilities live.

What differences in cultural knowledge and perceptions affect attempts to implement programmes?
At issue here is the significance that people attach to various kinds of disability and the expectations they have about prognosis.

What kinds of social circumstances determine the situation of a person with a disability?
This question focuses attention on the individual in his or her context. In many developing countries an individual’s prospects depend on household resources, a fact that programmes often fail to take into account.

Knowledge and traditions

Knowledge about sickness, death and other misfortunes is coloured by perceptions of the body and how it functions, the place of the individual in the social order, and the cosmological forces that affect human beings. Many studies of local knowledge systems emphasize the “exotic” causes to which chronic conditions and disabilities are attributed. Witches, spirits or pollution resulting from improper behaviour may be regarded as the causes of mental or physical impairment. Such cultural explanations are ways of putting disability in context, of making sense of it in relation to social conflicts, moral lapses and the influence of unseen powers. They help people to understand an individual’s condition in terms of the whole life situation.

Causes often focus attention on family relationships and therefore they have implications for the family as well as the impaired individual. Explaining a condition as the result of conflicts, witchcraft or moral failure on the part of parents brings in the element of blame. In Botswana severe mental retardation may be labelled as mopakwane, said to be caused by the breaking of sexual taboos by parents during confinement. Families are often stigmatized for moral laxity when this happens, although mentally impaired children of the unions concerned are not subjected to this penalty. Thus impairment is put in a wider social and moral context, and disability is seen as a matter for families, not merely for individuals.

Identifying causes is often a first step towards treatment. In many health cosmologies, dealing with the reason for a condition holds out the hope of a permanent cure. Dealing merely with symptoms may only give temporary relief until another disaster strikes; the underlying social and moral problems remain. Eliminating pollution, counteracting witchcraft or making offerings to spirits are efforts to tackle the powers responsible for problems and thus to solve them once and for all. Of course, it often happens that a person with a disability does not improve when measures of these kinds have been adopted. Other causes may then be sought until the affected family accepts that the condition cannot be changed. It is at this point that people in East Africa begin to speak of the ‘work of God’, unalterable by the efforts of humans (3,4). The difference between misfortunes which can be dis-

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...elled and the workings of fate which cannot be changed only becomes evident over time.

In contrast, rehabilitation programmes are based on the cultural belief that disability can be diminished through constant effort, training, individual adjustment and, to
some extent, environmental adaptation. The goal is improved function, not cure. The individual is the object of long-term special attention. Here technical aids and training are the key, rather than attempts to eliminate the wider social and moral causes of the problem. Rehabilitation officers complain that families are insufficiently committed to such extended efforts over months and years, and that they are disappointed when there is no immediate improvement. There is a cultural gap but the problem is not necessarily that people are trapped by traditional beliefs about disability. Culture is a matter of experience and most people in developing countries have little experience of the results of effective rehabilitation programmes. Consequently there is little commitment and confidence until the value of programmes has been demonstrated.

Social circumstances

The economic and social circumstances of families are also significant in shaping the situation of people with disabilities, the vast majority of whom live with their relatives. The daily life and prospects of people with disabilities are greatly influenced by the income, size and social status of their households.

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Abuse also has to be seen in the context of household resources. Some impairments require so much special attention that a household may be unable to give the required amounts of time and personal care. Solutions such as tying up impaired persons or locking them in may be resorted to.

Rehabilitation programmes should take into consideration the differing abilities of families in order to conceal their existence. Even rehabilitation workers resort to such explanations when they do not succeed in persuading families to comply with their plans. Yet most families care for their disabled relatives to the best of their ability (1,5,6). It is in situations of dire poverty that household members are subjected to neglect, and people with disabilities are particularly vulnerable.

Two boys from neighbouring villages in Somalia had similar types and degrees of developmental disability. One came from a prestigious family and was treated well by his fellow villagers. The cause of his condition was said to be that his mother was of a lower status, but he was treated with the respect due to the son of an important man. The other boy was a homeless orphan. People said he had been affected by a spirit and children threw stones at him in order to hit the spirit. He was teased and despised. The explanations of cause reflected the boys’ different social circumstances. The orphan’s lack of family resources had a great effect on his situation, in addition to the cultural beliefs about disability.

Source: reference 4
Freed by treatment

In Botswana a man with epilepsy and mental impairment became so violent at times as to be a danger to others. To avoid catastrophe, the family kept him tied on a long rope in their yard. Given proper medication, however, he calmed down and the family was happy to release him, whereafter he walked freely around the village without problems.

households to cope with the care of infirm members. This is a matter of the human and economic resources available and of priorities for the use of such resources. Labour migration may result in some rural households consisting of only old, young and disabled people who are all dependent on remittances of money from towns, commonly sent on an irregular basis. Such households are in quite different circumstances from large ones with stable economic activities of their own and members who have the time and resources to pursue the possibilities offered by rehabilitation programmes.

Modern rehabilitation programmes are based on principles of individual rights and biomedical models of the body and its functioning. Autonomy, self-sufficiency and independent living are valued goals. Technical means of achieving them often focus on parts of the body, such as impaired organs, senses or limbs that can be compensated for or made to function better. In contrast, the reality for most people in developing countries is that of the individual in context: persons with disabilities are seen and value themselves in terms of their place in their households and communities. This does not mean that individuals do not also have goals for

Globally, there are cultural differences in explanations of disability and in expectations for treatment. There is a tendency to speak of cultural barriers in local societies, and to see culture as a burden for target groups. It should be realized, however, that programmes themselves contain assumptions and values that are cultural. In order to establish improved intercultural communication between programmes and their users it is first necessary to analyse the cultural assumptions of both sides.

Cultural differences should not deflect attention from economic ones. Differences in the social circumstances of households

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are just as important as the beliefs held about disability. It is difficult to help the poorest people because they often do not have the resources to reach and take advantage of existing programmes. It would be an oversimplification to blame
this state of affairs on cultural beliefs.

It is important to remember that culture is fluid. Disability programmes themselves are instrumental in reshaping ideas. In many developing countries there are few disability programmes, and those that exist function poorly and are not sustainable. Local perceptions are likely to change when it is demonstrated that people with disabilities can be enabled to help their families more effectively.

References


Early action prevents disability from leprosy

Most leprosy patients do not have disabilities or deformities when the disease first appears, and develop them later. Even when patients develop disabilities and deformities, they are mild and reversible to begin with and become severe and permanent only later on. Indeed, many conditions leading to disability and deformity can be cured if action [e.g., daily skin care, treatment of callusities, cracks and wounds, etc.] is taken at an early stage, and the development of disabilities and deformities can be prevented.