

Chapter 13

Disability and Rehabilitation: reflections on working for the World Health Organization

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Introduction

As a trained medical doctor I have been involved with disabled people and their families throughout my working life. Much of my work experience has been in the poorly resourced 'developing' nations of the majority world; first, as a voluntary worker in Africa and later as Chief Medical Officer of the World Health Organization's (WHO) Disability and Rehabilitation Team (DRT). Although my medical training impelled me, almost exclusively, toward individually based solutions to the problems encountered by disabled people and their families, these experiences led me to think that a wider, more holistic approach was needed commensurate with the notion of Community Based Rehabilitation (CBR). Notwithstanding that CBR may be criticised on several different levels (Stone 1999; Ingstad 2001; Barnes and Mercer 2003), it is, for me, an approach that is very similar to that advocated by disability activists such as Vic Finkelstein (1998) and sometimes referred to as the social model of disability. It is also a strategy that was advocated and adopted by the WHO's DRT following my appointment in 1990. To explain the reasoning behind this claim I shall provide a brief overview of the experiences that have influenced my views on CBR.

Learning about CBR

After my initial training in the medical profession I decided to specialise in paediatrics. Because of my interest in children's health, especially in poor nations, I decided to work in Africa. I spent more than five years as a voluntary worker in Uganda and Kenya. In order to gain a greater insight into the difficulties delivering effective health care and support in difficult circumstances, I chose to work in the 'bush' rather than in an urban environment similar to that of large cities. Through these experiences I quickly became aware that my training in western medicine had left me ill-prepared for

the situation in Africa, where the resources, including hospitals, trained staff and essential drugs, necessary for the delivery of the most basic of health 'care' services are extremely scarce. These experiences taught me that apart from our involvement in emergency health situations, such as injuries resulting from accidents, the most important intervention that medical and rehabilitation professionals could make is to provide health education to the general population. The aim is to give them the knowledge and skills to take responsibility for the prevention and management of minor diseases.

Upon my return to Italy and practice in western medicine I specialized further in children's neuropsychiatry. After a short while I was appointed as head of a children's rehabilitation department based in a hospital in which many multi-disciplinary teams were operating. It soon became evident that inter-professional rivalries within these groups were preventing them from functioning effectively. This was because individual doctors and rehabilitation professionals in the team tended to prioritise their own particular interests and involvement with patients, and they were not sharing information with colleagues. Also, as the multi-disciplinary team was staffed mainly by professionals 'allied to medicine' they concentrated almost exclusively on the bio-medical components of health. In so doing they overlooked the social elements of the health experience: in particular, that good health depends on the individual's sense of physical, mental and social well-being.

Through these observations I began to realise that the conventional individualistic medical approach to disability and rehabilitation could not provide disabled people with the facilities and support needed to achieve equal opportunities within their communities. Whilst retaining the role as Chief of the Interdisciplinary Team, I later accepted the role of Social Co-ordinator for Rehabilitation in the region. This gave me the opportunity to work with local municipal officials and council leaders. Through this involvement I tried to convince them that successful rehabilitation is about far more than medical interventions and treatments, and that it involves the entire community. Furthermore, they, as local leaders and policy makers, had a responsibility to ensure the well-being of all their citizens including disabled people.

Concerned that I would lose the insights and skills that I had learnt in Africa, I then returned to voluntary work with an Italian non-government organisation (NGO) working with people with leprosy. After joining this organisation I moved to India where I was involved in a community based support programme for people with leprosy in the slums of Bangalore. Here I witnessed first hand the stigma associated with leprosy and disability generally. It was also evident that the stigma associated with disability not only affects the individuals with impairment, but also their families, and, in the case of leprosy,

the professionals that work with them. Taken together these first hand experiences re-affirmed my growing conviction that in order to support disabled people in their own homes and reduce or eliminate stigma altogether it is necessary to educate the wider community that disability is almost always bound up with poverty and hardship.

While working with the NGO the organisation became involved with the WHO's Disability and Rehabilitation programme. At a meeting at their offices in Geneva, I met the then Director of the WHO DRT who invited me to observe and contribute to the establishment of WHO CBR schemes in developing countries on behalf the Italian NGO. The idea of launching a CBR type programme had been introduced in 1976 and adopted by the World Health Assembly later in the same year. The programme was presented as part of the strategy toward *Health for All by the Year 2000* (WHO 1988). It was aimed mainly at developing countries and was the first attempt to create a world-wide model that could be applied across very different cultures (Ingstad 2001). Subsequently, governments were encouraged to co-operate with the WHO and NGOs to plan for the setting up of CBR projects within the context of primary health care (PHC) (WHO 1982).

For the WHO primary health care:

is the central focus of health reform. It places a variety of services in the community's environment. Although the services lie largely within the domain of health professionals, PHC also incorporates community participation and promotes the concept of community ownership over health (WHO 1998: 4).

During trips to Burma and Mauritius I learned a great deal about CBR and was particularly impressed by the way in which this approach attempted to bring together the medical and social aspects of the rehabilitation process.

The major objectives of CBR are to ensure that persons with disabilities are able to maximise their physical and mental abilities, have access to regular services and opportunities, and achieve full social integration within their communities and societies (WHO 1998: 4).

Before implementing CBR in developing countries I felt it would be both beneficial and instructive to introduce a similar strategy to the area in Italy where I was still employed as the social co-ordinator for the regional rehabilitation programme. The reasoning behind this course of action stems from my sincere conviction that it is not proper to implement a CBR type approach in countries with few medical and rehabilitative if it is not equally

applicable to other social and environmental contexts. With hindsight, it was not an easy task to introduce CBR in Italy. This was mainly because the majority of the professionals involved held the view that CBR was ideally suited to the needs of those working in the developing world, but it was not applicable to the situation in developed nations and, therefore, not for them. Despite these reservations we devised and established a small CBR scheme as a pilot project. In a relatively short space of time the sceptics quickly realised that the constructive involvement of family members, neighbours and teachers in the rehabilitation process helped produce more positive results.

In 1990, I was appointed Chief Medical Officer for the WHO DRT. I was impressed by the CBR programme already in place and made plans to develop it further. Drawing on previous experience a key aim was to equip volunteers and family members with the knowledge and skills to provide rehabilitation services and support to people with impairments living in rural areas where there are no specialists. In the initial stages of the programme several pilot projects were set up in which voluntary workers were trained by international rehabilitation consultants.

However, although these projects were supported by donor organisations, it was not possible to implement this strategy in large rural areas due to a chronic shortage of funds. Further, disabled people's organisations were cynical about the benefits of CBR. They considered it an inappropriate strategy because the services were provided by family members and volunteers rather than by professionals and specialists and, therefore, lacked the quality of provision and support that was assumed to be available to other sections of the community. In response we tried to consider how primary health care professionals could provide rehabilitation as specified in the WHO's (1988) Declaration of Alma-Ata. Certainly we believed that in all countries, even the poorest, disabled people should have access to similar services and support that is available to all citizens, regardless of the degree or nature of impairment and, also, that they be served by the same health care system.

Implementing CBR

As already noted, a significant justification for the implementation of the CBR programme was the successful integration of disabled people into the community. But from the outset one of the main problems encountered when implementing CBR through existing governmental health care systems was the severe shortage of trained rehabilitation specialists in poor nations. Moreover, most of these worked in the large cities or the nation's capital while in rural areas medical services are usually provided by nurses. In order to overcome this

problem we devised a two way communication system whereby relevant information could be transferred from primary health care workers in rural areas to rehabilitation specialists working in cities and back again. In this way workers in the field could access specialist knowledge.

Several countries including Mongolia and Indonesia agreed to support pilot projects. These early schemes provided the kind of information needed for effective implementation. For example, established practice was for technical aids and assistive devices to be stored and distributed from a central location: usually in a large city. It was evident from the experiences of people working at a pilot scheme in Vietnam that the management and delivery of such items as prosthetics was significantly improved through the involvement of community based primary health care workers. It was also apparent that before the effective transfer of knowledge was possible, it was necessary to identify the different organisational levels involved in the national health care system. In general, three levels were identified; community, district and regional/central levels. It was also clear that regionally based specialists could not be held responsible for training rehabilitation workers at both the district and community levels as it would undermine the role of district level staff and their relationship with community based workers. To resolve the problem it was necessary to develop a cascade approach to training. Regional staff train district staff who, in turn, are responsible for training community workers. Also, to ensure that the flow of knowledge is both accurate and effective, follow-up and re-training schemes were incorporated into the training programme.

The WHO is concerned with the promotion and development of a holistic model of health care and support for all citizens. In reality though, its involvement with Member States' Ministries of Health mean that its main activities are inevitably limited to medical considerations and physical well being. Although many disabled people's organisations are concerned about the lack of adequate medical services in developing countries, their main concern tends to relate to disabled people's social well being and their exclusion from educational and economic activities. Whilst these considerations are outside the DRT's brief and are covered by various United Nations (UN) agencies, where possible we decided to adopt a multi-sectoral approach.

This approach was adopted in various countries including Guyana, Nepal, Cambodia and Eritrea. It involved co-ordinating policy initiatives at the national level that involved several government departments including health, social welfare, education and labour. However, we encountered several problems. First, whilst many health departments have staff working at the regional and community levels they are concerned solely with primary health care and are not equipped to adopt a multi-agency approach to health and rehabilitation.

Similarly whilst education departments have teachers in most villages they too are not trained for community development work, Further some government agencies although enthusiastic about disabled people's economic and social inclusion were, in most cases, very centralised and had very limited resources beyond the nation's capital.

In order to exchange expertise and avoid duplication the DRT collaborated with other relevant UN agencies such as the International Labour Organisation (ILO) and United Nations, Education, Science and Culture Organisation (UNESCO). Meeting colleagues from these organisations proved to be very productive. We were able to harmonize our programmes and in order to avoid different interpretations a Joint Position Paper on CBR was edited and distributed. In this way we were able to provide a more authoritative and unified approach in discussions with representatives of national governments and various government departments.

As a result, joint multi-sectoral pilot projects were established and developed in Ghana and Namibia. These were co-ordinated by staff from the ILO and were supported by each nation's Ministry of Social Welfare. However, it soon became apparent that where one government department is viewed as responsible for a particular programme, other departments will be reluctant to get involved and, most importantly, are not prepared to commit the resources needed to put the programme into practice.

To strengthen the multi-sectoral approach and to secure the participation of disabled people's organizations in the development of and co-ordination of rehabilitation policy, it was decided to organise national CBR committees in many nation states. The committees included representatives from disabled people's organisations, staff from relevant government departments, and delegates from NGOs. Unfortunately, the impact of these committees was not always as effective as had been hoped. It was concluded therefore that an international conference would be useful in order to exchange ideas and develop new ideas. This event was organised and coordinated with the help of the Indonesian Ministry of Health.

Several important issues were discussed. One of the most interesting outcomes concerned the location and membership of the national committees for CBR. It was suggested that in order to avoid the problems of inter-agency rivalry, and reluctance on the part of some government agencies to become involved in disability and rehabilitation issues, that future multi-sectoral initiatives must be co-ordinated at the highest level. In the case of South Africa and Mexico this meant that they were situated in the President's Office. In addition, the Committee must be chaired by someone with sufficient authority

to ensure that the different stakeholders participate in an effective and appropriate manner. It was also suggested that these committees should not operate in isolation. A similar structure had to be in place at the community level. Furthermore, as with the national bodies, these groups must be chaired by a local leader, village chief, or someone with similar local standing. Community based committees should also include delegates from across the community. These might include women, children, religious leaders and representatives of other local organisations. In situations where local CBR committees needed the input of government departments and ministries in order to achieve their designated goals, they should elicit support from established regional and national administrative authorities such as the Governor's office. Such a structure was tried and tested by the WHO and International NGOs in Eritrea with the full support of the national Government.

However, there is a well-established link between disability and poverty. Indeed, the main causes of chronic illness and long-term impairment in 'majority world' countries are poverty, inadequate sanitation, poor diet and bad housing (WHO 2001a). But in developing countries poverty is a general experience and not confined to disabled people. This raises the question is it fair to ask poor communities to take responsibility for the support of disabled people?

In response, the WHO developed a programme of action to address the problems of what are often termed 'slum communities'. These are areas characterised by squalid, usually urban, environments with few or no public amenities and populated by desperately poor people living in overcrowded and often unsanitary conditions. Workshops were organised for slum dweller leaders in Manila in the Philippines, and for refugee leaders in Kampala, Uganda. The proposed CBR programme was presented by WHO workers and the discussions that followed were extremely positive. Delegates were generally agreed that not only could a well-organized CBR programme promote equal opportunities for disabled people 'but that the promotion of a caring community will reinforce community linkages and promote inter community development' (WHO 1998: 16). Participants identified a number of potential problems and proposed several recommendations on how CBR could be implemented under such difficult conditions.

A little funding was made available for initial training but community leaders were confident that they could mobilise existing community resources. It soon became clear that commonly held assumptions about people living in 'slum' conditions are often quite incorrect. A frequently held view is that such communities have scarce resources, and are in desperate need of help and interventions from external sources. But although the environment may be poor,

the people who live there are often rich in human kindness and solidarity. In my experience, people in very poor communities are both keen and able to help and support the poorest among them. For example, it was proposed that to be effective, the CBR programme must address the needs of all disadvantaged groups within the community. In addition to disabled people these included women with HIV and AIDS and children who had been abandoned, or had no-one to look after them.

It was also apparent that no single CBR strategy could be implemented across all communities. Indeed, different communities within the same country often have different needs. A CBR approach has to be flexible enough to adapt to the differing needs of different communities. In order to make a positive impact, CBR must belong to the community and reflect the culture and needs of the host community and not the theories and practices of external experts, international agencies and NGOs.

Revising the Disability and Rehabilitation Team's activities

The work of the Disability and Rehabilitation Team (DRT) is bound to follow the WHO's Constitution. In this, health is defined in terms of physical, mental and social well-being. Additionally, the WHO Declaration of Alma-Ata states that primary health care should address the main health problems within the community. To fulfil this goal preventive, curative and rehabilitative services should be provided along with general health promotion strategies. Furthermore, the DRT is also committed to incorporate the approach of the United Nations (1993) *Standard Rules on the Equalisation of Opportunities for Persons with Disabilities*. This was introduced following the UN Decade of Disabled Persons (1982-1992) and comprised twenty two 'rules' to facilitate full participation and equality for disabled people. These cover all aspects of daily living, including awareness raising, medical and support services, education, employment, leisure and cultural activities. The DRT is concerned with the first four rules. These cover awareness raising, medical, rehabilitation and support services and are considered as preconditions for wider social participation:

Rule 1: States should take action to raise awareness in society about persons with disabilities, their rights, their needs, their potential and their contribution,

Rule 2: States should ensure the provision of effective medical care to persons with disabilities

Rule 3: States should ensure the provision of rehabilitation services to persons with disabilities in order for them to reach and sustain their optimum level of independence and functioning.

Rule 4: States should ensure the development and supply of support services for persons with disabilities, including assistive devices, to assist them to increase their level of independence in their daily living and to exercise their rights (WHO 1993: unpagged).

To ensure that our projects were compatible with the Standard Rules it was agreed that we should discuss future plans with the UN Special Rapporteur on disability, Bengt Lindqvist, and his panel of experts before presenting them to the WHO Director for approval. It was a fruitful decision that gave us the opportunity to discuss in some detail the work of the DRT with representatives of several leading international disabled people's organisations who were also members of the UN's panel of experts. Many suggestions were made that helped the WHO Team clarify its policy on disability and rehabilitation.

These discussions provided the stimulus for a major revision of the Team's programme. Three core initiatives were identified: *Rethinking Care from Disabled Peoples Perspectives*, a review of CBR, and a review of medical rehabilitation and assistive devices.

a) Rethinking care from disabled peoples' perspectives

The first of these projects included data collection from various sources on recent developments within the general area of health and disability and concluded with a conference: 'Rethinking Care from Disabled People's Perspectives' held in Oslo in 2001. It was founded on the idea that disability and rehabilitation cannot be understood solely in terms of orthodox medical interventions and conventional notions of care. Instead, it set out to achieve the following aim:

give disabled people requiring health and social support an opportunity to contribute to the process of Rethinking Care with respect to policy regarding the development of health and social services, and, in so doing, provide new insights and knowledge for the formulation of appropriate recommendations for WHO Member States (WHO 2001a: 9).

To accomplish this aim data were collected from various sources. These included the commissioning of the discussion paper written by Vic Finkelstein (1998) *Rethinking Care in a Society Providing Equal Opportunities for All*, and a request for testimonials and additional papers from disabled people and

professionals from all over the world. During the year 2000, ‘Over 3500 responses were received, over 80 per cent from disabled individuals themselves and many by email’ (WHO 2001a: 7). These testimonials and papers are available from the WHO as *Voices* (WHO 2001b) and *Rethinking Care from Different Perspectives* (WHO 2001c).

The Rethinking Care Conference brought together disabled people, parents and ‘carers’ of disabled individuals, professionals and policy-makers from rich and poor countries to reflect on and discuss relevant issues and concerns with reference to current provision within the context of the first four UN Standard Rules in order to formulate appropriate policy recommendations for WHO Member States with respect to awareness-raising, medical care, rehabilitation and support services. A conference report was later produced which contained an outline of the proceedings and recommendations.

Adopting a broadly social model approach to disability the recommendations included:

the recognition that Member States must adopt a holistic approach that incorporates the introduction of policies to eliminate poverty and secure equal access to *all* community-based services and facilities. These include medical services, education, employment, housing, transport, and public amenities.

This must be accompanied by the introduction of comprehensive and enforceable anti-discrimination laws and policies to secure the active and meaningful involvement of disabled people and their organizations in all future policy developments.

States must adopt a truly inclusive approach to these issues that addresses equally the needs of *all* disabled people. This includes disabled women, disabled children, and people with complex and/or multiple impairments with potentially high dependency needs (WHO 2001: 4).

Delegates also made several recommendations for the implementation of policies on medical care, rehabilitation, support services and awareness-raising and stated that access to medical and related services is a basic human right and, therefore, must *not* be determined by the ability to pay. Moreover,

the responsibility for introducing and financing these developments rests with national governments. High-income states, international monetary institutions and transnational organizations should make resources

available to the governments of low-income countries that do not have the means to secure these developments (WHO 2001a: 5).

b) Reviewing CBR

The second initiative involved a review of the DRT's CBR strategy in collaboration with other UN organisations, WHO member States, NGOs, and disabled people's organisations. The Government of Finland agreed to host and support this review which culminated with a conference staged in Helsinki during May 2003 (WHO 2003).

From 2000 to 2002 the WHO sponsored a series of meetings on CBR. These identified four major topics for the improvement of the impact of CBR: i) community involvement and ownership; ii) multi-sectoral collaboration in the implementation of CBR; iii) the role of disabled people's organisations in CBR; and iv) the scaling up of CBR programmes. In addition the participants discussed the evolution of CBR from a model that was often viewed as medical to one that promoted the inclusion and rights of disabled people within their respective communities.

It was agreed that creating awareness about CBR requires activities that focused on both the community and decision makers. Furthermore, awareness-raising cannot be general but must be appropriate to specific groups. Dialogue between participants must be culturally sensitive and use appropriate language. Participating states should have a national policy on disability issues. There must be a 'political will' at all levels and within all ministries for the implementation of CBR to be truly successful. This must recognise that accessibility, participation and inclusion are matters of human rights. In recognition of the fact that without Government support the 'scaling up' of CBR will not take place, disabled people's organisations and NGOs should use the media to lobby governments (WHO 2003).

All participants in the review considered CBR a useful strategy to promote the human rights of, and equal opportunities, for disabled people regardless of the nature or severity of their impairment. Highlights from the recommendations generated by the review include the following:

- All stakeholders in CBR should work to ensure the human rights of disabled people.

- Government policy and support are essential; for the development of CBR programmes including the policies that support the rights of disabled people.
- Multi-sectoral collaboration is essential to CBR, including co-ordination and co-operation between community and referral services and agencies.
- Disabled people's organisations have a key role to play in educating disabled people with regard to their rights and advocating for those rights to all stakeholders involved in the development and implementation of CBR.
- All UN agencies, international and local NGOs should collaborate with governments in the promotion of CBR as a strategy for the inclusion of disabled people in all programmes for the reduction and prevention of poverty (WHO 2003: ii).

c) Review of medical rehabilitation

The final element of the DRT's strategy revision was a proposal to review medical rehabilitation and the provision of assistive devices. This is another collaborative venture involving governments, international medical organisations, and disabled people's organisation. The recommendations from the first two initiatives, outlined above, have been incorporated into the review guide. The review is currently being conducted; once complete the results will be presented to the WHO General Assembly.

As will be very evident from this discussion, the WHO DRT does not work in isolation. Depending on the project, team members often collaborate with other WHO units and groupings sharing knowledge and experience in order to provide a more comprehensive and valuable service. Important recent developments from this type of collaborative activity include the *International Classification of Functioning, Disability and Health* (WHO 2001d) finalized by the WHO's 'Classification, Assessment, Surveys and Terminology Unit' and the *Innovative Care for Chronic Conditions: Building Blocks for Action* (WHO 2002) initiative that was produced by the WHO's Health Care Team.

Unlike its predecessor, *The International Classification of Impairments, Disabilities and Handicaps* (WHO 1980), the new classification of functioning and disability addresses not only bodily functioning and structure as impairments, but also activity and participation in community, social and civic

life. 'Activity' represents the execution of daily living tasks and 'participation' refers to involvement in life situations and the interaction between the individual and the community. These are all influenced by personal and environmental factors. This new classification system recognizes that when there is a facilitative environment, disability is reduced, and when the environment is hindering, disability is made worse. For further discussion of the strengths and weaknesses of this new approach see Bury (2000), Hurst (2000) and Pfeiffer (2000).

The *Innovative Care for Chronic Conditions* initiative starts from the premise that most health care systems are not prepared or equipped to cope with people who have long term or chronic conditions. Therefore, it is argued that interventions should be directed toward the effective prevention and management of chronic conditions. This requires the shift in emphasis from an approach that is based on an episodic care model in favour of one clustered around a more comprehensive system of care and support. The key aim of this approach is to give those with long term health problems the knowledge and skills for self management. This involves goal-setting and problem-solving linked directly to existing community resources. In order to facilitate this transformation, medical and rehabilitation teams must restructure their working practices to improve the development and delivery of the range of services needed to empower individuals and their families to live within rather than apart from the community. To this end the traditional prescriptive role of the medical professional must give way to one of consultation; doctors and associate professionals must become a community resource.

Conclusion

In this chapter, I have described my experiences as a medical physician coming to terms with the problems faced by disabled people mainly in the poorer countries of the developing world. My experiences in Africa taught me that poverty and disability go hand- in-hand and that the difficulties disabled people and their families encounter in their everyday lives cannot be solved by medical interventions alone. This awareness was strengthened after I became involved with CBR, the WHO's disability and rehabilitation programme, and disabled people's own organisations. For me, there is little doubt that CBR policies can only be successful with the full support of the entire community, and that disabled people's organisations and NGOs must work together to bring about meaningful change. Disability is a human rights issue. However, the development and recent revision of the WHO's CBR programme clearly emphasises that there is a continuing need for appropriate medical and

rehabilitative interventions, and that these should complement disabled people's on-going struggle for equal opportunities and human rights.

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