

**World Health Organization
Disability and Rehabilitation Team**

Rethinking Care

From the Perspective of Disabled People

**Conference Report and
Recommendations**

(Draft)

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Rethinking Care

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This report would not have been possible without the assistance and commitment of a great many people. This includes the host of disabled people, parents of disabled children, service providers, policy-makers, politicians, and academics who contributed to the 'Rethinking Care' initiative as well as those who attended the 'Rethinking Care' Conference. Very special thanks must also go to Ann Goerd, for her patience and assistance collecting the material from the Conference, the Norwegian Government and the Norwegian Ministry for Health and Social Affairs for providing the necessary resources to stage this important sequence of events.

The author of this Report has tried to synthesise 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 were not communicating in their first language.

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

Executive Summary

Although it is now two decades since the United Nations' *International Year of Disabled People*, disabled people across 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 disabled peoples' needs. There is, therefore, an urgent need for an approach that cares not simply about disabled people but also about society and the way it is organized.

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 nations must adopt a holistic approach that includes 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, public amenities etc.

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 the needs of *all* disabled people equally. This includes disabled women, disabled children, and people with complex and/or multiple impairments with potentially high dependency needs.

Access to medical and related services is a basic human right must *not* be determined by the ability to pay. With this in mind several important and practical recommendations were devised for the future implementation of the first four *UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. These concern medical, rehabilitation, and support services and awareness raising campaigns.

Finally, the responsibility for introducing and financing these developments rests with national governments. But where necessary high-income states, international monetary institutions and transnational organizations, should make resources available to the governments of low-income countries to secure the successful implementation of these initiatives.

1. Introduction

'Everything is structured in such a way that people with disability are entirely left out' (*A disabled student: 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: the 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' (*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 non-government organization for disabled people*).

These statements represent the wide range of views submitted to the

World Health Organization's (WHO) *Disability and Rehabilitation* (DAR) Team during 2000. They were received in response to an informal request for testimonials on the experience of disability and rehabilitation from disabled people, parents and 'carers' of disabled individuals from across the world. Over 3500 responses were received, almost 80 per cent of these were from disabled individuals themselves and many by email.

What is striking about all the testimonials received is the alarming degree of multiple deprivation: economic, political and social, experienced. Also, 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.

But whilst this is the case in all countries, whether high or low-income, 'developed' or 'developing', it is particularly acute in the low-income, nations of the majority world where medical and rehabilitation resources are disturbingly scarce, and where abject poverty is a common experience. There is a growing disenchantment with current provision amongst both users and providers that can be traced back at least to the 1960s if not before and especially in developing countries.

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

The Conference brought together various stakeholders from across 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 concern the provision of awareness raising, medical care, rehabilitation and support services^{*}. 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 Rules were adopted by the UN General Assembly in 1993 and are shortly to be reviewed.

^{*} See UN. 1993: *Standard Rules on the Equalization of Persons with Disabilities*, United Nations:New York.

Organized by the DAR Team, funded by the Norwegian Government and hosted by the Norwegian Ministry of Health and Social Affairs, the *Rethinking Care* Conference was held at the *Radisson Hotel*, Oslo, from the 22nd to the 24th of April, 2001. Participants included disabled people, parents and 'carers' of disabled individuals, rehabilitation professionals, politicians and policy makers (see Appendix 1).

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 was the organization and structure of the services upon which the overwhelming majority of disabled people had to depend. Disabled people around the world began to demand a greater say in the organization and running of disability services and/or to develop their own.

The movement grew in stature and confidence during the 1970s and culminated with 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*.

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

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

The following year 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 next ten years was designated the *UN Decade of Disabled Persons*. Between 1990 and 1993 member states in close collaboration with international disabled peoples' organizations developed the *Standard Rules* referred to above.

These developments generated a gradual realization that disabled people must have a greater say 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. But meaningful progress has been relatively slow.

Nonetheless, the WHO's DAR Team has actively supported these developments. Located in the WHO's Department for the Management of Non-communicable Diseases in Geneva, Switzerland, 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. With a minimum of resources it has promoted and supported several Community Based Rehabilitation (CBR) projects in developing countries.

All of which has 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. This 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 papers* and the organization of the *Rethinking Care* Conference.

3. Conference aims and objectives

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

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.

- ◆ Bring together disabled people, 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 *Standard Rules on the Equalisation 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 conference proceedings and recommendations for distribution to WHO member states.

4. Language, meaning and rethinking 'care'

The language of the conference was English. However, although used widely internationally many English words and phrases often 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'.

Therefore 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 across 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.*

For many people this distinction can become blurred in their own lived experiences. The phrase 'people with disabilities' helps perpetuate this confusion. But it is vital to maintain this distinction when analysing and planning services and strategies to address the problems faced by disabled people and their families. These definitions help to keep the focus on tackling economic and social deprivations rather than on the flawed and unhelpful assumption that the only way to tackle disabled peoples' disadvantage 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' * 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.

But when applied to disabled people 'care' usually means 'to be looked after', 'protected' or 'supervised'. From disabled peoples' perspectives this is an overtly patronising 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 disabled people are the result of society's *failure* to care about their needs.

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

* Hawkins, J. M. 1988: **The Oxford Large Print Dictionary**, Oxford, Oxford University Press.

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, bad housing, environmental pollution, industrial and road traffic accidents, violence and war.
- ◆ Whilst there is a growing need for the most basic of medical treatments across the globe, and particularly in low-income countries, a disproportionate amount of resources, both financial and human, are increasingly being poured into the development of costly medical treatments which will benefit only a relatively small percentage of the world's population.
- ◆ Irrespective of diagnosis and subsequent labelling, in societies geared for non-disabled living all chronic conditions and impairments have both physiological and psychological consequences.
- ◆ Rehabilitation and related interventions are extremely limited in what they can achieve in terms of enabling disabled individuals to live in a society organized almost exclusively for non-disabled lifestyles.
- ◆ Worldwide, people with accredited chronic diseases and impairments encounter various economic, political, cultural and social barriers which cannot be resolved by traditional individualistic, medical type solutions.

The process of 'rethinking care' therefore must go way beyond conventional notions of medicine and rehabilitation, and consider wider and sometimes more contentious issues: economic, political, cultural and social. From this perspective, therefore, to care about disability and rehabilitation means to care about society, how it is organized and about its future.

5. Organization of the Conference

A three day event (the complete programme is reproduced in

Appendix 2), the Conference opened on Sunday 22nd April with speeches from Mrs Guri Ingebrigtsen, Norwegian Minister for Social Affairs, Dr Ala Alwan, Director, Management of Non-communicable Diseases, WHO, and Mr Lars Ødegård, Secretary General of the Norwegian Association of the Disabled.

The following two days consisted of a series of presentations and workshops concerned with 'current issues', Monday 22nd and 'needs and challenges', Tuesday 23rd.

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

These were summarised into 37 proposals and presented to participants on the morning of Wednesday 24th. This was followed by a Round Table discussion entitled 'Putting "Rethinking Care" on the Political Agenda'. In the ensuing discussion various 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 were carefully incorporated into the recommendations listed below.

The Conference concluded with a contribution from Mrs Inga Marit Eira, Political Adviser to the Norwegian Ministry of Health and Social Affairs.

6. Current Issues (Monday 22nd 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 disabled persons 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; and the attitudes of health professionals and of society generally 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 toward 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, whatever the nature of their impairment: physical, sensory or cognitive.

It was pointed out that health professionals in China look down on women who have disabled children. Instead of giving advice on how to promote the development of disabled children, they suggest that nothing can be done. They often advise families to put the disabled child in institutions without considering what can be done in the home or in the 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 how to use it, and no suggestions for coping at home. No community based support services are available, so her 75-year-old mother had to look after her and her family's limited resources were used to hire a 'care' giver. In her experience those who worked as 'caregivers' are often unreliable, sometimes report for work drunk,

and occasionally steal from disabled people.

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 United Nations (UN) *Standard Rules* as a basis for the development of a national plan for the welfare and integration of disabled people.

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* was formed from this work. 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. These included the link between poverty and disability, the importance of disabled people's participation in service delivery and the challenges faced by service providers.

Centring on poverty and disability, it was stated that the slum areas of major cities present a particularly difficult challenge for those trying to help disabled people lift themselves out of poverty. In Bombay a CBR programme is addressing the issue. Disabled people work 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 was 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 Paralysed' (CRP) has incorporated user involvement into its service design and provision. People with 'spinal cord lesions' (SCL) help run the organization so services are more responsive to users' needs. Some have been employed by CRP for 15 to 20 years; some have left and taken jobs with international agencies. and others have set up a self-

help group for disabled people. CRP's services are far more effective because of the involvement of service users.

In Lebanon disability issues are addressed by medical personnel, NGOs and academics. The output or units of service are reliant on available resources. The impact of provision depends on the responsiveness and appropriateness of the services provided. The challenges faced by the various sectors include the following: the priorities and the expectations of the disabled individual, the family and the larger social group; the impact of the rehabilitation services and of the social support systems; and the cost of services for the individual and for the society.

Workshop participants identified several problems with current provision.

Summary of workshop discussions

a/ Medical services

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

Current funding policies and practices create major problems for disabled people 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 have to go without services or accept substandard interventions. Consequently treatments are often provided by families

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

disabled people.

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

Many doctors and health professionals do not know how to provide basic medical treatments or health advice to disabled people and/or their families. Hence, disabled people often do not get the services they need.

Medical services increasingly concentrate on prevention and acute treatments rather than long-term support. Long term treatment is a particular issue for 'mental health' system users. Treatment of all kinds is often only provided in hospitals and institutions usually 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 disabled women.

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.

b/ Rehabilitation services

In many countries rehabilitation type services are even less widely available than medical ones. Again, there are huge disparities in the availability of services in 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 type services may be provided by governments and NGOs. But often, and especially in low-income

nations, provision seems to be financed solely by NGOs and or charities. 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. But due to the general lack of availability, family members, usually women, provide this type of support.

Most rehabilitation type services tend to target people with physical impairments. Training programmes are often on-going 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.

The main focus of current provision is almost exclusively on improving individual functioning. This is of limited value if the disabled person does not have the opportunity to use those functions within their local community.

Often CBR programmes are not well-understood, even by those who implement them. This leads to a great deal of confusion over their meaning and hence their impact. In contrast, when CBR schemes are successful they can sometimes generate discomfort among non-disabled people as empowered disabled people may be perceived as a threat to traditional wisdom and established ideas.

c/ Support services

Of all the services discussed it was agreed that community based support services are the least widely available. There was considerable confusion amongst participants over what support services actually mean. Many believed that they referred solely to the supply of technical aids and assistive devices. Only a small minority were aware that support services included personal assistance services for disabled people and their families.

As with 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 the same. All too often sites where assistive devices are supplied are not accessible for all. Families who support disabled members rarely have access to any form of support system.

Assistive devices and support services are funded by governments but more commonly by NGOs and charities. 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 these countries. The need to pay privately for services is well known in low-income nations and is now increasingly common in high-income states. Hence, affordability affects accessibility.

What services exist are generally controlled and dispensed by medical or health service professionals. Disabled people are rarely consulted, so there is often a difference between what is wanted and what 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 for those in need.

The overwhelming majority of community support for disabled people in both high and low-income states alike is provided by other, usually women, family members. This means that 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 disabled people to participate fully in community life.

d/ Awareness raising

There was general agreement that awareness raising programmes have been implemented in several high and low-income countries. In high-income nations government, NGOs and charities often finance these. 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 disabled individuals as a special group sometimes generates reactionary forces that can be counter-productive.

A major concern is that disabled people are not appropriately involved in awareness raising programmes. Big media campaigns often fail to seek disabled people's advice and, as a result, tend to reinforce traditional negative stereotypes. It was also unclear what many of the most recent campaigns had set out to achieve.

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

There is an urgent need for campaigns that target disabled people. This is necessary to generate greater self awareness and grassroots activity. This is especially important for people living in institutions and/or in isolated rural areas.

It was concluded that although disabled people have found their voices, they are not being heard. In many countries, disabled people's organizations are still relatively weak and have great difficulty confronting the dominance of medical professions and the on going demand for greater resources 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, 23rd 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. In Iran NGOs are best placed for the development of rehabilitation services for disabled persons.

The second presentation reported that prejudice against disabled people is common in Ghana due to traditional beliefs about the nature and causes of impairment. Disabled people 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 disabled children are able to experience its benefits.

Drawing on personal experience, as both user and provider, the following 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 to 12 million people are disabled. Current services reach only 10,000 disabled people a year. Nonetheless, the *Centre for Disability and Development*, 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 next 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: 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 due 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 disabled people. To avoid overlap, to maximise the use of resources and to strengthen collaboration with government institutions, Cambodia's *Disability Action Council (DAC)* was established in 1997. 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 is necessary because in Cambodia, there is a severe lack of medical and rehabilitation services, assistive devices and community based support for disabled people. Other social problems such as discrimination, environmental barriers and illiteracy are common. Hence, many disabled people and their families are unable to achieve any degree of economic security and have little food. Any ensuing emotional problems are rarely addressed due to stigma and a general lack of awareness.

The next speaker expressed the hope that the Conference would truly rethink 'care' and that the outcome would go beyond familiar issues and the often repeated demand for more funds, more rehabilitation personnel and more medical and social services. His wish for the Conference was that participants would discuss not more, but *different* services. He noted that everyone at some point in life, or perhaps at many points, needs 'care'.

In order to rethink 'care' the culture of disability and the culture of 'care' must be addressed. There is a need for a new community based 'recipient requested' support profession and service. We need to discuss what might go into making a new profession that is designed by disabled people 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.

The subsequent presentation identified the growing tendency amongst doctors to use 'do not resuscitate' procedures to deny disabled people life saving treatments as an example of the negative attitudes toward disability amongst health professionals and society at large. It was acknowledged that disabled people do not have access to the same standard of preventive health 'care' that exists for other people. Indeed, nurses are ill equipped to counsel disabled women regarding contraception, pregnancy, or the many other issues that concern women during their life span.

A key factor in addressing these problems is the education of health service providers. Disabled people 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 were asked to think about solutions. She pointed out that it is necessary to both 'rethink' care and to 're-do' services. To achieve these goals four changes are needed. 1) The change must start with disabled people leading the services they need. 2) These services must be part of a new paradigm that enables disabled people to find and use their power as individuals and as a group. 3) The services must open doors to communities rather than shut disabled people away. 4) 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 amongst all contributors that a holistic approach that goes way beyond conventional notions of medical 'care' is urgently needed if we are to address the numerous problems associated with disability and rehabilitation.

a/ A holistic approach: access, legislation and funding

To reduce unnecessary and escalating health and disability related expenditure, therefore, 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 people with 'mental health' problems and/or multiple impairments and potentially high dependency needs such as deaf/blind people, for example.

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 disabled people 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.

National governments are primarily responsible for funding all policies to bring about the meaningful inclusion of disabled people into the mainstream of the economic and cultural life of their respective communities. This will inevitably involve a much greater investment in health and rehabilitation services; community based support and awareness raising campaigns.

But many countries, particularly in the developing world, do not have sufficient resources for such an investment. Therefore, in an increasingly globalized world where the interdependence of high and low-income nations is becoming ever more evident, high-income states, international monetary institutions such as the World Bank and the International Monetary Fund, and transnational corporations

have a moral responsibility to contribute to the health related needs of low-income countries.

Therefore states must encourage international organisations such as the United Nations and the European Union to devise policies that ensure high-income nations, international financial institutions, and transnational corporations put more resources into the development of health related services in low-income states. Care must be taken to ensure that these contributions are provided as of 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 free and 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 disabled people and their representatives are fully and equally involved in discussions of how medical and health services budgets are 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. All too often low-income countries do not have the necessary resources to compete with the financial incentives available to qualified staff in high-income nations. The continuous drift of medical service professionals from low to high-income states simply compounds the problem of inadequate medical provision in the developing world.

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' systems users, and people with complex and/or multiple impairments such as deaf/blind people, for example.

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 disabled women, disabled children, people with communication difficulties, people with learning difficulties, 'mental health' systems 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 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 disabled people should be 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 sterilisation, abortions, electric shock treatments, experimental drug therapies, and/or corrective surgeries are not imposed on disabled people without full, proper and accountable consultation with all concerned. This might include disabled individuals, their families and independent NGOs run and controlled by disabled people.

States must introduce mandatory procedures to ensure that assessment and certification procedures for accessing medical and disability related services should be determined by disabled people, their families, and independent NGOs that are accountable to their members.

All states must introduce policies to ensure that in crisis situations such as wars, floods, earthquakes etc. emergency services 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. But 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 must be 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 disabled people that are accountable to their members.

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 disabled people's participation through the identification and effective mobilisation of appropriate local resources. States must ensure that local disabled people, their families, and disabled representatives of independent NGOs accountable to their members 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 accountable to their members are fully involved in the development of all future community based services, facilities and projects.

States must ensure that where necessary disabled individuals 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, and deaf/blind people, are fully addressed in all community-based programmes and projects. Equally important, the interests of cultural and linguistic minorities within the disabled population such as Deaf people, for example, must also be safeguarded 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 disabled women, disabled children 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 accountable to their members 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 is sensitive to local environments and cultures.

States must introduce legislation to prevent the distribution in low-income countries of unwanted and inappropriate technical aids, equipment, and associate support services by NGOs based in high-income nations.

States must encourage and support the development of community based self-help groups and support services run and controlled by disabled people sometimes referred to as *Centres for Independent or Integrated Living*.

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. This must include those living in long term institutions. Awareness raising amongst disabled people is needed to help disabled individuals develop positive self-identities and a shared disability culture and consciousness.

States must ensure that all awareness-raising programmes are targeted at all elements of the media including television, radio, film, newspapers and advertising. Special attention must be paid to the cultivation and support of high profile positive disabled role models within the media.

States must ensure that awareness-raising campaigns are augmented by short training programmes focusing exclusively on disability equality issues. These must be provided for all sections of the community including religious leaders, politicians, policy makers,

local government officials, health service professionals, teachers, employers and disabled people and their families.

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

States must ensure that awareness raising campaigns should 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 commercialisation and unequal distribution of medical and health related services throughout the world are a major awareness raising issue.

States must urge the UN to establish a UN Convention on the human rights of disabled people.

Further Reading

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Appendix 1: List of participants

Ms Nadia Ait-Khaled — International Union against Tuberculosis and Lung Disease: France

Mr Per Aage Bjørke — International Rheumatism Association: Norway

Dr Michael Boland — World Organization of Family Doctors: Ireland

Ms Thorild Bråthe — International Federation of Social Workers: Norway

Ms Maria Soledad Cisternas Reyes — Public Interest Actions Programmes: Chile

Ms Susan M. Daniels — Rehabilitation International: United States of America

Ms Irene Feet — International Council of Nurses: Norway

Mr Vic Finkelstein — Centre for Disability Studies: United Kingdom

Ms Guro Fjellanger — International Federation for Hydrocephalus and Spina Bifida: Norway

Dra Gabriella Garé Fabila de Zaldo — Mexico

Dr Anita Ghai — India

Mr Martin Gittelman — World Association for Psychosocial Rehabilitation: United States of America

Dr P.K. Gopal — International Association for Integration, Dignity and Economic Advancement: India

Dr Dena Hassouneh-Phillips — Oregon Health Sciences University: United States of America

Ms Joan L. Headley — International Polio Network: United States of America

Ms Marjorie January — South Africa

Ms Elaine Johansson — Inclusion International: Sweden

Ms Annlaug Kældman — International Federation of Multiple Sclerosis Society: Norway

Dr Nadim Karam — Lebanon

Ms Liisa Kauppinen — World Federation of the Deaf: Finland

Mr Kalle Könkkölä — Finland

Ms Kari Krogh — Canada

Ms Karin Liabø — International Association of Occupational Therapists: Norway

Mr Bengt Lindqvist — UN Special Rapporteur of the Commission for Social Development on Disability: Sweden (unable to attend because of illness)

Ms Karen Ling — China

Ms Anika Rahman Lipy — Centre for Disability and Development: Bangladesh

Mr Joshua Malinga — Disabled Peoples' International: Zimbabwe

Ms Nisha Miller — India

Mr A.K.M. Momin — Centre for the Rehabilitation of the Paralysed: Bangladesh

Mr Pen Mony — National Coordinating Body for Disabilities and Rehabilitation: Cambodia

Ms Brenda Myers — World Confederation for Physical Therapy:
United Kingdom

Mr Fred Mzoma — Office of the Minister of State Responsible for
Persons with Disabilities: Malawi

Dr Usha S. Nayar — TATA Institute of Social Sciences: India

Ms Alice B. Nganwa — Ministry of Health: Uganda

Ms Kicki Nordström — World Blind Union: Sweden

Ms Mary O'Hagan — World Network of Users and Survivors of
Psychiatry: New Zealand

Mr Stig Ohlson — World Federation of Deaf-blind: Sweden

Dr William J. Peek — International Society of Physical Medicine and
Rehabilitation: Netherlands

Mr Nassibi Pourazar — Iranian Society of Disabled Persons: Iran

Ms Carmen Reyes-Zubiaga — Philippines

Professor Alan J. Sinclair — International Diabetes Federation:
United Kingdom

Ms Sumintra Singh — Guyana

Ms J.O. Sinyo — Member of Parliament: Kenya

Ms Bente Skansgård — Norway

Ms Franca Smarrelli — World Stroke Association: Australia

Mr Aimo Strömberg — International Cerebral Palsy Society: Finland

Mr Abdul Salim Usman — Ghana

Rapporteurs

Professor Colin Barnes — United Kingdom

Dr Ann Goerdts — United States of America

WHO Regional Office for Europe (EURO)

Mr Rüdiger Krech — Denmark

WHO Regional Office for the Americas (PAHO)

Mr Armando Vásquez — Nicaragua

WHO Regional Office for South-East Asia (SEARO)

Mr Madan P. Upadhyay — India

WHO/DAR Norway

Ms Eli Knøsen

WHO/DAR Switzerland

Dr Ala Alwan

Dr Sunil Deepak

Ms Margaret Naegeli

Ms Marie-Christine Nédélec

Ms Eva Sandborg

Norwegian Ministry of Health and Social Affairs

Mr Jon Olav Aspås

Ms Inger Marit Eira

Mr Gunnar Follesø

Ms Birgit Friele

Ms Guri Ingebrigtsen

Ms Eldrid Røine

Ms Hilde Caroline Sundrehagen

Ms Anne Sofie Trosdahl Oraug

Ms Inger Lise Vestby

Norwegian State Council on Disability

Ms Anne-Margrethe Brandt

Ms Ellen Rønneberg

Mr Johans Sandvin

Ms Beate Sundt Larsen

Ms Anne Tøndevold

Norwegian Association for the Disabled (NAD)

Mr Lars Ødegård

Ms Marianne Ziesler

Norwegian Federation of Organizations of Disabled People (FFO)

Mr Svein-Erik Myrseth

Disability Expert Norway

Ms Ann-Marit Sæbønes

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Ms Anne Elise Oppedal

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Ms Carina Schweizer Burguete: for Mr Stig Ohlson

Ms Nory Delano: for Ms Maria S. Cisternes Reyes

Ms Anne Finkelstein: for Mr Vic Finkelstein

Ms Pia Fransmann: for Mr Kalle Könkkölä

Ms Siphokazi Gcaza: for Ms Marjorie January

Mr Bjørn Hecter: for Ms Bente Skansgård

Ms Carina Hoffman: for Mr Stig Ohlson

Ms Ronia Malinga: for Mr Joshua Malinga

Ms Kati Marjanen: for Ms Liisa Kauppinen

Ms Eva Sagström: for Mr Bengt Lindqvist

Ms Lisa Svedlund: for Mr Stig Ohlson

Ms Virpi Thurén: for Ms Liisa Kauppinen

Ms Jocelyn C. Villarina: for Ms Carmen Reyes-Zubiaga

Mr John W. Watson: for Ms Susan M. Daniels

Ms Christina Welander:

for Ms Kicki Nordström

Appendix 2: Conference programme

Sunday 22 April

Welcome

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|-------------|--|
| 14.00–16.00 | Registration |
| 16.00–17.30 | Opening of the Conference:
Ms Guri Ingebrigtsen, Norwegian Minister of Social Affairs
Dr Ala Alwan, Director, WHO
Mr Lars Ødegård, Secretary General of the Norwegian Association of the Disabled, on behalf of the Local Organizing Committee for the Conference |
| 19.00 | Reception |
| 19.30 | Dinner |

Monday 23 April

Current situation — Experiences and constraints

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|-------------|--|
| Chair | Mr Jon Olav Aspås, Norwegian Ministry of Health and Social Affairs |
| Vice chair | Mr Johans Sandvin, Norwegian State Council on Disability |
| 09.00–09.30 | Overview:
Dr Ala Alwan, Director, WHO |
| 09.30–11.15 | Experiences of Services in Different Settings by Users and Service Providers:
Ms Nisha Miller — India
Ms Karen Ling — China
Ms Marjorie January — South Africa
Dra Gabriella Garé Fabila de Zaldo — Mexico |

Dr Usha S. Nayar — India
 Mr A.K.M. Momin — Bangladesh
 Dr Nadim Karam — Lebanon

- | | |
|-------------|---|
| 11.15–11.45 | Refreshments |
| 11.45–12.15 | The Role of Standard Rules in <i>Rethinking Care</i> :
Mr Bengt Lindqvist, UN Special Rapporteur on
Disability (Cancelled because of Mr Lindqvist's
illness) |
| 12.15–13.45 | Lunch |
| 13.45–14.00 | Introduction to Working Group Sessions:
Professor Colin Barnes |
| 14.00–15.30 | Working Group Sessions (discussing current status,
identifying constraints in the following areas:
medical care, rehabilitation, support services and
awareness-raising) |
| 15.30–16.00 | Refreshments |
| 16.00–17.30 | Round Table Discussion with the Rapporteurs from
Working Group Sessions |
| 19.00 | Dinner. Hosted by the Norwegian Ministry of Health
and Social Affairs, Minister of Social Affairs |

Tuesday 24 April

Needs and challenges

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|-------------|--|
| Chair | Dr Ala Alwan, Director, WHO |
| Vice chair | Mr Svein-Erik Myrseth, Norwegian Federation of
Organizations of Disabled People |
| 09.00–09.30 | Summary of Previous Day's Work: |

Professor Colin Barnes and Dr Ann Goerdt

- 09.30–10.30 Presentations on Needs and Challenges by Users and Service Providers:
 Mr Nassibi Pourazar — Iran
 Mr Abdul Salim Usman — Ghana
 Ms Anika Rahman Lipy — Bangladesh
 Ms Alice B. Nganwa — Uganda
 Mr Pen Mony — Cambodia
- 10.30–11.00 Refreshments
- 11.00–12.00 *Rethinking Care*
- Chair Mr Johans Sandvin, Norwegian State Council on Disability
- Presentations:
 Mr Vic Finkelstein — United Kingdom
 Dr Dena Hassouneh-Phillips — United States of America
 Ms Mary O'Hagan — New Zealand
- 12.00–13.30 Lunch
- 13.30–13.45 Introduction to Working Group Sessions:
 Professor Colin Barnes
- 13.45–15.15 Working Group Sessions (on Needs and Challenges)
- 15.15–15.45 Refreshments
- 15.45–17.30 Round Table Discussion (This session was cancelled in order to give workshops more time to discuss needs and challenges)
- Chair Mr Lars Ødegård, Norwegian Association for the Disabled

Central Issues from the Working Group Sessions:
 Mr Joshua Malinga — Disabled Peoples' International
 Professor Alan J. Sinclair — International Diabetes Federation
 Ms Franca Smarrelli — World Stroke Association
 Mr Aimo Strömberg — International Cerebral Palsy Society
 Ms Elaine Johansson — Inclusion International
 Dr Michael Boland — World Organization of Family Doctors
 Ms Brenda Myers — World Confederation for Physical Therapy
 Dr William J. Peek — International Society of Physical Medicine and Rehabilitation
 Ms Karin Liabø — International Association of Occupational Therapists

19.00–20.30 Reception at Oslo City Hall. Hosted by the Mayor of Oslo

21.00 Dinner

Wednesday 25 April

Rethinking care: Strategies for the future

Chair Ms Ann-Marit Sæbønes, Disability Expert Norway

Vice chair Mr Lars Ødegård, Norwegian Association for the Disabled

09.00–09.30 Summary of Previous Day's Work:
 Professor Colin Barnes and Dr Ann Goerdt

09.30–11.00 Round Table Discussion:

Chair Ms Ann-Marit Sæbønes — Norway

Putting *Rethinking Care* on the Political Agenda:

Ms J.O. Sinyo — Kenya
Mr Kalle Könkkölä — Finland
Ms Kicki Nordström — Sweden
Mr Fred Mzoma — Malawi

- 11.00–11.30 Refreshments
- 11.30–12.30 Conclusions and Recommendations:
Professor Colin Barnes and Dr Ann Goerd
- 12.30–13.00 Closure of the Conference:
Ms Inger Marit Eira, Political Adviser, Norwegian
Ministry of Health and Social Affairs
- 13.00–14.30 Lunch