

Presentation for the meeting in Geneva with the Standing Committee on
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I would like to share with you some of the results from a global survey made by WHO, Disability and Rehabilitation Team, based on the four UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, linked to health based on answers from Governments.

The first four Rules in the UN Standard Rules document are gathered under the heading: Preconditions for Equal Participation. The message conveyed is that measures in these areas must be taken, because they constitute necessary measures to enable the individual to participate actively in the community. Three of these Rules, Medical Care, Rehabilitation and Support Services are areas of responsibility of the World Health Organization.

In discussions during 1998 between WHO, Disability and Rehabilitation Team, and the Special Rapporteur on Disability, Mr Bengt Lindqvist, and his Panel of Experts, it was agreed that a survey on the implementation of the Rules in these areas should be conducted by WHO.

Information was gathered in 1999 through a questionnaire, sent to all 191 WHO Member States and to more than 600 national nongovernmental organizations in the disability field. The information collected covers issues related to the four Rules on Medical Care, Rehabilitation, Support Services and Personnel Training. The questionnaire, which consists of 35 questions, was distributed in April 1999.

The objective of the study was twofold: To identify various government policies regarding the four rules and to identify various strategies adopted and problems encountered when working in the field of medical care and rehabilitation of persons with disabilities.

Respondents were asked to answer this questionnaire in order to identify the official policy of the country. Totally 104 governments responded within the dead-line and 12 after the dead-line, which must be deemed as a very satisfactory result.

Replies were received from countries representing the different world regions as follows: 17 from America, 25 from Europe, 20 from the Western Pacific region, 4 from the South East Asian region, 11 from the Eastern Mediterranean region and 27 from Africa.

A classification according to the socio-economic criteria of the governments responding, shows that there are 18 developed market economies, 9 countries with economies in transition and 77 developing countries, of which 24 least developed countries.

115 responses came from NGOs. A classification of NGO responses according to their organizational belongings, looks as follows. 18 responses were received from member organizations of Disabled Peoples' International, 28 responses from Inclusion International (for intellectually disabled), 24 responses from Rehabilitation International,

23 responses from the World Blind Union, 14 responses from the World Federation of the Deaf and 8 responses from the World Network of Users and Survivors of Psychiatry. The total number of countries covered by responses from governments and NGOs is 130.

The government information was provided by the division or unit within the responsible Ministry, (usually the Ministry of Health and/or the Ministry of Social Affairs). Although the constraints imposed by this method of compiling information - it presupposes that the questionnaire will be answered by the most well informed official within the field, or that the official takes the time to find answer elsewhere in case he/she is not capable to answer - the survey represents a unique distillation of information on policy and practice world-wide. It will hopefully be of assistance to policymakers, administrators, rehabilitation specialists and representatives of organizations in the disability field. The study provides a significant contribution to our knowledge and understanding of the world situation. The full report on the outcome of the survey was published in connection with the International Day of Disabled People in December 2000. The work continues with analysis of the responses from NGOs and a comparative study between governmental and NGO answers.

My presentation relates to, to what extent services in the defined areas exist, the involvement of governments and other entities and the influence of persons with disabilities, their families and their organizations in these services.

Medical Care

According to the opening sentence in the Rule on Medical Care: "States should ensure the provision of effective medical care to persons with disabilities". The first question concerned the extent to which States comply with this recommendation. An overwhelming majority of Member States (99 of 104) provide services to persons with disabilities. Medical care for children with disabilities is included within the general health care system in 90 countries.

Regarding the first paragraph in the Rule on Medical Care: "States should work towards the provision of programmes run by multidisciplinary teams of professionals for early detection, assessment and treatment of impairment." The majority of countries include prevention and treatment of impairment and rehabilitation techniques in the medical care system and other programmes. Less common to be included are programmes for counselling of parents and early detection and diagnosis. **15 countries do not include programmes for early detection and diagnosis.**

Another question concerned the degree of involvement of organizations of persons with disabilities in planning and evaluation of these programmes. In the majority of countries (59 of 103), the organizations of disabled people are **sometimes** involved. Only in three countries, they are **always** involved, whereas in 12 countries they are **never** involved. In 29 countries the organizations are **often** involved.

One question requested information whether persons with disabilities receive regular medical treatment to preserve or improve the level of functioning and in the countries where they do not, what it depends on. In 85 (of 103) countries, persons with disabilities receive regular medical treatment. Concerning the 18 countries, where medical treatment

is not provided, the following reasons were indicated: lack of specific programmes (16), lack of staff (12), economic constraints in the family (12), negative societal attitudes (9) and lack of training (8).

Regarding funding of medical care, responses indicate that persons with disabilities in 31 countries (of 104) pay fully themselves. In the remaining countries medical care is either provided free of charge or covered by mixed systems with patient payment, state subsidies or social insurance. In the 62 countries responding to the question about social insurance coverage of medical care expenditure, the following might be observed: There are 22 countries in which 20% or less of the population are covered. In 27 countries 81-100% of the population are. The discernible pattern is that when medical care is paid by social insurance, it is either for a small part of the population (probably often publicly employed people) or it is almost for everybody.

Another question concerned the provision of medical care in villages and poor urban areas. Out of 102 responding countries, 97 indicate that services are provided in these areas. The subsequent question was aimed to find the form of services provided in villages and in poor urban areas. The most frequent form is primary health care, 88 countries. 44 countries provide medical care through community-based programmes.

Finally, respondents were asked to indicate what services are provided to facilitate information and communication for persons with disabilities in medical care. According to responses received, the most frequent service provided for this purpose is easy reading information, 62 countries. 50 countries provide sign language interpretation and one third of the countries provide information in Braille or information on tape.

Rehabilitation

In a first general question information was requested to what extent national rehabilitation programmes are provided in Member States. In 73 of 102 of the countries responding, national rehabilitation programmes exist.

51 countries (of 104 responding) provide community-based rehabilitation programmes at local level. Nearly as many provide it at district level. 13 countries indicate that they have no community-based rehabilitation. Concerning institutional rehabilitation responses indicate the following: 74 countries have rehabilitation institutions at national level, 56 at provincial level, 46 district level and 22 at local level. In 8 countries no institutional rehabilitation programmes exist.

One question concerned what groups receive rehabilitation services. Generally, the responses indicate that rehabilitation programmes are available for many groups in most countries. They are most frequently provided to persons with mobility impairments (99 of 104 responding), followed by hearing impairments (90), visual impairments (89), intellectual disabilities (86) and deaf (84). It is worth observing that even for learning disabilities(e.g. dyslexia) rehabilitation services are provided in a considerable number of countries (69). There are rehabilitation services in as many as 74 countries for persons with mental illness.

These high frequencies are in themselves encouraging, but it must be added that they tell little about the actual availability for all those persons in different groups who are in need of rehabilitation. The availability may differ from covering all who need, down to a small fraction of the group concerned. **It must also be borne in mind that the figures mentioned indicate that no services are available in a considerable number of countries, in 14 countries for persons with hearing impairments and in 15 countries for those with visual impairments.**

One question concerned in what forms persons with disabilities, their families and their organizations are involved in rehabilitation services. According to the information received, persons with disabilities are most often involved through community-based rehabilitation and as trained teachers, instructors and counsellors. Least involved are persons with disabilities in the formulation and evaluation of rehabilitation programmes.

The same pattern is to be found concerning the families of persons with disabilities, though families are more frequently involved in the above mentioned activities than persons with disabilities themselves. Regarding the organizations of persons with disabilities the reverse pattern emerged. Organizations are most frequently involved in the design and organization of rehabilitation services and in the formulation and evaluation of rehabilitation programmes. Representatives of organizations are also most involved as trained teachers. **It must also be noted that in a great number of countries, organizations are not involved at all. This is also the case and even to a greater extent for persons with disabilities and their families.** Concerning community-based rehabilitation, the organizations have an equal frequency as persons with disabilities; in 44 countries they participate.

Support services

In this presentation I have only selected questions concerning the provision of assistive devices and equipment. Information was requested about government involvement in the provision of assistive devices. In 87 countries, of 96 providing information on this issue, governments are involved in the provision of assistive devices. **This high level of involvement of governments is encouraging, but at the same time it must be observed that this frequency of involvement does not indicate to what extent persons with disabilities in need of assistive devices really get services.**

A question concerning the funding of assistive devices and equipment gave the following result. 104 countries responded. The most common way of funding this service is through shared responsibility between government Ministries and persons with disabilities. In 28 countries government Ministries or municipalities pay fully. In 9 countries assistive devices and equipment are paid fully by social insurance schemes. In 18 countries they are paid fully by persons with disabilities themselves and in 13 countries the NGOs pay fully. **In 32 countries government Ministries or municipalities do not pay at all for the provision of assistive devices and equipment.**

Concerning what kinds of assistive devices and equipment are provided by the government, the outcome is the following: the most frequently provided aids are crutches (87 of 104 responding). In 83 countries prostheses/orthoses are provided. In 77 countries wheelchairs. In 64 countries hearing devices and in 62 countries visual aids are provided.

In 48 countries devices for daily living are provided and in 23 countries computers. **The most frequent kind of devices provided, are those for people with mobility impairments, followed by equipment for persons with hearing or sight impairments.** Naturally, there is a cost element in the different levels of provision of various kinds of equipment. One surprising result is that devices for daily living are not provided by more than half the number of countries, providing information.

In almost one third of the countries, responding to the question concerning the degree of involvement of persons with disabilities and/or their organizations in the planning of support services, they are not involved.

Personnel training

The first question was if governments ensure that all authorities/agencies providing services in the disability field give training to their personnel. Of 96 responding governments, 64 indicate that training is ensured.

Between 76 and 47 governments indicate that disability is a component in the professional training of different groups of staff (physiotherapists, nurses, social workers etc.) in the areas of medical care and rehabilitation.

43 governments (of 92 responding) indicate that they consult with organizations of persons with disabilities when developing staff training programmes.

The most remarkable result from this part of the study is that one third of the governments do not ensure that authorities/agencies providing services in the disability field offer training to their personnel.

Conclusions

This study reveals that rehabilitation is provided in a majority of countries, but in a basic traditional form as regards services and professional personnel available in practice. One obvious factor is that nurses predominate at all levels, in both medical care and rehabilitation. Another factor is that medical care is not fully provided everywhere; specialized doctors are not available in many countries at local or district level. Thus, persons with disabilities may need to travel great distances from their homes to consult specialized medical staff.

A noticeable pattern is that many countries do provide rehabilitation programmes, but there is a great gap between these services and the percentage of the population receiving it. Discrimination – in the sense of not including of persons with disabilities in general programmes - is still practised in some countries.

Persons with disabilities still lag behind as a pressure group. This is reflected in the observation that there are many people working in the disability field who have not received relevant professional training.

The organization of rehabilitation programmes and services is still not well implemented, implying the waste of resources by not ensuring trained personnel in disability issues as

well as the waste of not involving persons with disabilities, their families and their organizations in the planning of programmes and education. The quality aspect of medical care, of rehabilitation programmes and of services cannot be stressed enough.

Another pattern in this study is that the main participants within the field are, on one hand, the state/government and, on the other, the families/persons with disabilities themselves. In some areas the NGOs play an important role. It is astonishing how families of disabled and disabled persons can afford to take upon themselves such a great share as, in general, they are economically weak and need to spend much effort in managing their daily lives.

The objective of the Standard Rules concerning provision of assistive devices – crutches, hearing devices, etc. – has been implemented to a great extent. It seems, as if Governments assume their responsibility for the provision.

From an age group perspective it is clear that children are best provided for in medical care and rehabilitation. However, there is a great risk of being disabled as an adult owing to war, famine, accidents at the work place, diseases or traffic accidents. During old age there is an increasing possibility of being disabled. Therefore, it is to be regretted that adults and, in particular, the elderly are not supported to any great extent by medical care, rehabilitation programmes and services.

As I mentioned earlier, the work continues and in a couple of months, I hope, we shall have finalized the NGO reports. Next year we plan to organize workshops based on the outcome of these reports, in at least two WHO regions, in order to support Member States in their efforts to develop and implement policies for disabled people.