

**World Health Organization
Disability and Rehabilitation Team**

Rethinking Care

**From the Perspective of Disabled
People**

**Conference Report and
Recommendations**

August 2001

Rethinking Care

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The Local Organizing Committee comprised representatives from the Norwegian Ministry of Health and Social Affairs, the Norwegian State Council on Disability, the Norwegian Association for the Disabled, the Norwegian Federation of Organizations of Disabled People and experts on disability issues. This Committee, chaired by Anne Sofie Trosdahl Oraug, is gratefully acknowledged for the preparation and organization of the Conference. Eli Knosen, a WHO consultant acting as coordinator for the conference participants, is also acknowledged. Many thanks are extended to the Norwegian Government for providing the necessary resources to stage this important sequence of events.

Comments from the author

It is important to mention at the outset that the author of this Report has tried to synthesize and reproduce as faithfully as possible the proceedings of and recommendations from the entire *Rethinking Care Initiative* without undue duplication or distortion of meaning. This has been a difficult task not only because of the number of people involved and the various views expressed, but also because many participants were not communicating in their first language.

Any misrepresentation therefore is unintentional and the sole responsibility of the author: Colin Barnes.

Executive summary

Although it is two decades since the United Nations *International Year of Disabled People*, people with disabilities throughout the world still encounter severe economic, cultural and social deprivations. The problem is generally worse for those living in rural areas and is especially acute for *all* disabled people living in low-income states.

Clearly, health and rehabilitation can no longer be understood solely in terms of orthodox medical interventions and conventional notions of 'care'. These centre almost exclusively on the perceived limitations of individuals rather than on society's failure to accommodate the needs of people with disabilities. Thus, there is an urgent need for an approach that cares not only about disabled people but also about society and its structure.

Responding to this insight, the WHO *Rethinking Care Initiative and Conference* brought together disabled people and other stakeholders from high- and low-income countries to identify key issues and propose recommendations for Member States to address this need.

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 people with disabilities 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 women with disabilities, children with disabilities, and people with complex and/or multiple impairments with potentially high dependency needs.

From the perspective of disabled people, access to medical and related services is a basic human right and, therefore, must *not* be determined by the ability to pay. Thus, several important and practical recommendations have been devised for the future implementation of the first four United Nations *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. These concern medical care, rehabilitation, support services and awareness-raising.

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.

1. Introduction

“Everything is structured in such a way that people with disability are entirely left out.” (*A student with disabilities: Ghana*)

“Over the fifteen years of my disability, I have learned what it is like to be isolated, segregated, and discriminated against. I know this not only because of my own experience, but because I have joined an organization of others who have the same condition, and who have the same experiences.” (*A psychiatric system survivor: United States of America*)

“Disabled people have been the most destitute of Africans. Government planners have tended to emphasize the majority and thus they have ignored the needs of disabled people and their families. African society already accorded women a lower status than men... disabled women face discrimination because they are women and because they are disabled.” (*A disabled woman: Zambia*)

“We (disabled people) have to gain control of our own lives, our own physical rehabilitation, our own personal assistance.” (*A disabled activist: Belgium*)

“Today’s challenge is the participation of disabled people as members of civil society; as leading characters in the diagnosis, elaboration and evaluation of public policies... so as to reach a better approach.” (*A disabled lawyer: Chile*)

“Society has to acknowledge that, until there is a coordination of effort between a range of medical, allied health, and developmental services, families (with disabled children) will go on facing stress and pain.” (*A professional working with families with disabled children: India*)

“All treatment should have the objective to improve human life, not just the body.” (*A representative of an international nongovernmental organization for people with disabilities*)

These statements represent the wide range of views submitted to the World Health Organization (WHO) *Disability and Rehabilitation* (DAR) Team during the year 2000. They were received in

response to an informal request for testimonials from people with disabilities, parents and 'carers' of disabled individuals throughout the world on their experience of disability and rehabilitation. Over 3500 responses were received, almost 80% from disabled individuals themselves and many by email.

What is striking about the testimonials is the alarming degree of multiple deprivation experienced: economic, political and social. Also striking is that this situation is widely attributed to the inadequacy and/or ineffectiveness of current 'care' services, both medical and rehabilitational, for this increasingly large section of the world's population.

While this is the case in all countries, whether high-income ('developed') or low-income ('developing'), it is particularly acute in the low-income nations where medical and rehabilitation resources are disturbingly scarce, and where abject poverty is a common experience. There is growing disenchantment with the current provision of services amongst both users and providers that can be traced back to the 1960s.

Thus, there is an urgent need for a substantial reformulation of current thinking on services for people with disabilities and their families at the international level. The WHO *Rethinking Care Initiative and Conference* has marked a significant stage in this process.

The conference brought together stakeholders from all over the world to reflect on and discuss current policies within the context of the first four United Nations (UN) *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. These four rules concern the provision of awareness-raising, medical care, rehabilitation and support services (see Appendix 1). There are 18 other Standard Rules covering different aspects of economic and social life but only the first four fall within the WHO remit. The Standard Rules were adopted by the UN General Assembly in 1993 and are shortly to be reviewed.

Organized by the DAR Team, mainly funded by the Norwegian Government, and hosted by the Norwegian Ministry of Health and Social Affairs, the *Rethinking Care Conference* was held on 22–25 April 2001 at the *SAS Radisson Hotel*, Oslo. Participants included people with disabilities, parents and 'carers' of disabled individuals,

rehabilitation professionals, politicians and policy-makers (see Appendix 2).

2. Background: the growing demand for change

The general disenchantment with disability services began in the late 1960s with the politicization of disability by disabled activists and disability organizations in different parts of the world. Notable early examples include the American Independent Living Movement (ILM), the Swedish Self Advocacy Movement and a host of self-help groups throughout Europe.

Orthodox thinking on the causes of disability was increasingly challenged and so too were the organization and structure of the services upon which the overwhelming majority of disabled people had to depend. People with disabilities around the world began not only to demand greater participation in the organization and running of disability services, but also to develop their own.

The movement grew in stature and confidence during the 1970s and culminated in the formation of Disabled Peoples' International (DPI). The DPI is an international umbrella organization controlled and run exclusively by disabled people. It held its first World Congress in Singapore in 1981.¹

These initiatives generated a flurry of activity at the national and international levels. Several national governments now have some form of anti-discrimination law to secure the equal rights of disabled persons. Government responsibility for securing such equal rights was formally recognized at the international level by the UN in 1981: the UN *International Year of Disabled People*.

One year later the UN General Assembly adopted by consensus a *World Programme of Action Concerning Disabled Persons* outlining a global strategy on the prevention of disability and the realization of the full potential of disabled persons. The following ten years were designated the UN *Decade of Disabled Persons*. Between 1990 and 1993 Member States in close collaboration with international disabled peoples' organizations developed the UN *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*.

¹ DPI. *Disabled Peoples' International, Proceedings of the First World Congress*, Sweden, Disabled Peoples' International, 1981.

These developments generated a gradual realization that persons with disabilities should play a greater role in the development and delivery of disability and rehabilitation services. Equally important is the recognition that in all countries residential facilities are appropriate for acute conditions and particular medical treatments only, and that disability services and support should be situated within, rather than without, the community. However, meaningful progress has been relatively slow.

Nonetheless, the DAR Team has actively supported these developments. Located in the Department for the Management of Noncommunicable Diseases at the WHO, its mission is to enhance the quality of life and equality of opportunity for disabled people by supporting Member States in framing policy, developing appropriate services, and strengthening community participation. It has promoted and supported several Community-Based Rehabilitation (CBR) projects in developing countries during the last 25 years.

These efforts have led to a growing recognition that health and disability can no longer be understood in purely medical terms and that a more holistic approach is required. This prompted the DAR Team to devise the *Rethinking Care Initiative and Conference*, which included the commissioning of the *Rethinking Care* discussion paper by the internationally renowned disability activist and scholar, Vic Finkelstein, the request for testimonials and additional papers² and the organization of the *Rethinking Care Conference*.

3. Conference aims and objectives

The primary aim of the *Rethinking Care Conference* was to:

“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”.

To fulfil this aim the conference set out to achieve the following objectives:

² These papers and testimonials are available from the WHO, Geneva, as two documents: *Rethinking Care from Different Perspectives* and *Voices*.

- Bring together people with disabilities, parents and carers of disabled individuals, professionals and policy-makers from all over the world to reflect on and discuss relevant issues and concerns.
- Identify the strengths and weaknesses in current provision within the context of the first four UN *Standard Rules on the Equalization of Opportunities for Disabled Persons*.
- Formulate appropriate policy recommendations for WHO Member States with respect to awareness-raising, medical care, rehabilitation and support services.
- Produce a report outlining the conference proceedings and recommendations for distribution to WHO Member States.

4. Language, meaning and rethinking ‘care’

The working language of the conference was English. However, many English words and phrases have quite different meanings when translated into other languages. To complicate matters further there is considerable debate over the meaning and use of specific terminology within the English-speaking world. Consequently, because of these difficulties many conference participants used different phrases to describe disabled people, for example, ‘people with disabilities’. In this Report the phrases ‘people/persons with disabilities’ and ‘disabled people/persons’ are used interchangeably because the intention of the WHO is to reflect accepted usage in different parts of the world.

To ensure clarity of analysis the terminology of the ‘social model of disability’ will be used throughout this Report. Developed and supported by disabled activists in many nations throughout the world, the social model makes the important distinction between ‘impairment’ and ‘disability’. *Impairment* refers to an individual’s biological condition (often referred to in everyday language as ‘disabilities’). In contrast, *disability* denotes the collective economic, political, cultural and social disadvantage encountered by people with impairments.³

³ See: DPI. ‘Agreed Statement’ at Human Rights Plenary in Support of the European Day of Disabled Persons, London, Disabled Peoples’ International, 1994; Linton S. *Claiming Disability*, New York, New York University Press, 1998; UPIAS. *Fundamental Principles of Disability*, London, Union of the Physically Impaired Against Segregation, 1975.

For many people this distinction becomes blurred in their own lives. The phrase ‘people with disabilities’ helps perpetuate this confusion. Nevertheless, it is vital to maintain the distinction when analysing and planning services and strategies to address the problems faced by disabled people and their families. Such definitions help to focus on tackling economic and social deprivations rather than on the flawed and unhelpful assumption that the only way to overcome the disadvantage of disabled people is to change the individual and not society.

The word ‘care’ is equally misleading. Besides ‘have a liking’ or ‘desire for’, to ‘care’ means ‘to be concerned about’ or ‘to look after’. It is also associated with the concepts of ‘protection’ and ‘supervision’⁴ and is used with reference to many sections of the community. We care about family and friends. We care about particularly vulnerable groups such as small children, older ‘frail’ people, and people with serious and life-threatening illnesses.

However, when applied to people with disabilities ‘care’ usually means ‘to be looked after’, ‘protected’ or ‘supervised’. From the perspective of disabled people this is an overtly patronizing and, indeed, unhelpful use of the term. First, it implies that disabled people can never achieve any degree of independence within their communities. Second, it conceals the fact that there is overwhelming evidence that many of the problems encountered by persons with disabilities are the result of society's *failure* to care about their needs. For example:

- The main causes of chronic diseases and long-term impairments in both high- and low-income nations throughout the world are poverty, inadequate sanitation, poor diet, substandard housing, environmental pollution, industrial and road traffic accidents, violence and war.
- While there is a growing need for the most basic medical treatments worldwide, and particularly in low-income countries, a disproportionate amount of resources, both financial and human, is increasingly being poured into the development of costly medical treatments that will benefit only a relatively small percentage of the world's population.

⁴ Hawkins JM. *The Oxford Large Print Dictionary*, Oxford, Oxford University Press, 1988.

- Irrespective of diagnosis and subsequent classification, in societies geared for non-disabled living, all chronic conditions and impairments have both physiological and psychological consequences.
- Rehabilitation and related interventions to help disabled individuals have limited success as society is organized primarily for non-disabled lifestyles.
- Worldwide, people with accredited chronic diseases and impairments encounter various economic, political, cultural and social barriers that cannot be resolved by traditional individualistic, medical solutions.

Thus, the process of *rethinking care* must go beyond conventional notions of medicine and rehabilitation, and consider wider and sometimes more contentious issues: economic, political, cultural and social. From this perspective, to care about disability and rehabilitation means to care about society, how it is organized and how it will evolve.

5. Organization of the conference

The three-day conference (see Appendix 3 for the complete programme) opened on Sunday 22 April with speeches by Ms Guri Ingebrigtsen, Norwegian Minister of Social Affairs, Dr Ala Alwan, Director, Management of Noncommunicable Diseases, WHO, and Mr Lars Ødegård, Secretary General of the Norwegian Association for the Disabled.

The following two days comprised a series of presentations and workshops concerned with the 'current situation' on Monday 23 April and 'needs and challenges' on Tuesday 24 April. The presentations are summarized below and are reproduced in full in Appendix 4.

Participants were divided into six workshops. Following Monday's presentations they were asked to identify any major problems with current provision (see below). Building on these insights and those of the papers presented on Tuesday morning, the participants were then asked to formulate a series of recommendations for WHO Member States.

These were summarized into 37 proposals and presented to participants on the morning of Wednesday 25 April. This was followed by a Round Table discussion entitled *Putting Rethinking Care on the Political Agenda*. In the ensuing discussion, participants made several additional points and proposals.

Participants were also asked to forward by email or fax any further comments to the conference rapporteurs for inclusion in the final list of recommendations. Many important comments were subsequently received. These have been carefully incorporated into the recommendations listed below.

A contribution by Ms Inger Marit Eira, Political Adviser to the Norwegian Ministry of Health and Social Affairs, brought the proceedings to a close.

6. Current situation (Monday 23 April)

Summary of presentations

The first presentation provided relevant background information on the current causes of impairments and the importance of *rethinking care* in order to respond to the needs of different groups of persons with disabilities throughout the world.

Service users then presented papers. Topics included:

- differences in services provided in high-income and low-income countries;
- insensitive treatment of disabled people by health professionals;
- rehabilitation services that do not assist in planning for discharge and life at home and in the community;
- lack of support services in the home and community;
- attitudes of health professionals and of society in general that continue to devalue the lives of children and adults with impairments.

All speakers noted a general insensitivity to disability issues amongst health service personnel. Particular mention was made of the attitudes of health professionals towards disabled women who wish to have children. They often lack the knowledge needed to help women in these circumstances; their approach is to tell women they cannot be parents. This situation affects all disabled

women irrespective of the nature of their impairment: physical, sensory or cognitive.

It was revealed that health professionals in China show contempt for women who have children with disabilities. Instead of giving advice on how to promote the development of a disabled child, they suggest that nothing can be done. They often advise families to put a child with disabilities in an institution without considering the facilities available in the home or community.

Major differences were noted between high- and low-income countries. Attention centred on inadequate facilities and acute staff shortages for 'mental health' services in low-income countries. It was pointed out that 'rehabilitation' services were often good in designated centres, but this provision frequently did not include advice, assistance or support for the transition from the centre to the home and community.

One speaker reported that, following her discharge from a rehabilitation institution, she was given a wheelchair but no instructions on its use and no suggestions for coping at home. As no community-based support services were available, her 75-year-old mother looked after her and her family's limited resources were used to employ a 'caregiver'. In her experience those who work as 'caregivers' are often unreliable, sometimes report for work intoxicated, and occasionally steal from people with disabilities.

In Mexico, as in many countries, parents of disabled children have formed a self-help group to deal with the negative attitudes and poor services from health and education professionals. The organization began in 1970 and is now a major force for change, but much more must be done. Mexico has used the UN *Standard Rules on the Equalization of Opportunities for Disabled Persons* as a basis for the development of a national plan for the welfare and integration of people with disabilities.

Mexico has also worked with other Latin American countries to examine the physical, social and cultural barriers faced by disabled people and their families. The 1993 *Declaration of Managua* evolved from this collaboration. It calls for a society based on equality, justice, equity and interdependence; one that ensures a better quality of life for all without discrimination.

Papers from service providers in India, Bangladesh and Lebanon were then presented. These presentations were also based on personal experience and reflected common concerns within and across many countries, such as the link between poverty and disability, the importance of disabled people being able to participate in service delivery and the challenges faced by service providers.

Concerning the link between poverty and disability, it was stated that the slum areas of major cities present a particularly difficult challenge for those trying to help people with disabilities lift themselves out of poverty. In Bombay a CBR programme is addressing the issue. Disabled people collaborate with programme workers to identify both problems and solutions. Service users are assisted in obtaining a Certificate of Disability to gain access to relevant services. A survey of needs has been implemented and the results shared with the community in order to generate a change in attitudes.

In Bangladesh, the *Centre for the Rehabilitation of the Paralyzed* (CRP) has incorporated user involvement into its service design and provision. People with spinal cord lesions (SCL) participate in the organization so that services are more responsive to users' needs. CRP has employed disabled workers for 15 to 20 years; some have now left and taken jobs with international agencies; and others have set up a self-help group for people with disabilities. The services offered by CRP are far more effective because of this involvement of service users.

In Lebanon, medical personnel, nongovernmental organizations (NGOs) and academics address disability issues. Services provided are reliant on available resources. However, the impact of provision depends on the responsiveness and appropriateness of the services provided. The challenges faced by the various sectors include the following:

- priorities and expectations of the disabled individual, the family and the larger social group;
- impact of the rehabilitation services and of the social support systems;
- cost of services for the individual and for the society.

Workshop participants identified several problems with current provision.

Summary of workshop discussions

Medical services

There is a great disparity in the availability of medical services between high- and low-income countries, and within all nations between urban and rural areas. This issue was of particular concern for delegates from low-income states where lack of services means that many people die needlessly.

Current funding policies and practices create major problems for people with disabilities and their families. Access to medical services increasingly depends on the ability to pay. Most governments provide some funding but in low-income countries provision is frequently dependent on NGOs and/or charities. Therefore, services are often inadequately or inappropriately resourced.

In all countries some people lack services or accept substandard interventions. Thus, treatments are often provided by families.

Lack of trained health personnel in low-income nations is a major problem and is due, in part, to the migration of qualified staff to high-income states. This affects all health services but especially those providing for people with disabilities.

Medical services are generally organized and devised by medical professionals without consultation with disabled people, their families, and/or representatives of NGOs controlled and operated by disabled people.

Many doctors and health professionals lack the expertise required to provide basic medical treatments or health advice to disabled people and/or their families. Hence, people with disabilities often receive inadequate services.

Medical services increasingly concentrate on prevention and acute treatments rather than long-term support. Such support is a particular issue for 'mental health' system users. The complete spectrum of treatments is usually only provided in hospitals and institutions located in cities. This poses major problems for those who live in rural areas.

Where medical services are available they are sometimes imposed on disabled people against their will. Examples include electric shock treatments for people with 'mental health' problems and enforced sterilization for women with disabilities.

Medical services alone are unable to empower disabled people to live independently in the community. Prolonged medical intervention, particularly for people with 'mental health' problems, is often dis-empowering.

Rehabilitation services

In many countries rehabilitation services are even less widely available than medical services. Again, there is a great disparity in the availability of services between high- and low-income nations, and between rural and urban areas in all states. Also, services are usually located in hospitals or institutions and have little relevance to the mainstream of local community life.

Funding for rehabilitation services may be provided by governments and NGOs. Provision often seems to be financed solely by NGOs or charities, especially in low-income nations. Hence, rehabilitation projects are frequently inadequately and/or inconsistently resourced.

Medical professionals and NGO volunteers, often from overseas, are generally responsible for delivering CBR programmes in low-income nations. In practice, due to the lack of such personnel, family members, usually women, provide this type of support.

Most rehabilitation services tend to target people with physical impairments. Training programmes are often ongoing with no clearly defined community-based goals. Such schemes can compound a sense of inadequacy, and do not empower people to live independently in the community.

Current provision is almost exclusively focused on improving individual functioning. This is of limited value if the disabled population does not have the opportunity to use those functions within their local community.

CBR programmes are often not well understood, even by those who implement them. This leads to a confusion over their meaning

and hence their impact. In contrast, when CBR schemes are successful they can generate discomfort among non-disabled people because empowered disabled people may be perceived as a threat to traditional wisdom and established ideas.

Support services

Of all the services discussed it was agreed that community-based support services are the least widely available. There was considerable confusion among participants over the meaning of 'support services'. Many believed that they referred solely to the supply of technical aids and assistive devices. Only a minority were aware that support services included personal assistance services for people with disabilities and their families.

For all disability services, there is a great disparity in availability between and within nations. Services are more likely to be provided in high-income countries and in high-income areas within states. Provision is especially sparse in rural regions of all societies; particular mention was made of this problem in South America.

Availability and accessibility are not equivalent. All too often sites where assistive devices are supplied are not accessible to all. Families who support disabled members rarely have access to any form of support system.

Assistive devices and support services are funded more commonly by NGOs and charities than by governments. In low-income nations NGOs are often dependent on foreign charitable donations. Indeed, the funding problem for all support services is far more significant in low-income countries than it is in high-income ones.

This makes the problem of achieving an independent lifestyle far more difficult for disabled people living in low-income countries. The need to pay privately for services is well known in low-income nations and is now increasingly common in high-income ones. Hence, affordability affects accessibility.

Services that do exist are generally controlled and dispensed by medical or health service professionals. People with disabilities are

rarely consulted, so there is often a difference between services wanted and services that professionals deem appropriate.

There is also a cultural/linguistic barrier associated with the supply of technical aids and assistive devices. Inappropriate or out-dated technology is often passed from high- to low-income countries with no advantage to those in need.

The overwhelming majority of community support for disabled people in both high- and low-income states is provided by family members, usually women. Thus, not only disabled individuals but also their entire family are disempowered by society's failure to provide adequate provision.

It was concluded that the present organization of support services is generally unable to empower people with disabilities to participate fully in community life.

Awareness-raising

There was general agreement that awareness-raising programmes have been implemented in several high- and low-income countries. In high-income nations, governments, NGOs and charities often finance such programmes. In low-income states, they are more likely to be funded by NGOs and charities.

Hitherto, awareness-raising campaigns have been relatively ineffective as the main focus has been on the disabled individual and/or their needs rather than on environmental and cultural barriers and disability as a human rights issue.

One of many concerns is the negative images of disabled people in the mass media such as television, newspapers and film. It was also noted that the emphasis on individuals with disabilities as a special group sometimes generates reactionary forces that can be counter-productive.

A major concern is that persons with disabilities are not appropriately involved in awareness-raising programmes. Media campaigns often fail to seek advice from disabled people and, as a result, tend to reinforce traditional negative stereotypes. In addition, the goals of the most recent campaigns had not been clearly defined.

In contrast, where disabled peoples' organizations had initiated awareness-raising campaigns, they did not receive adequate media access. Consequently, the campaigns had been relatively ineffective.

There is an urgent need for campaigns that target people with disabilities. This would generate greater self-awareness and grassroots activity, and be especially important for people living in institutions and/or in isolated rural areas.

It was concluded that although disabled people have found their voice, they are not being heard. In many countries, disabled peoples' organizations are still relatively weak and have great difficulty confronting the dominance of medical professions and the ongoing demand for greater resources. Such resources are devoted exclusively to medicine, to the detriment of other equally important needs such as community-based support, education and employment.

7. Needs and challenges (Tuesday 24 April)

Summary of presentations

The first presentation reaffirmed that many national economies do not provide an equal quality of life for all citizens. The economic status of disabled people has remained among the lowest of all groups throughout the world. Iranian research shows that while disabled people have less income, their living costs are greater for housing and transportation. They also encounter prejudice, poor health and education services, unemployment and poverty. According to the speaker, NGOs in Iran are best placed for the development of rehabilitation services for persons with disabilities.

The second presentation reported that prejudice against disabled people is common in Ghana due to traditional beliefs about the nature and causes of impairment. People with disabilities are rejected and have little opportunity to enter the political arena. Health and rehabilitation services are inadequate and expensive, and disabled people are unable to afford them. NGOs provide some services but they are also inadequately funded. Education is also lacking and only a few children with disabilities are able to experience its benefits.

Drawing on personal experience, as both user and provider, the speaker from Bangladesh drew attention to the disparity of provision between high- and low-income countries. Bangladesh has a population of 124 million; estimates suggest that between 6 and 12 million people are disabled. Current services reach only 10 000 disabled people a year. Nonetheless, the *Centre for Disability and Development* (CDD), formed in 1996, works for equal opportunities and the full participation of disabled persons. It provides training courses for other organizations, including disability awareness for managers, community development workers for rehabilitation services, and social communication.

The subsequent presentation described the findings of research conducted by the Rehabilitation Section of the *Ugandan Ministry of Health* focusing on the perspectives of service users and providers. Key issues for users are the negative attitudes, lack of information, physical inaccessibility to facilities, difficulties in communication, and lack of rehabilitation facilities and assistive devices. Providers concerns include inadequate training, ignorance about disabled peoples' needs, inadequate time for users, staff shortages, poor career structures, and low funding owing to the low priority accorded disability services in Ugandan society.

It was then reported that Cambodia is one of the poorest nations in the world and that international NGOs provide most of the services for people with disabilities. Cambodia's *Disability Action Council* (DAC) was established in 1997 to coordinate activities, maximize the use of resources, and strengthen collaboration with government institutions. The DAC serves as a focal point for disability issues and the development of a comprehensive national approach to rehabilitation, equal opportunities for disabled people, and prevention of impairments.

This action council is necessary because there is a severe lack of medical and rehabilitation services, assistive devices and community-based support for disabled people in Cambodia. Other social problems such as discrimination, environmental barriers and illiteracy are common. Hence, many people with disabilities and their families are unable to achieve any degree of economic security and have little food. Any ensuing emotional problems are rarely addressed owing to stigma and a general lack of awareness.

Three speakers then gave presentations focusing on *rethinking care*. One speaker expressed the hope that the conference would truly rethink 'care' and that the outcome would reach beyond familiar issues and the repetitive demand for more funds, more rehabilitation personnel and more medical and social services. He wished that conference participants would discuss *different* services, not more services. He noted that everyone needs 'care' at some stage in life.

In order to rethink 'care' the cultures of disability and of 'care' must be addressed. There is a need for a new community-based 'recipient requested' support profession and service. Conference participants should discuss how to create a new profession that is designed by people with disabilities to replace existing 'care' professions. *Centres for Independent or Integrated Living* run by disabled people may provide a model for a new community-based support system.

Another presentation highlighted an example of the negative attitudes towards disability among health professionals and society at large, i.e. the growing tendency among doctors to use 'do not resuscitate' procedures that deny disabled people life-saving treatments. It was acknowledged that disabled people do not have access to the same standard of preventive health 'care' that exists for the non-disabled. Indeed, nurses are ill equipped to counsel women with disabilities regarding contraception, pregnancy, or the many other issues that concern women.

A key factor in addressing these problems is the education of health service providers. People with disabilities should be recruited into nursing and other health service professions. The presentation concluded with the hope that the conference would serve as a 'wake-up call' to the nursing profession for critical reflection and a will to change.

The final speaker began with a reminder that participants had been asked to think about solutions, pointing out that it is necessary to 'rethink' care and 'redo' services. To achieve these goals four changes are needed:

- The change must start with disabled people leading the services they need.

- These services must be part of a new paradigm that enables people with disabilities to assert themselves as individuals and as a group.
- The services must open doors to communities rather than shut out persons with disabilities.
- This new paradigm of ‘care’ must stand firmly on the fertile ground of human rights, not on the stony ground of charity, coercion and containment, as it has in the past.

8. Recommendations

Although a wide range of views were expressed there was a general consensus among all contributors that a holistic approach is urgently needed that goes beyond conventional notions of medical ‘care’ if the numerous problems associated with disability and rehabilitation are to be addressed.

(a) A holistic approach: access, legislation and funding

To reduce unnecessary and escalating health and disability related expenditure, states must invest in the eradication of poverty and the development of fully accessible community-based services and facilities. These must include medical and rehabilitation services, housing, schools and colleges, public buildings and amenities, transport systems, etc.

States must ensure that ‘fully accessible facilities’ include access for people with mobility related impairments, accessible information media for people with learning difficulties, sign language interpreters for deaf people, and appropriate support services for those with ‘mental health’ problems and/or multiple impairments and potentially high dependency needs such as deaf/blind people.

States must introduce comprehensive mandatory anti-discrimination laws to secure the systematic removal of environmental and cultural barriers to disabled peoples’ meaningful participation at all levels and in all areas — economic, political and social — of mainstream community life.

States must establish and/or support an independent network of NGOs run and controlled by people with disabilities that are suitably accountable to members, to advise, monitor and, where

necessary, secure through the law courts the implementation of anti-discrimination policies, practices and procedures.

States must encourage international organizations such as the United Nations and the European Union to devise policies that ensure high-income nations, international financial institutions, and transnational corporations assign more resources to the development of health related services in low-income states. Care must be taken to ensure that these contributions are provided as a right and without any legal or moral obligation on the part of recipient nations.

(b) Medical services

States must ensure that access to high quality medical services and facilities is a basic human right and must be freely available to all people regardless of the nature and/or severity of impairment, age, gender, race, ethnicity, and sexual orientation.

States must ensure that the right to life is assured in the delivery of medical and health services to all people and especially to disabled people regardless of the nature and/or severity of impairment, age, gender, race, ethnicity, and sexual orientation.

Given that these recommendations have important ethical and economic implications for the future development of medical services, states must ensure that all stakeholders and especially people with disabilities and their representatives are fully and equally involved in discussions of how medical and health service budgets will be allocated and used.

High-income states that actively recruit medical and health service personnel from low-income countries must be legally bound to pay the full cost of recruitment and training of new staff and to compensate for the loss of expertise to low-income nations.

States must introduce mandatory policies to ensure that all medical services and facilities are made fully accessible to all disabled people and their families. This must include accessible physical environments, information services for people with visual impairments, deaf people, and people with learning difficulties, and suitable support services for 'mental health' system users, and

people with complex and/or multiple impairments such as deaf/blind people.

States must take the appropriate steps to secure disabled peoples' active and meaningful involvement at all levels and in all areas of the organization, development and delivery of mainstream medical services.

States must introduce appropriate measures to secure the equal and effective treatment of all disabled people within mainstream medical services. Particular attention must be paid to the needs of women with disabilities, children with disabilities, people with communication difficulties, people with learning difficulties, 'mental health' system users and survivors, and people with severe, complex and/or multiple impairments.

States must ensure that medical services are provided in hospitals or residential institutions only when absolutely necessary and that, where hospital-based treatment is considered appropriate, patients should not be discharged prematurely and certainly not without their own or their family's consent.

States must ensure that the educational curriculum for trainee medical and health service personnel includes core components on impairment and disability related issues and concerns. Steps must be taken to ensure that suitably qualified people with disabilities become actively involved in the development and delivery of these elements of the medical training programmes.

States must ensure that appropriate measures are taken by medical schools and similar establishments to recruit and train disabled people as doctors, nurses, and related medical service personnel.

States must take steps to ensure that unwanted and unnecessary medical and related interventions, such as sterilization, abortions, electric shock treatments, experimental drug therapies, and/or corrective surgeries, are not imposed on disabled people without full, proper and accountable consultation and consent with all concerned. Those concerned might include the disabled individuals themselves, their families and independent NGOs run and controlled by people with disabilities.

States must introduce mandatory procedures to ensure that people with disabilities, their families, and independent NGOs determine the assessment and certification procedures for accessing medical and disability related services.

All states must introduce policies to ensure that emergency services in crisis situations such as wars, floods, and earthquakes, are adequately equipped and prepared to provide appropriate medical treatments and support for disabled people and their families.

(c) Rehabilitation services

Medical services should give disabled people optimum functioning at the individual level. However, their successful rehabilitation into the mainstream of community life cannot take place without the effective removal of environmental and cultural barriers to their participation. Therefore, all states must ensure that the primary aim of all rehabilitation programmes is the systematic removal of these barriers. This process must involve meaningful consultations with disabled people, their families, and representatives of NGOs run and controlled by people with disabilities.

To facilitate effective barrier removal at the local level, states must establish suitable training programmes for the education and training of locally based community workers. The aim of these schemes must be to provide local people with the knowledge and skills to identify and remove environmental and cultural barriers to the participation of disabled people through the identification and effective mobilization of appropriate local resources. States must ensure that local disabled people, their families, and disabled representatives of independent NGOs are fully involved in the education and training of these community-based professionals.

To avoid the creation of new barriers to participation, states should ensure that disabled representatives of independent NGOs are fully involved in the development of all future community-based services, facilities and projects.

States must ensure that, where necessary, individuals with disabilities are provided with the appropriate education, training and skills to secure their meaningful participation in the economic and cultural life of the local community.

States must ensure that the particular interests of disabled women, disabled children and people with potentially complex support needs such as people with learning difficulties, 'mental health' system users and survivors, deaf and deaf/blind people, are fully addressed in all community-based programmes and projects.

(d) Support services

States must ensure that support services for disabled people and their families include appropriate technical aids and assistive devices, interpreters for deaf people and personal assistance services. Particular attention must be paid to the interests of women with disabilities, children with disabilities and people with potentially complex support needs such as people with learning difficulties, 'mental health' system users and survivors, and deaf/blind people.

States must introduce appropriate legislation to ensure that access to these services is a basic human right for all disabled individuals and their families, and that provision is free and not dependent on the ability to pay.

States must ensure that disabled people, their families and disabled representatives of independent NGOs are fully involved at all levels and in all areas of the development and delivery of community-based support services.

States must ensure that the development, production and delivery of technical aids and assistive devices are sensitive to local environments and cultures.

States must introduce legislation to prevent the distribution of unwanted and inappropriate technical aids, equipment, and associated support services in low-income countries.

States must encourage and support the development of community-based self-help groups and support services run and controlled by people with disabilities.

(e) Awareness-raising

States must ensure that awareness-raising campaigns focus on the disabling consequences of environments and cultures that do

not take account of the needs of disabled people and their families regardless of the nature and/or severity of impairment, age, race, ethnicity, and sexual orientation.

States must ensure that awareness-raising campaigns target all sections of the community including policy-makers, politicians, religious leaders, teachers, health and social service professionals, disabled people and their families. Those living in long-term institutions must also be reached. Awareness-raising among disabled people themselves is needed so that they can develop positive self-identities and a shared disability culture and consciousness.

States must ensure that awareness-raising programmes target all elements of the media. Special attention must be paid to cultivate and support positive high-profile disabled role models within the media.

States must ensure that short training programmes focusing exclusively on issues of equality for people with disabilities are planned to augment awareness-raising campaigns. These programmes must be provided for all sections of the community including religious leaders, politicians, policy-makers, local government officials, health service professionals, teachers, employers, disabled people and their families.

States must ensure that disabled people and disabled representatives of NGOs are fully involved at every level in the development and delivery of all public awareness-raising campaigns.

States must ensure that awareness-raising campaigns go beyond impairment and disability issues, and address the complex relationship between health and wealth within and between countries.

Awareness-raising campaigns must draw attention to the increasing gap between rich and poor people within and between nations, and its consequences for health and related issues. The increasing commercialization and unequal distribution of medical and health related services throughout the world are major awareness-raising issues.

States must urge the UN to establish a UN Convention on the human rights of persons with disabilities.

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