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Folder Title:
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**Special Rapporteur of the Commission for Social Development on
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Speech on the Standard Rules
by Mr. Bengt Lindqvist, Former M.P. and Cabinet Minister, Sweden

IPWH Conference, Kyoto, 5-7 November 1997

Ladies and Gentlemen,
Dear Participants,

I am both honoured and delighted to have this possibility to speak to you on the philosophy and contents of the new United Nations instrument in the disability field, entitled *the Standard Rules on the Equalization of Opportunities for Persons with Disabilities*. Before I do this, I would like to briefly comment on the events which led to the adoption of these Rules.

As you remember, 1981 was the International Year of Disabled Persons. This was an event of historical importance. The greatest contribution of this event was, in my opinion, the theme of the Year: Full Participation and Equality. This must be considered as a recognition on the highest possible political level of the rights of persons with disabilities to full participation and equal opportunities in the society they belong to. This important achievement was followed by the adoption of the World Programme of Action concerning Disabled Persons, which outlines the policies in harmony with the theme of the Year.

As you know the idea was that these policies should be implemented during the subsequent Decade of Disabled Persons, 1983 - 1992. Some important achievements were made during this period, but already in the middle of the decade it was obvious that too little happened. The international disability community therefore requested that the United Nations should assume a stronger leadership role in the development of better living conditions for persons with disabilities. The response to this request was the elaboration of the Standard Rules, which took place between 1990 -1993, when they were adopted.

Ladies and Gentlemen,

"In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms and making it difficult for them to participate fully in the activities of their societies. It is the responsibility of States to take appropriate action to remove such obstacles." This is probably the two most important sentences in

the whole Standard Rules document. You find them in the Introduction, paragraph 15. The process outlined in the Rules is to identify and remove obstacles to full participation. The Rules indicate that this should be done both by empowering persons with disabilities and by creating an accessible society. Governments of countries are responsible for taking action to remove such remaining obstacles.

Well, as you see, we now already know three important things about the Standard Rules. The objective is to achieve full participation and equal opportunities. The method to use is to identify and remove remaining obstacles and governments are responsible for the necessary measures.

The Standard Rules instrument summarizes the contents of the World Programme and also takes into account some new aspects, which were emphasized during the decade. Above all the stronger emphasis on the human rights perspective, which developed during the decade, has been incorporated. In comparison with the World Programme there are mainly three features which distinguish the Rules document. The language of the Rules is more concentrated in form. The message of the Rules is directly addressed to member states, i.e. the governments of countries. The third characteristic is that the Standard Rules will be monitored through a separate monitoring system.

The Standard Rules include an introduction, a preamble, 22 different Rules and a description of the monitoring system. The actual Rules are divided into three sections: preconditions for participation, target areas for equal participation and implementation measures.

The first section, dealing with the preconditions for participation, mainly presents Rules on different forms of support to the individual, medical care, rehabilitation and various forms of support services. The purpose of these services is to reduce the functional limitations and increase the independence of the individual.

The section on target areas deals with sectors of society, which are of general importance for the quality of life. There is an initial Rule on accessibility, which deals with all the various aspects of access to physical environment and activities and services generally available to non-disabled persons. There are Rules on how to make sectors like education, employment, social security, culture and recreation accessible. The Rule on family life and personal integrity is new and has no corresponding chapter in the World Programme. It reflects an area, which has attracted considerable attention during the decade.

The third section of the Rules, the implementation measures, presents a number of important measures, which are well-known in social engineering. I should here like to draw your attention to three of these Rules. In the Rule on legislation (Rule 15) the

message is that states should create a legal base for measures to achieve full participation and equality for persons with disabilities. Legislative action may also be needed to remove conditions which may adversely affect the lives of persons with disabilities.

In Rule 18 it is said that states should recognize the right of the organizations of persons with disabilities to represent their groups at all levels. States should encourage and support the formation and strengthening of such organizations.

The third measure I should like to point to concerns coordination (Rule 17). Disability involves all spheres of society and therefore it is necessary to use a multisectorial approach. This also means that there is a constant need for coordination. It is therefore stated in the Rule that states are responsible for the establishment and strengthening of national coordinating committees or similar bodies.

The chapter on monitoring among other things contains the following:

"The purpose of the monitoring mechanism is to further the effective implementation of the Standard Rules. It will assist each State in assessing its level of implementation of the Standard Rules and in measuring its progress. The monitoring should identify obstacles and suggest suitable measures that would contribute to the successful implementation of the Rules."

"The Rules shall be monitored within the framework of the sessions of the Commission for Social Development. A Special Rapporteur shall be appointed for three years to monitor the implementation of the Rules."

"International organizations of persons with disabilities having consultative status with the Economic and Social Council should be invited to create among themselves a panel of experts, on which organizations of persons with disabilities shall have a majority to be consulted by the Special Rapporteur and, when appropriate, by the Secretariat."

Ladies and gentlemen,

I think we are all aware that access to employment and income earning opportunities is necessary both for the realization of the goal of full participation and in our struggle against poverty, inequality and social exclusion. Therefore, a strategy to provide employment opportunities for different groups of persons with disabilities must be part of any national plan to create better living conditions for these groups.

The commitment to full employment was given new life at the World Summit for Social Development in Copenhagen, 1995. The world's leaders stated: "We commit ourselves to promoting the goal of full employment as a basic priority of our economic and social

policies, and to enabling all men and women to attain secure and sustainable livelihoods through freely chosen productive employment and work."

"Enabling all men and women to attain secure and sustainable employment" is a far-reaching goal, set by the world's leaders. Naturally this goal is also highly relevant for our discussion. What are the methods through which people with disabilities will get jobs? Well, we know a lot about the policies and programmes which have been tried and which are still in use in the world. We know that they are partly different and take different points of departure. After having studied statistics and reports on the situation during my monitoring of the Standard Rules, I found that I had reason to say, in my report to the UN Commission for Social Development: As long as the employment rates for persons with different disabilities are dramatically lower than for the population in general, we have reason to speak about failure globally in finding effective labour market policies for persons with disabilities, which would lead to employment rates, resembling those for the general population. In other words, one could say that we know a lot about how to fail in this field and little about how to succeed.

Against this background it is interesting to study the contents of Rule 7 on employment, which is the most recent attempt by the world community to formulate a disability policy, based on available experience. The contents of Rule 7 has been elaborated in close consultation with the International Labour Office - ILO.

The essence of Rule 7 on employment is that persons with disabilities should be empowered to exercise their right to gainful employment and that it is the responsibility of States, i.e. governments of countries, to remove all remaining obstacles to employment. As far as possible, and it is possible to a far greater extent than today, persons with disabilities should have jobs in the regular labor market. When this, despite all efforts, does not seem to be possible, jobs should be offered in more protected forms.

Let me quote the following paragraphs from the text:

"Laws and regulations in the employment field must not discriminate against persons with disabilities and must not raise obstacles to their employment"

"States should actively support the integration of persons with disabilities into open employment"

"States, worker's organizations and employers should cooperate with organizations of persons with disabilities concerning all measures to create training and employment opportunities"

The text also contains a list of various technical measures, which could be taken by governments, in order to obtain these objectives.

In the related area of income maintenance and social security it is, of course, difficult to establish global guidelines due to the fundamental differences in economic conditions existing in the world today. Still it has been possible for the UN General Assembly to agree on some universal principles, which should be observed by all. Because of the close link between employment, income maintenance and social security I also want to introduce to you the contents of Rule 8 on that subject. I should here like to quote the following parts of this Rule, which outline the basic responsibility of governments:

“States are responsible for the provision of social security and income maintenance for persons with disabilities“

“States should ensure the provision of adequate income support to persons with disabilities who, owing to disability or disability-related factors, have temporarily lost or received a reduction in their income or have been denied employment opportunities”

“In countries where social security, social insurance or other social welfare schemes exist or are being developed for the general population, states should ensure that such systems do not exclude or discriminate against persons with disabilities“

“Social security systems should include incentives to restore the income-earning capacity of persons with disabilities”

Ladies and Gentlemen,

I would now like to make a few comments on Rule 7 on employment. In the initial statement, which is an indication of an overall goal for labour market policies, the emphasis is on providing opportunities for gainful employment. Governments are requested to remove all remaining obstacles to open employment. We all know that there are obstacles of many different kinds. They vary from group to group. They are different in different societies and on different levels of economic and social development. And, also very important, they vary from individual to individual. Therefore, naturally, global guidelines must be broad and flexible.

However, certain things are in common. Above all, this is obvious concerning the role of Governments. A national policy to create job opportunities for persons with disabilities must build on a certain quantity of Government intervention. Usually this is taking the form of a combination of legislation and different kinds of economic arrangements.

In some cases, for some groups or individuals, it is sufficient to provide initial support - adequate training, adapted tools and equipment and/or an accessible work place. In other cases, a reduced productivity will inevitably accompany the individual and then some additional arrangement has to be made. This might be in the form of a wage subsidy or some similar arrangement, which could encourage the employer.

Another general measure would be to consider some form of quota system, which would put the same duty on all employers, both private and public. As we are all aware, there are both pros and cons in connection with quota systems and they have to be combined with other measures anyway.

Ladies and Gentlemen,

One thing is clear. In all countries there is a group of people with disabilities, who have extreme difficulties in getting jobs in the open labour market. They are mainly severely disabled persons but also persons with disabilities which are especially difficult to handle on the regular labour market. The goal of full participation and equality does not exclude anyone. It therefore makes it necessary to bother about this group, too. Hence the formulation in Rule 7, para 7: "For persons with disabilities whose needs cannot be met in open employment, small units of sheltered or supported employment may be an alternative." In other words, it is necessary for all nations to include programmes for this group of persons with disabilities. However, in my opinion, one might add that the better the open market functions, the smaller this group will be. There is nothing static about this, and this is important to remember.

Keeping the goal of full participation in mind, all arrangements with sheltered or specially provided jobs should include two important features. One is that only those who are really in need of sheltered employment, should be offered this possibility. Sheltered work opportunities must never grow into an excuse for doing less in the open market. The other thing is that there should always be a function to assist those in sheltered work in trying to get employment in the open market.

Finally I should like to add that sheltered or supported employment in small units can be organized in modern work units with a good environment and with meaningful jobs in the context of industry, administration or service production. Over a period of years I have witnessed this transformation in the Swedish system, SAMHALL, and I am sure you can find it in other countries, too. It is important to get rid of the stigma that different forms of specially provided job opportunities must take place in poor social settings and must contain less meaningful production.

Ladies and Gentlemen,

Before I close, I should like to inform you about the great ILO project, which is running this and next year. ILO is dedicating its biennial General Survey to labour market policies and Disability. In a world-wide investigation ILO is compiling information on the implementation of both Convention 159 and Recommendation 168. The results will be reported at the ILO Conference in June next year. Obviously we all have reasons to study the outcome and look for new and inspiring experiences, which could lead us to find more effective instruments for the attainment of our goals.

One thing is quite clear: We will not be in a position to say that we are approaching the goal of full participation and equal opportunities without considerable improvements in the employment situation of persons with disabilities. Until this happens social exclusion and poverty will reflect our failure. However, with the enormous and exciting development of new technology and with the summary of world policies from the global community, it looks as if the next few years will be very exciting. It is up to us to use this opportunity.

Thank you for your attention!

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SHIA Seminar on the Standard Rules and Gender Aspects
22-24 August 1997

Speech by Mr. Bengt Lindqvist, UN Special Rapporteur on Disability

Dear Participants,

May I first of all tell you how delighted I am to have this opportunity to meet you. I consider this seminar of great importance for me as Special Rapporteur and for the UN disability programme. I am sure you will understand why during my presentation.

Another thing I want to say initially is that all the documents, which have come out as a result of your activities as a delegation, are of great value and quality. I have studied them and they have informed, enlightened and inspired me.

At this seminar I will give you a general presentation of the Standard Rules and of the activities in the monitoring project, which has now run for three years. For your information I will use this opportunity to give you a general presentation of the Rules and my final report on my monitoring task to the UN Commission for Social Development, which I delivered in February this year. The last pages of this report contain my recommendations for future monitoring exercises, which to a large extent were picked up by the Commission in a special resolution.

I also want to give my answers to a number of questions, which seem relevant to ask, when I now for the first time as Rapporteur have the opportunity to analyze the implications of the Rules from a gender perspective together with a group of advocates for the long neglected rights of disabled women. Throughout the day I am sure that we will have a lot of exchange of views and hopefully also formulate a few ideas and initiatives together.

What are the Standard Rules?

Well, there are many answers to this question. The Rules are not an international convention and are therefore not legally binding for governments of Member States. Formally the Rules must be characterized as just another declaration. However, there is much more to be said in this matter. For instance, if you compare the Rules with the World Programme of Action concerning Disabled Persons, adopted after the International Year, three things characterize the Rules:

- a. The Rules are much shorter and more concentrated in form (closer to legal language),
- b: The Rules directly and systematically address Governments, and
- c: As part of the adoption of the Rules, it was decided that there should be an independent monitoring mechanism attached to the Rules. These three features make the Rules more distinct and powerful than is usually the case with declarations.

Another circumstance which renders the Rules special importance is the reason why they were elaborated. Towards the end of the 80's there was much dissatisfaction concerning the very meager results achieved on the basis of the World Programme and the Decade. The UN was asked to play a more active role in making Member States actually implement the modern, human rights based policy that was born in connection with the International Year. This was the main reason for elaborating the Rules. In this sense the Rules were built on the often negative experiences made during the Decade. This explains why the role of Governments is so very clearly defined and why so much importance is attached to the monitoring mechanism under UN leadership.

Another thing, which naturally makes the Rules document stronger, is that there was a wide interest to participate in the drafting process. The fact that they were elaborated at three large conferences, where about 75 Government delegations and all major international disability organizations participated, and then unanimously adopted by the UN General Assembly, makes this document extremely strong both politically and morally.

Finally, it should be taken into account that all the six world conferences, organized by the UN system between 1993-1996, include strong support of the implementation of the Rules.

In summary, all these different circumstances make the Rules far more than just another UN declaration. The Rules are now the dominating and most widely recognized international policy document in the disability field.

Do the Rules convey a gender perspective?

There are four things I want to say in reply to this question. First of all, the general presentation is done with the understanding that the suggested guidelines and policies concern all people with disabilities, irrespective of race, gender, age etc. This interpretation follows the tradition from the field of human rights. Secondly, there are a few direct references to the gender dimension. The most general one is the sentence in para. 15 in the Introduction, where the following is said: "The purpose of the Rules is that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others."

The gender perspective is mentioned in some other instances in the Introduction. In the Preamble we find support for the Convention on the Elimination of All Forms of Discrimination against Women, particularly the sections on disabled women. In Rules 4 on Individual Support, Rule 6 on Education and Rule 9 on Family Life and Personal Integrity special attention is drawn to the needs of girls and women with disabilities.

Thirdly, the Rules must always be related to the concrete situation in a country. In doing so, there is a need for interpretation and for putting the emphasis or focus on certain conditions or circumstances. It is, for instance, necessary in many cases to emphasize the need to include special measures for disabled women in adult education, medical care, rehabilitation and the provision of technical aids. This kind of exemplifying and concretization must also be used much more in future monitoring.

Fourthly, it is very important to combine the provisions of the Standard Rules and those contained in the Convention on the Elimination of All Forms of Discrimination against Women. This possibility must be further developed through cooperation between the appropriate bodies within the UN, the special agencies, international NGOs and all concerned entities on the national level. I hope we can begin this work here.

Finally, in reply to this question, of course, one would have wished for a more clearly spelt out gender dimension in the Rules document. However, by using all these different means, which I have pointed to, I am sure that we can make it a strong and useful tool also in the struggle for empowerment and full participation by disabled women in their societies.

How can we use the Rules in our struggle?

First of all, there are a few things that you must never forget about the Rules. They were worked out and adopted unanimously by Governments in close cooperation with your organizations. Governments have committed themselves to implement these Rules.

Also remember that the main purpose of these Rules is to make Governments accept the responsibility for measures which will lead to the realization of the goal of full participation and equality. The Rules contain lots of things that Governments must do to move towards this goal - adopt a legal base for this work, recognize the role of the organizations of disabled people, supply the necessary support to the individual, create access to education, employment and other crucial sectors of society. These things are all clearly indicated in the Rules. However, again, there is a need to interpret and concretize many things in every Rule area. This is something that you people in the organizations must do.

As you, of course, know, the representatives of disabled people and Governments often have very different opinions concerning what needs to be done. Therefore, do not wait for the Government opinion! Make your own interpretations and agenda, built on the Rules and make it known to the Government! When the organizations do this, it is naturally important to include gender aspects in all relevant areas.

May I also add that it is important to use the Rules in the discussions on cooperation and assistance project with international funders. With very few exceptions, both funders and Governments of developing countries forget or neglect the many disability dimensions of their development projects. The inclusion of disability measures in mainstream development will be a key area for the monitoring of the Rules in the time to come.

We can also learn from the past. In my monitoring I have found that there are a number of main ways, in which the Rules have been used. A considerable number of countries have used the Rules as a basis for new legislation. In some countries plans of action have been formed, based on the Rules. A third way has been to use the Rules as a basis for a national evaluation of the situation in the disability field. In improving the structure for cooperation between the Government and the organizations of persons with disabilities many countries have built on the guidelines of the Rules.

All these ways are commendable and have proved to be useful. In addition to this, of course, the contents of different Rules have been used to improve conditions. Employment, education, the provision of technical aids, rehabilitation, constructing a national monitoring system, measures to increase research are all examples of such areas. Finally, there is no doubt that the Rule on recognition and support of organizations of persons with disabilities (Rule 18) has played a significant role in strengthening the position of many national organizations. These many different ways must be used and developed further in the future.

May I finally point to one possibility, which has been tried with some success. When the movement of disabled people wanted to obtain certain changes in policies or programmes, it would sometimes be effective to invite The UN Rapporteur or a member of the UN Panel of Experts to assist in the advocacy. As you know, some things will be more acceptable, if they come from international representatives than if maintained by people from the national organizations in the country. In strategically important instances this possibility should be used also in future.

How can we cooperate in future?

As you know, we are now right between two monitoring periods. We have drafts of a work plan and a budget, but these have not yet been decided on within the UN system. According to these plans the Rapporteur will give priority to talks with individual governments, participation at regional and national seminars with both Government and organization representatives, cooperation with UN agencies in their field of responsibility and policy discussions on human rights and development cooperation. According to the instruction from the UN Commission for Social Development emphasis must be given to gender issues, disabled children and people having disabilities from

mental illness. How these special dimensions should be dealt with, is still an open question.

In my opinion there are mainly two ways to proceed. In all presentations, talks, discussions, surveys we consciously select examples from these areas. The other way is to create special activities. It is obviously not a question of either or. We must do both. The fact is, however, that up to now no preparations have been made. This is why I am so pleased with this meeting. It has already made me learn and think a lot, but there is certainly room for more. I hope that much will come out of our discussions.

When I met the Panel of Experts earlier this year, we decided that I should contact the UN Commission on the Status of Women to explore the possibilities of cooperation. I will take this initiative after this seminar.

As you know, half the number of the Panel members are women. Should they be mobilized as a group to prepare initiatives and improve our messages from a gender point of view? Perhaps. We have not discussed this in our group. Will you continue to be a group and could you then play an advisory role in this process? Well, let's discuss these many issues.

Finally, may I add a few words in general.

The 1990's have turned out to be important for the process towards a final recognition of the human rights and dignity of people with disabilities. New legislation in many countries, a re-orientation of disability policy towards the goal of full participation in a great number of countries, the establishment of a pattern of cooperation between Governments and organizations in all regions of the world, these are important indications of progress. Several initiatives in the area of monitoring human rights mean a break-through, which we have been waiting for.

All these achievements and many others are the result of our own efforts. We can be proud of what we have achieved but more remains to be done. We are on the move and nothing will stop us now. I look forward to our discussions and take this opportunity to wish you success in your future struggle.

Thank you for your attention!

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UNESCO
General Conference
Twenty-eight session
Paris 1995

Statement by Bengt Lindqvist on agenda item 5.13

Mme/Mr. President,

Permit me first of all to express my sincere appreciation for having been given this opportunity to speak on the subject of special needs education before the UNESCO General Conference. I do this in my capacity as the Special Rapporteur on disability, appointed in 1994 by the UN Secretary-General, for monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

The Standard Rules were adopted by the UN General Assembly in 1993 in order to encourage and facilitate the implementation by Governments of the philosophy and policies developed since the International Year of Disabled Persons. This modern philosophy is based on a human rights perspective. It could be summarized as "the right to full participation and equal opportunities for persons with disabilities". As we are all aware, there are still many obstacles making it difficult for persons with disabilities to participate in their societies.

As a matter of fact we live in an exclusive society, where persons with disabilities are often excluded from family life, social relationships, mainstream services and employment. This has certainly marked persons with disabilities and perpetuated negative attitudes, which have influenced policies and practice. This is particularly true for developing countries, where often the majority of children and adults with disabilities live in isolation and do not receive any support at all. According to the Standard Rules "it is the responsibility of Governments to take appropriate action to remove such obstacles". This should mainly be done by empowering the individual with a disability to cope better with his or her situation and by making the surrounding society accessible. In the 22 Rules measures along these two lines are recommended. As the ultimate goal of this process is full participation in the society, where the individual lives, the whole approach could be described as integrated and inclusive.

One of the 22 Rules is on education (Rule 6). It has been elaborated in close cooperation with the experts within UNESCO. It goes without saying that access to education is of fundamental importance for the whole process towards full participation. In agreement with the special Panel of Experts belonging to the monitoring mechanism, I have decided to concentrate, for the remaining two years of this first monitoring period, on education and five other Rule areas, including employment. In this context I will, to a large extent, depend on the close cooperation with the expertise within UNESCO.

Mme/Mr. President,

Permit me to congratulate UNESCO and the Government of Spain on the excellent outcome of the World Conference on Special Needs Education, held in Salamanca in June 1994. The Salamanca Statement is a powerful document, proclaiming inclusive education as the leading principle in special needs education. This principle is outlined in the following way:

- * "Every child has a fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning,

- * every child has unique characteristics, interests, abilities and learning needs,

- * education systems should be designed and educational programmes implemented to take into account the wide diversity of these characteristics and needs,

- * those with special educational needs must have access to regular schools which should accommodate them within a childcentred pedagogy capable of meeting these needs.

- * regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all."

In its clarity and determination to accept exceptions to this main principle only if there are compelling reasons for them, this statement represents a historical step forward in realizing the goal of Education for All.

A comparison between Rule 6 on education and the Salamanca Statement shows that the goals and directions of the two documents are very similar. The Salamanca Statement, however, is clearer and for the first time launches the concept of "inclusive education". Where the Salamanca Statement talks about inclusive education, the Standard Rules uses the phrase "education in integrated settings". The text of Rule 6 further states that "education for persons with disabilities should form an integral part of national educational planning, curriculum development and school organization.... Adequate accessibility and support services, designed to meet the needs of persons with disabilities, should be provided."

In other words, there is good harmony in principle between the two documents. It will therefore be easy and natural to cooperate in realizing our common goals. The framework for Action attached to the Salamanca Statement forms an excellent basis for common action.

Mme/Mr. President,

Another important contribution in emphasizing the significance of education in all human development, was made by the World Summit for Social Development, held in Copenhagen in March 1995. In the World Summit Declaration, commitment 6, our attention is drawn to the educational needs of persons with disabilities in the following way:

"We will ensure equal educational opportunities at all levels for children, youth and adults with disabilities, in integrated settings, taking full account of individual differences and situations."

Through these three major international documents, the Standard Rules, the Salamanca Statement and the World Summit Declaration, we have been made aware of the important task before us and of how it should be performed. We must make room for change, for inclusion and integration. We must stop feeding parallel and marginal systems for certain groups. The main responsibility lies with Governments to move towards inclusion and thereby towards a community living in harmony, wholeness and integration.

To make this change a success UNESCO must continue its leading role in special needs education. May I remind you that UNESCO's role in pursuing the principle of inclusion goes far beyond education. It concerns UNESCO responsibility in sectors like culture, communication and social science. Also in these sectors we expect UNESCO to include the concerns and interests of all persons, including persons with disabilities. Also other international organizations like the United Nations, UNICEF, ILO and WHO, and funding agencies like UNDP and the World Bank have an important role to play in this process of inclusion.

It is time for us all to move from words to concrete action in order to include children, youth and adults with disabilities in our efforts to develop educational opportunities and other spheres of society.

Finally, ladies and gentlemen: A school, good for children with special needs is a better school for all. Indeed, the principle of inclusion is the only way to realize the noble goal of Education for All.

I thank you for your attention.

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Nordic cooperation in disability research more than welcome

Statement by Bengt Lindqvist

Distinguished Participants, Dear Friends,

The International Year of Disabled Persons in 1981 was an event of historical importance. Through the adoption of the theme of the Year "full Participation and Equality" and the World Programme of Action concerning Disabled Persons, the global community through the United Nations recognized the rights of every disabled person to participate on equal terms in the activities of the society they belong to. During the Decade of Disabled Persons, which followed the Year, it unfortunately turned out that the nations of the world were slow in implementing these goals and guidelines. Therefore, to facilitate and speed up the implementation, a new international instrument in the disability field was elaborated.

This new implementation tool is entitled the Standard Rules on the Equalization of Opportunities for Persons with Disabilities. One prominent feature of this UN document is that the implementation will be actively monitored. Since I was made responsible for this monitoring exercise in 1994, I have been working with this task for three years. My work has resulted in a number of reports, which could be made available upon request. One observation I can make after this period is that the Standard Rules document is by now recognized and used as guidelines for development in a great number of countries.

Ladies and Gentlemen,

What do these Rules then say about research and other forms of knowledge accumulation? Before I answer this question, I should like to quote the following, to give you a notion of what approach the Rules apply:

"In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms and making it difficult for them to participate fully in the activities of their societies. It is the responsibility of States to take appropriate action to remove such obstacles."

This is probably the two most important sentences in the whole Standard Rules document. You find them in the Introduction, paragraph 15. The process outlined in the Rules is to identify and remove obstacles to full participation. Governments of countries are responsible for taking action to remove such remaining obstacles.

In this process knowledge is naturally a key element. In the Standard Rules this has been strongly emphasized in two main ways. First of all it is necessary to involve disabled people themselves in the development of policies and programmes which concern them. This is why there is such strong emphasis throughout the document on cooperation with disabled people and their organizations. Among the 22 Rules, one (Rule 18) is dealing solely with the position and role of such organizations. Among other things it recommends that States (i.e. governments of countries) should support the formation and strengthening of organizations of persons with disabilities. States should also recognize the right of such organizations to represent their groups in all matters concerning them. In the Nordic countries we have a long tradition in this area and we know that we need the contributions from disabled people and those who represent them to be able to develop good and functioning measures. The close and constructive cooperation between them and decision-makers in society is one of the most efficient ways to secure relevant knowledge.

The other way, in which emphasis has been given to the need for knowledge, naturally concerns research in many different forms. Without statistical knowledge of causes, kinds and numbers in the disability field our planning will be defect, or even paralyzed. Without knowledge of actual living conditions we can not know what is needed. Without knowledge about the effectiveness of various measures, services and programmes we can not improve conditions. Good disability programmes must therefore be built on knowledge and they should include mechanisms for monitoring and evaluation. The Standard Rules recognize the need for constant accumulation of knowledge as a basis for planning.

To illustrate more concretely how the Rules deal with the issue of research and cooperation in research I have taken a closer look at three of the 22 Rules. Rule 13 "Information and Research" obviously deals directly with this matter. In this Rule it is said that the State has the ultimate responsibility for the collection and dissemination of information on the living conditions of persons with

disabilities. States should promote comprehensive research on all aspects, including obstacles that affect the lives of persons with disabilities. At regular intervals States should collect gender-specific statistics on the living conditions. In doing this States should cooperate with universities, research institutions, organizations of persons with disabilities etc. States are also recommended to develop and adopt terminology and criteria for the conduct of national surveys. Finally States should support the exchange of research findings and experiences.

Rule 20 deals with "Monitoring and Evaluation". The general recommendation is that States are responsible for the continuous monitoring and evaluation of the implementation of programmes and services in the disability field. Evaluation should occur regularly and systematically. States should participate in international cooperation in order to develop common standards for national evaluation.

In the last Rule, Rule 22 on "International Cooperation" States are strongly recommended to participate generally in the international exchange of information and experiences. Particularly, States should encourage and support the exchange of knowledge and experiences in specific areas - research being one such mentioned area.

Ladies and gentlemen,

What I have been trying to say is the following: In our efforts to create better living conditions for people, who happen to be disabled, we can not do without knowledge and we can not do without cooperation. Therefore I, as a representative of the international community outside the Nordic countries, am delighted to welcome this initiative to establish a Nordic forum for people active in disability research. Based on the recommendations in the Standard Rules it would be appropriate for the Nordic Governments to find ways to support this excellent initiative. I take this opportunity to wish you success with this initiative and in your future research efforts. Of course, I look forward to cooperating with you in all ways possible.

Thank you for your attention!

**Preliminary Travel Plans August - December 1997
for Bengt Lindqvist, UN Special Rapporteur on Disability**

Aug 14-15: Nordic Conference on Cooperation in Disability Research, Fredrikshamn, Denmark

September 8: Informal Inter-agency Meeting at UNESCO, Paris, France

September 17-28: Roundtrip including participation at Regional Seminar on the Standard Rules, Amman, 18-19 sept, Visit at ESCAP Office in Bangkok, 23-24 Sept, Participation at 1997 International Seoul Conference on Disability, 27-28 sept.

October 6: Participation at the meeting of the Committee monitoring the Child Convention, Geneva, Switzerland

October 13-16: Participation at meeting concerning the funding of a second monitoring period and meetings with the UN Secretariat, New York

Nov 6-7: Participation at international meeting concerning employment opportunities, Kyoto, Japan

November 15: Participation at activities concerning employment of the disabled, Sevilla, Spain

November 18: Participation at a one day conference on disability policy, Dublin, Ireland

November 24-28: Participation at national seminar on the Standard Rules, Santiago, Chile

GOVERNMENT IMPLEMENTATION OF THE STANDARD RULES AS SEEN

BY THE MEMBER ORGANIZATIONS OF

REHABILITATION INTERNATIONAL (RI)

CONTENTS

PART I - SUMMARY

Introduction
General policy
Legislation
Accessibility
Organizations of persons with disabilities
Co-ordination of work
Conclusion

Industrialized countries

REHABILITATION INTERNATIONAL, DENMARK (22)
REHABILITATION FOUNDATION, FINLAND (30)
HELLENIC SOCIETY FOR DISABLED CHILDREN, GREECE (53)
THE ORGANIZATION OF HANDICAPPED IN ICELAND AND THE NATIONAL FEDERATION
FOR THE AID OF THE HANDICAPPED, ICELAND (153)
NATIONAL REHABILITATION BOARD, IRELAND (8)
JAPANESE SOCIETY FOR REHABILITATION OF DISABLED PERSONS, AND THE JAPAN
ASSOCIATION FOR EMPLOYMENT OF THE DISABLED, JAPAN (162)

Middle East and North Africa

KUWAIT SOCIETY FOR THE HANDICAPPED, KUWAIT (18)

Countries in transition

ASSOCIATION OF DISABLED PERSONS IN THE CZECH REPUBLIC, RI, CZECH REPUBLIC
(62)
INSTITUT REPUBLIKE SLOVENIJE ZA REHABILITACIJO, SLOVENIA (135)

Latin America and the Caribbean

REHABILITATION INTERNATIONAL, ARGENTINA (39)
ASOCIACION DOMINICANA DE REHABILITATION, RI, DOMINICAN REPUBLIC (73)

South, East Asia and the Pacific

REHABILITATION INTERNATIONAL, HONG KONG (87)
MALAYSIAN LEPROSY RELIEF ASSOCIATION, MALAYSIA (46)
NATIONAL COUNCIL OF SOCIAL SERVICE, SINGAPORE (170)
NATIONAL COUNCIL ON SOCIAL WELFARE OF THAILAND, THAILAND (160)

INTRODUCTION

This report analyses the replies to the questionnaire sent not only to the governments of the UN Member States, but also to 600 national NGO's within the disability field. The number of responses from the NGO's was not as high as from the governments of Member States. However, it represents a very interesting material. In this report I will separate, among the total of 163 replies from NGO's, the 15 replies from Rehabilitation International (RI).

Part I of this report presents and analyses the results from the NGO's belonging to RI, which have answered the questionnaire. Each table corresponds to a specific question in the questionnaire (the number of the question is marked). For each question, after the presentation of the results, comparisons are made between a) the results from the organization in question and the results from the total of NGO's responding to the questionnaire, and b) the results from the organization in question and the replies from the governments. In this way we can locate issues where convergence, or divergence, of views exists, between the particular NGO's and all the NGO's having responded to the questionnaire, and between the particular NGO's and the governments.

The information in Part II is presented in a rather detailed form, in order to expose the collected data of the responding NGO's.

The decision to send the questionnaire, not only to governments of the Member States, but also to NGO's of these states within the disability field, proved to be worthwhile. The different perspectives and views indicate a more complex picture of the degree of achievement each country as to the implementing of the Standard Rules. When the government and one, or many, NGO's give the same answers there is a guarantee for the reliability of the received data, but when, on the other hand, the answers differ many questions arise. For instance: Who knows what about whom? Does the organization for the blind know the conditions for the mentally disabled? Is there a trend that governments give an idealizing description, while NGO's give a pessimistic one? The comparisons in this report are not aiming at indicating the greatest possible differences, but to find out the greatest possible achievements with the standards, set out by the Rules. Yet, attention has to be paid to cases where the answers from one and the same country are not concordant. For several questions, the difference between the percentages reported by RI organizations and governments, is ten percent or more. What do such differences tell us?

The answers differ, now and then, on specific details on very essential issues, like what kind of services that are available, and what persons with disabilities are entitled to. That the answers differ, on issues such as the role of the co-ordinating committee, is rather evident, since it is a question of assessing, of evaluating a process between two or more parties. But in case of divergent answers about social and economic rights questions arise. Is there an information gap even among the most prominent spokesmen for persons with disabilities? Do organizations have too small resources in order to keep themselves well-informed? Or do the disability organizations work rather separately from each other; concentrating on their own, specific disability group, due to the complexity of the matter, that is 'disability' is it a too big an issue to keep record of?

The divergence is of course in many cases the result of a different perspective due to different roles: The government is the actor implementing policies within a wide range of issues, while NGO's are expert actors in a specific field, who therefore very well know what is happening in a limited area. The answer from the NGO's can thus sometimes be the verification, or falsification, of the answer from the government. The government answer giving a more optimistic view than the answer from the NGO's could depend on the fact that - being the responsible part for the implementation of policies, conventions and rules such as the Standard Rules - the government wants to demonstrate that it has carried out its obligations.

By elaborating the specific replies of different NGO's, comparing the answers with the NGO's as a whole - a rather common procedure - and with the governments, one trait has emerged, rather unexpectedly: that specific NGO's diverge on one or many issues with the NGO's in general but converge with the answer from the government. In order to explain this, and other interesting findings, further monitoring is needed.

Distribution of NGOs belonging to RI according to regions

<i>Regions</i>	<i>Frequency</i>	<i>Percent</i>
South, East Asia and the Pacific	4	26,7
Industrialized countries	6	40,0
Latin America and the Caribbean	2	13,3
The Middle East and North Africa	1	6,7
Sub-Saharan Africa	0	0,0
Countries in transition	2	13,3
Total	15	100,0

The region with most respondents among RI organizations is the one of industrialized countries. No replies were received from RI organisations from Sub-Saharan Africa.

GENERAL POLICY

Table 1 (Question No. 1)

Number of RI organizations reporting on officially recognized disability policy:

<i>Disability policy expressed in:</i>	<i>Frequency</i>	<i>Valid Percent</i>
Having an officially recognized policy	12	92,3
Not having an officially recognized policy	1	7,7
Law	8	61,5
Guidelines adopted by the Government	7	53,8
Guidelines adopted by a disability council	7	53,8
Policy adopted by political parties	4	30,8
Policy adopted by NGOs	6	46,2

Total 13, No answer 2

As Table 1 shows the majority of RI organizations are reporting that there is an officially recognized disability policy. The majority of RI organizations are reporting that the disability policy is expressed in law and in guidelines, adopted by the government. The replies from the NGOs generally exhibit the same pattern. There are

no clear differences regarding the percentages, except for the guidelines adopted by the National Disability Council, the percentages reported by RI organizations being higher when compared with the percent reported by NGOs in general. There are great differences, when compared with the percentages reported by governments. RI organizations report a lower percentage regarding the disability policy expressed in law, but a higher percentage regarding the policy expressed in guidelines adopted by a disability council, the policy adopted by political parties and the policy adopted by NGOs.

Table 2 (Question No. 2)
The emphasis of disability policy

<i>Emphasis in national policy</i>	<i>Number of RI org. indicating respective emphasis</i>				
	1	2	3	4	5
Prevention	2	1	3	3	2
Rehabilitation	4	6	2	-	-
Individual support	6	1	1	3	-
Accessibility measures	-	3	6	3	-
Anti-discrimination law	-	1	-	2	6

1 = very strong emphasis

5 = very weak emphasis

According to RI organizations, the strongest emphasis is on rehabilitation, while the weakest emphasis is on anti-discrimination law and accessibility measures. The same pattern prevails as with the NGOs in general. The same pattern also emerges, when compared with government responses.

Table 3 (Question No. 3)
Government action to convey the message of full participation

<i>Conveying the message of full participation</i>	<i>Frequency</i>	<i>Valid Percent</i>
RI organizations reporting Gvt. action	7	58,3
RI organizations reporting no Gvt. action	5	41,7

Total 12, No answer 3

As Table 3 shows, almost 42% of the organizations are reporting that the governments have not done anything to initiate or support information campaigns conveying the message of full participation, since the adoption of the Rules. More RI organizations report a government action than NGOs generally do. There are clear differences, when compared with the percentages reported by governments. RI organizations report a lower percentage regarding government action for conveying the message of full participation than the governments themselves.

LEGISLATION

Table 4 (Question No. 4)

Types of legislation to protect the rights of persons with disabilities

<i>Types of legislation</i>	<i>Frequency</i>	<i>Valid Percent</i>
Special legislation	1	6,7
General legislation	6	40,0
Special and general legislation	8	53,3

Total 15, No answer 0

As Table 4 shows, the most common type of legislation, according to RI organizations is to use a combination of special legislation and general legislation. The second most frequent type of legislation is general legislation, applicable to all citizens, while the least common type is special legislation, specifically referring to disabled persons' rights. There is, however, a high percentage of countries, where the rights of persons with disabilities are protected only by general legislation. Though the pattern is the same compared with the NGOs in general, there is a clear difference regarding the percentage of countries having only special legislation. The valid percentage for the NGOs in general is 23,6%. There are clear differences, when compared with the percentages reported by governments. RI organizations report a higher percentage concerning countries using only general legislation and a lower percentage for countries using a combination of special and general legislation.

Table 5 (Question No. 5)

Mechanisms to protect citizenship rights

<i>Judicial/no-judicial mechanisms</i>	<i>Frequency</i>	<i>Valid Percent</i>
Due process	7	58,3
Recourse procedure	3	25,0
Ombudsman	4	33,3
Governmental body (administrative)	10	83,3
Expert bodies	3	25,0
Arbitration/conciliation body	2	16,7

Total 12, No answer 3

As Table 5 shows, the majority of RI organizations are reporting that mechanisms have been adopted to protect the rights of persons with disabilities. The most frequent judicial mechanism adopted is legal remedy through the courts, while the most frequent non-judicial mechanism is a governmental body (administrative). There is a clear difference, compared with the NGO's in general, as regards the percentage of countries reporting due process and a governmental body (administrative). The percentages reported by RI organizations concerning due process are lower but the percentage concerning the existence of a governmental body (administrative) is much higher than the percentage reported by NGOs in general. There are also clear differences, when compared with the percentages reported by governments. RI organizations report a lower percentage of countries, where disabled persons can defend their rights through courts, but a higher percentage of countries using recourse procedure by a special agency as well as a government body (administrative), than the governments.

Table 6 (Question 6)

Civil and political rights of persons with disabilities

<i>RI organizations reporting that general legislation does not apply with respect to:</i>	<i>Frequency</i>	<i>Valid Percent</i>
Education	0	0,0
Employment	0	0,0
The right to marriage	4	30,8
The right to parenthood/family	4	30,8
Political rights	3	23,1
Access to court-of-law	4	30,8
Right to privacy	4	30,8
Property rights	4	30,8

Total 13, No answer 2

As Table 6 shows, there is a considerable number of RI organizations reporting that general legislation does not apply to persons with disabilities with respect to: the right to marriage; parenthood/family; political rights; access to court-of-law; the right to privacy and property rights. General legislation is in all countries applicable with respect to the right to education and the right to employment. It is interesting to note that general legislation applies with respect to the right of employment in all countries. The same pattern prevails as with the NGOs in general, but with differences in the percentages reported, concerning the right to parenthood/family and political rights where the percentages reported by RI organizations are lower than the NGO's in general. When compared with the percentages reported by governments there are clear differences only regarding two of the rights listed above, namely the right to education and the right to employment. The governments do not have as low a percentage as the RI organizations (0%).

Table 7 (Question No. 7)

Economic and social rights of persons with disabilities

<i>RI organisations reporting that the following benefits are not guaranteed by law:</i>	<i>Frequency</i>	<i>Valid Percent</i>
Health/medical care	5	33,3
Rehabilitation	3	20,0
Financial security	5	33,3
Employment	9	60,0
Independent living	10	66,7
Participation in decisions affecting themselves	9	60,0

Total 15, No answer 0

According to RI organizations, the following rights are less often guaranteed by law to persons with disabilities: independent living; employment and participation in decisions affecting themselves. The right most frequently guaranteed by law is the right to rehabilitation. Regarding the right to employment, it is interesting to make a comparison with question no. 6, enabling an inference that general legislation is not a sufficient guarantee for disabled persons' rights. For instance, though there are *no legal hindrances* for disabled persons in any of the countries with regard to the right to

employment, only in 40% of the countries this right is *guaranteed by law*. Obviously, this makes a difference. Compared with the NGOs in general, there are no clear differences, except regarding the right to financial security. The percentage reported by the NGOs in general is 60%, to be compared with the 33%, reported by RI organizations. There are clear differences, when compared with the percentages reported by governments. RI organizations report a higher percentage of countries where the following benefits are not guaranteed by law: health/medical care, employment, independent living and participation in decisions affecting themselves.

Table 8 (Question No. 8)

New legislation concerning disability since the adoption of the Rules

<i>Legislation on disability</i>	<i>Frequency</i>	<i>Valid Percent</i>
RI reporting enactment of new legislation	7	50,0
RI reporting no enactment of new legislation	7	50,0

Total 14, No answer 1

As Table 8 shows, 50% of RI organizations are reporting that no new legislation concerning disability has been enacted, since the adoption of the Rules. There are clear differences, compared with the percentages reported by the NGOs in general, the enactment of new legislation reported being 37%. There are no clear differences, when compared with the percentages reported by governments.

ACCESSIBILITY

Table 9 (Question No. 9)

Regulations to ensure accessibility in the built environment

<i>RI organisations reporting that:</i>	<i>Frequency</i>	<i>Valid Percent</i>
Accessibility standards exist	15	100,0
Accessibility standards do not exist	0	0,0

Total 15, No answer 0

As Table 9 indicates, none of the RI organizations are reporting that no accessibility standards exist. The same pattern prevails as with the NGOs in general though there are clear differences in the percentages. The percentage reported by NGOs in general, regarding the existence of accessibility standards, is 67%. There are also clear differences, when compared with the percentages reported by governments. RI organizations report a higher percentage of countries where accessibility standards exist.

Table 10 (Question No. 10)

Accessibility of the built environment

<i>RI organizations reporting accessibility in:</i>	<i>Frequency</i>	<i>Valid Percent</i>
Public places	15	100,0
Outdoor environment	10	66,7
Transportation	7	46,7
Housing	8	53,3

Total 15, No answer 0

As Table 10 indicates, all the RI organizations are reporting that accessibility standards concerning public places exist, but that accessibility standards concerning means of public transportation exist to a lesser extent. The same pattern, with the NGOs in general, with no clear differences in the percentages reported. There are, however, clear differences, when compared with the percentages reported by governments. RI organizations report a lower percentage regarding accessibility standards in the outdoor environment and in transportation, than the government.

Table 11 (Question No. 11)

Supervision of the accessibility in the built environment

<i>Accessibility in the built environment is observed by:</i>	<i>Frequency</i>	<i>Valid Percent</i>
National authority	9	60,0
Local Governments	8	53,3
The constructor	2	13,3
The organizers/providers of the activities	4	26,7
No responsible body exists	1	6,7

Total 15, No answer 0

As Table 11 shows, 7% of RI organizations are reporting that no responsible body exists to observe the accessibility in the built environment. Accessibility in the built environment, when existing, is most frequently observed by a national authority and by local governments. The same pattern prevails in replies compared with the NGOs in

general. There are, however, clear differences in percentages reported. RI organizations report a higher percentage regarding supervision by a national authority and by the organizers/providers of the activities, but a lower percentage regarding the existence of a responsible body. When compared with the percentages reported by governments, there are differences concerning the supervision of the accessibility in the built environment by the organizers/providers of the activities, RI organizations reporting a higher percentage regarding the existence of a responsible body and fewer RI organizations reporting that such a body does not exist.

Table 12 (Question No. 12)

Measures to facilitate accessibility of the built environment

<i>Government measures promoted:</i>	<i>Frequency</i>	<i>Valid Percent</i>
Levelling off pavements	12	80,0
Marking parking areas	13	86,7
Installing automatic doors, lifts and accessible toilets	12	80,0
Ensure accessibility in public places	12	80,0
Improving accessibility in housing	8	53,3
Financial/incentives support for accessibility measures	7	46,7
Special lighting/contrast colours for visually impaired	5	33,3
Provision of specially adapted motor vehicles	9	60,0

Total 15, No answer 0

According to RI organizations, the following measures to facilitate accessibility in the built environment are the most frequently promoted: marking parking areas, levelling off pavements, installing automatic doors, lifts and accessible toilets and ensuring accessibility in public places. The measure being the least of all promoted is special lighting/contrast colours for visually impaired. There are great differences in the percentage reported, when compared with the NGOs in general. RI organizations report a higher percentage regarding all the listed measures. There are also clear differences in almost all of the above mentioned measures, when compared with the percentages reported by governments. RI organizations report a higher percentage on the following measures: levelling off pavements, marking parking areas, installing automatic doors, lifts and accessible toilets, ensuring accessibility in public places, improving accessibility in housing and providing specially adapted motor vehicles.

Table 13 (Question No. 13)

Special transport system

<i>Special transport is available for:</i>	<i>Frequency</i>	<i>Valid Percent</i>
Medical treatment	12	92,3
Education	12	92,3
Work	9	69,2
Recreational purpose	12	92,3
No special transport system exists	2	13,3
Special transport exists	13	86,7

Total 15, No answer 0

There are 13% of the RI organizations reporting that no special transport system exists. When a special legislation exists, it is available, in most countries, for education and

medical treatment. There are clear differences in the percentages, when compared with the NGOs in general, regarding the existence of special transport system. The percentage reported by the NGOs is higher. When compared with the percentages reported by governments, there are clear differences. RI organizations report a lower percentage for the availability of special transport for work but a higher one for recreational purpose. The RI organizations also report a higher percentage of countries, where special transport exist.

Table 14 (Question No. 14)

Adaptation of the built environment

<i>Obstacles reported by RI when building accessible environments:</i>	<i>Frequency</i>	<i>Valid Percent</i>
Attitudinal factors	12	80,0
Economic/budgetary factors	11	73,3
Technical factors	0	0,0
Geographical and climatic factors	1	6,7
Lack of legislation and regulations	2	13,3
Lack of planning and design capacity	5	33,3
Lack of knowledge, research and information	3	20,0
Lack of user participation	4	26,7
Lack of co-operation from other organizations	4	26,7
Lack of enforcement mechanism	11	73,3

Total 15, No answer 0

As Table 14 shows, there are three main obstacles according to RI organizations, when building accessible environments, namely attitudinal factors, economic/budgetary factors and lack of enforcement mechanism. It is remarkable that 80% of the RI organizations are reporting attitudinal factors as the main obstacle when building accessible environments. There are clear differences compared with the NGOs in general. RI organizations are reporting a higher percentage regarding attitudinal factors and lack of enforcement mechanism but a lower percentage regarding lack of legislation and regulations, and lack of knowledge, research and information. There are differences in the percentages reported by governments in almost all of the above mentioned obstacles. RI organizations report a higher percentage concerning the following obstacles: attitudinal factors, lack of user participation, lack of enforcement mechanism, a lower percentage concerning technical factors, geographical and climatic factors, lack of legislation and regulations and lack of knowledge, research and information.

Table 15 (Question No. 15)

Disability awareness component

<i>Disability awareness in the training:</i>	<i>Frequency</i>	<i>Valid Percent</i>
There is a disability awareness component	7	53,8
There is not a disability awareness component	6	46,2

Total 13, No answer 2

The majority of RI organizations are reporting that a disability awareness component is incorporated in the training of planners, architects and construction engineers. There is a different pattern compared with the NGOs in general. There are also clear differences in

the percentage reported. There are no clear differences, when compared with the percentages reported by governments.

Table 16 (Question No. 16)

Status of sign language

<i>The status of sign language as reported by RI organizations:</i>	<i>Frequency</i>	<i>Valid Percent</i>
Recognized as the official language	6	42,9
As the first language in education	2	14,3
As the main means of communication	3	21,4
No officially recognized status	3	21,4

Total 14, No answer 1

As Table 16 indicates, 21% of RI organizations are reporting that sign language has no officially recognized status, while also 43% of the RI organizations are reporting that sign language is recognized as the official language of deaf people. There is no clear difference, compared with the NGOs in general. There are clear differences, when compared with the percentages reported by governments. The RI organizations report a higher percentage of countries, where sign language has an officially recognized status, but a lower percentage of countries, where sign language has no officially recognized status.

Table 17 (Question No. 17)

Accessibility measures in media

<i>Accessibility measures in media</i>	<i>Frequency</i>	<i>Valid Percent</i>
Reporting accessibility measures	10	66,7
Reporting no accessibility measures	5	33,3

Total 15, No answer 0

As Table 17 shows, the majority of the RI organizations are reporting that there are accessibility measures to encourage media to make their information services accessible for persons with disabilities. The percentage reported here, regarding the existence of accessibility measures, is higher compared with the percentage reported by the NGOs in general. When compared with the percentages reported by governments, the RI organizations report a higher percentage of countries that have taken measures to encourage accessibility measures in media.

Table 18 (Question No. 18)

Accessibility measures in public information services

<i>Public information services</i>	<i>Frequency</i>	<i>Valid Percent</i>
Accessibility measures in information	7	58,3
No accessibility measures in information	5	41,7

Total 12, No answer 3

The majority of the RI organizations are also reporting that there are government measures to make other forms of public information services accessible for persons with disabilities. A clear difference appears compared with the percentage reported by the

NGOs in general. There are no clear differences, when compared with the percentages reported by the governments.

Table 19 (Question No. 19)

Access to information and communication

<i>Services to facilitate information/communication</i>	<i>Frequency</i>	<i>Valid Percent</i>
Literature in Braille/tape	13	92,9
News magazines on tape/Braille	7	50,0
Sign language interpretation for any purpose	8	57,1
Sign language interpretation for major events	5	35,7
Easy readers for persons with mental disabilities	3	21,4
None	0	0,0

Total 14, No answer 1

As Table 19 indicates, none of the RI organizations report there being no services at all to facilitate information and communication between persons with disabilities and persons without. This is a clear difference with the percentage reported by NGOs in general. The services most frequently provided, according to the RI organizations are literature in Braille/tape and sign language interpretation for any purpose, whereas less frequently services such as easy readers for persons with disabilities are provided. The main difference appearing here, is that RI organizations are reporting a higher percentage regarding the provision of literature in Braille/tape and sign language interpretation for any purpose than NGO's in general. There are clear differences regarding two of the above listed services, when compared with the percentages reported by governments. The RI organizations report a higher percentage of countries, where sign language interpretation is provided for any purpose, but a lower percentage concerning easy readers for persons with mental disabilities.

ORGANIZATIONS OF PERSONS WITH DISABILITIES

Table 20 (Question No. 20)

National umbrella organization

<i>National umbrella organization</i>	<i>Frequency</i>	<i>Valid Percent</i>
There is umbrella organization	11	73,3
There is no umbrella organization	4	26,7

Total 15, No answer 0

As Table 20 shows, the majority of the RI organizations are reporting that there is an umbrella organization of organizations of persons with disabilities. Minor differences appear in the percentage reported, compared with those reported by the NGOs in general. There are no clear differences, when compared with the percentages reported by governments.

Table 21 (Question 21)

Participation in policy making

<i>Participation in policy-making</i>	<i>Frequency</i>	<i>Valid Percent</i>
RI organizations reporting participation	7	46,7
RI organizations reporting no participation	8	53,3

Total 15, No answer 0

As Table 21 shows, 53% of the RI organizations are reporting that no legal provisions exist mandating the representatives of persons with disabilities to participate in policy-making or to work with governmental institutions. There are only minor differences, compared with the percentage reported by the NGOs in general. There are clear differences, when compared with the percentages reported by governments. The RI organizations report a lower percentage regarding participation in policy-making.

Table 22 (Question 22)

Consultations with organizations of persons with disabilities

<i>Organizations are consulted:</i>	<i>Frequency</i>	<i>Valid Percent</i>
Never	0	0,0
Sometimes	3	20,0
Often	6	40,0
Always	6	40,0

Total 15, No answer 0

Table 22 shows that a majority of the organizations reports that consultations often/always take place, while the percentage is 0 for the RI organizations reporting that consultations with organizations of persons with disabilities never take place when laws, regulations and/or guidelines with a disability aspect are being prepared. There are main differences in the percentages compared with NGOs in general. The RI organizations are reporting a higher percentage when consultations are *often* and *always* taking place. There are clear differences in the percentages reported by governments. The RI organizations report a higher percentage when consultations *often* take place.

Table 23 (Question 23)

Level of consultations

<i>Level of consultations</i>	<i>Frequency</i>	<i>Valid Percent</i>
National	15	100,0
Regional	8	53,3
Local	8	53,3

Total 15, No answer 0

Table 23 shows that consultations, when taking place always occur at the national level. Great differences appear in the percentage reported concerning the regional and local levels, when compared with the NGO's in general. The percentage reported by NGOs in general are lower. There are clear differences, when compared with the percentages reported by the governments. The RI organizations report a higher percentage concerning consultations on the national and regional level.

Table 24 (Question 24)

Support to organizations of disabled people

<i>Kind of support</i>	<i>Frequency</i>	<i>Valid Percent</i>
Financial	12	92,3
Organizational/logistic	2	15,4
No support at all	0	0,0

Total 13, No answer 2

The majority of the RI organizations are reporting that the government gives financial support to organizations of persons with disabilities. There are no RI organizations reporting that no support at all is given to organizations of persons with disabilities. None of the RI organizations report that support is not given to organizations of persons with disabilities. The pattern is the same, but there are differences, when compared with the percentage reported by the NGOs in general, namely regarding financial and organizational/logistic support, the RI organizations report higher percentages for the former and lower for the later. There are clear differences, when compared with the percentages reported by the governments. The RI organizations report higher percentages concerning financial support but lower ones concerning organizational/logistic support.

Table 25 (Question 25)

Participation in political and public life

<i>Areas of political and public life</i>	<i>Number of countries reporting participation</i>		
	<i>Limited</i>	<i>Some</i>	<i>Great</i>
Government	6	5	4
Legislatures	5	3	5
Judiciary	9	3	0
Political parties	6	6	0
NGOs	1	2	12

1 and 2 = limited extent, 3 = some extent, 4 and 5 = great extent

Table 25 shows, that the majority of the RI organizations are reporting that persons with disabilities to a very limited extent participate in government, legislatures, judicial authorities and political parties, but to a great extent in NGOs. The same pattern prevails as that reported by the NGOs in general; no significant difference in the percentage. The same pattern emerges when compared with the responses from the governments.

Table 26 (Question 26)
The role of organizations

<i>Areas in which organizations are involved</i>	<i>Frequency</i>	<i>Valid Percent</i>
Advocating rights and improved services	14	93,3
Mobilize persons with disabilities	12	80,0
Identify needs and priorities	10	66,7
Participate in the planning, implementation	10	66,7
Contribute to public awareness	14	93,3
Provide services	14	93,3
Promote/organize income generating activities	10	66,7

Total 15, No answer 0

Table 26 shows, that according to the RI organizations, the organizations for persons with disabilities are foremost involved in: advocating rights and improved services, contributing to public awareness, providing services and mobilizing persons with disabilities. The RI organizations are reporting that the areas, in which these organizations are least involved, is: identifying needs and priorities, participating in the planning, implementing and evaluating services and measures concerning the lives of persons with disabilities, and promoting/organizing income generating activities. Nonetheless, the rates in all areas concerning organizations, the involvement are high implying that this group of NGO's apprehend their role to involve in a wide range of tasks. The pattern is the same as with NGOs in general. Although there are differences in the percentage reported concerning the role of organizations to identify needs and priorities and to promote/organize income generating activities. The percentages reported by the RI organizations concerning the former is lower, but concerning the latter higher. There are clear differences in two areas, when the percentages reported by governments are compared to those reported by the RI organizations. The RI organizations report a lower percentage regarding involvement to identify needs and priorities but a higher percentage concerning provision of services.

CO-ORDINATION OF WORK

Table 27 (Question 27)

Co-ordinating committee

<i>Co-ordinating committee</i>	<i>Frequency</i>	<i>Percent</i>
There is a co-ordinating committee	12	85,7
There is no co-ordinating committee	2	14,3

Total 14, No answer 1

Table 27 shows that the majority of the RI organizations are reporting the existence of a co-ordinating committee. Only 14% are reporting that there is no committee. There are differences in the percentage reported, when compared with NGOs in general. The RI organizations are reporting a higher percentage regarding the existence of a co-ordinating committee. The same pattern prevails when compared to governments. The RI organizations report a higher percentage of countries with a co-ordinating committee than the governments.

Table 28 (Question 28)

Where the co-ordinating committee is reporting to

<i>The co-ordinating committee is reporting to:</i>	<i>Frequency</i>	<i>Valid Percent</i>
A particular Ministry	7	58,3
The Prime Minister's office	3	25,0
Other	2	16,7
There is no co-ordinating committee	2	14,3

Total 14, No answer 1

According to the RI organizations, the authority to which the co-ordinating committee is usually reporting, is the Ministry of Social Affairs or any other Ministry. There are differences in the percentage reported, when compared with NGOs in general. The RI organizations report a lower percentage regarding reports to Ministries and higher regarding reports to the Prime Minister's office. There is a clear difference in the percentages reported, when compared with governments. The RI organizations report a lower percentage regarding co-ordinating committees' reports to a particular Ministry.

Table 29 (Question 29)

Representation in the co-ordinating committee

<i>Representatives of:</i>	<i>Frequency</i>	<i>Valid Percent</i>
Ministries	12	100,0
Organizations of persons with disabilities	10	83,3
Other NGOs	7	58,3
Private sector	5	41,7
There is no co-ordinating committee	2	14,3

Total 14, No answer 1

According to the RI organizations, the co-ordinating committee usually includes representatives from Ministries and from organizations of persons with disabilities. Representatives from other NGOs and from the private sector are not so often included in the co-ordinating committee. The same pattern prevails, when compared with the

NGOs in general, but there are differences in the percentage reported concerning the representation of other NGOs and from the private sector. There is only one difference, when compared with the percentages reported by governments. The RI organizations report a higher percentage concerning the representation of Ministries in the co-ordinating committees.

Table 30 (Question 30)

Participation in policy-development

<i>Involvement of the co-ordinating committee</i>	<i>Frequency</i>	<i>Valid Percent</i>
Participation in policy-development	10	90,9
No participation in policy-development	1	9,1
There is no co-ordinating committee	2	14,3

Total 13, No answer 2

Table 30 shows that 91% of the RI organizations are reporting that the co-ordinating committee is expected to participate in policy development. There are only minor differences in the percentage reported, when compared with those reported by the NGOs in general. There are no clear differences, when compared with the percentages reported by the governments.

Table 31 (Question 31)

Participation in performance of other tasks

<i>Involvement of the co-ordinating committee</i>	<i>Frequency</i>	<i>Valid Percent</i>
Reporting performance of other tasks	6	50,0
Reporting no performance of other tasks	6	50,0
There is no co-ordinating committee	2	14,3

Total 14, No answer 1

50% of the NGOs are reporting that the committee is expected to perform other tasks. The percentage reported by the NGOs in general is 57. There are clear differences, when compared with the percentages reported by the governments concerning involvement of the co-ordinating committees in other tasks. The RI organizations report considerably lower percentage.

Table 32 (Question 32)

Effects of the establishment of the co-ordinating committee

<i>Effects</i>	<i>Frequency</i>	<i>Valid Percent</i>
Improved co-ordination of programmes	10	83,3
Improved legislation	9	75,0
Improved integration of responsibility	7	58,3
Better dialogue in the disability field	10	83,3
More accurate planning	8	66,7
More effective use of resources	5	41,7
Improved promotion of public awareness	8	66,7
Too early for assessment	1	8,3
There is no co-ordinating committee	2	14,3

Total 14, No answer 1

According to the RI organizations, the establishment of the co-ordinating committee has had the following effects: improved co-ordination of programmes and a better dialogue in the disability field. 8% of the RI organizations report that it is too early for an assessment regarding the effects of the co-ordinating committee. There are differences in the percentage reported, when compared with NGOs in general for all the effects listed above. There are clear differences, when compared with the percentages reported by the governments. The RI organizations report a higher percentage concerning the involvement of the co-ordinating committees in improvement of legislation and in the more accurate planning but a lower percentage regarding the more effective use of resources.

Table 33 (Question 33)

Effects of the adoption of the Standard Rules

<i>The effects of the Standard Rules</i>	<i>Frequency</i>	<i>Valid Percent</i>
RI organizations reporting rethinking	7	58,3
RI organizations reporting no rethinking	4	33,3

Total 12, No answer 3

Table 33 shows that 58% of the RI organizations are reporting that the adoption of the Standard Rules has led to a rethinking of the approach to disability policy whereas 33% are reporting that it has not lead to a rethinking. The percentage reported by the RI organizations on the issue that the adoption of the Standard Rules has not led to a rethinking is much lower than that reported by the NGOs in general. There is a considerably lower percentage of RI organizations reporting a rethinking as an effect of the adoption of the Standard Rules than from the governments.

CONCLUSION

There are four questions in which a broad convergence of views exists between RI organizations, the NGOs in general and the governments, namely questions No 2, 20, 25 and 30. In none of the issues explored in these questions are there any divergent views between RI organizations, NGOs in general and governments.

There are a number of areas, where divergent views exist between RI organizations and governments. It is interesting to observe that the divergence in views is higher between RI organizations and NGOs in general than between RI organizations and governments.

There are also a number of areas, where divergent views exist between RI organizations, NGOs in general and governments. Divergence does not occur over the whole range of issues in these areas, but in most of them. The areas, where the divergence in views is most apparent, include the civil and political rights of persons with disabilities, the economic and social rights of persons with disabilities, the measures taken by the governments in order to facilitate accessibility in the built environment, the obstacles reported to facilitate accessibility in the built environment, the participation in political and public life, the effects of the establishment of the co-ordinating committee and the effects of the adoption of the Standard Rules.

Industrialized countries

REHABILITATION INTERNATIONAL, DENMARK (22)

General policy

The officially recognized disability policy is expressed in law, in guidelines adopted by a national disability council, in policy adopted by political parties and in policy adopted by NGOs. According to the Government, disability policy is not expressed in law but in guidelines, adopted by the Government. The emphasis in this policy is on rehabilitation, individual support and accessibility measures.

Since the adoption of the Standard Rules, the government has done nothing to convey the message of full participation. According to the Government, the following measures have been taken to convey the message of full participation: The Minister of Social Affairs has held a press meeting, in December 1994, the national council on disability has distributed material concerning the Standard Rules and an interministerial committee has been appointed in order to work out a plan of action, concerning accessibility and awareness raising.

Legislation

The rights of persons with disabilities are protected by a combination of special legislation and general legislation. The judicial mechanism adopted to protect the rights of persons with disabilities is recourse procedure by a special agency, dealing with anti-discrimination issues. Non-judicial mechanisms include: an Ombudsman, and a governmental body (administrative). According to the Government, the judicial mechanisms include due process (legal remedy through the courts), the non-judicial including an ombudsman and an independent expert body.

General legislation applies to persons with different disabilities with respect to education, employment, the right to marriage, the right to parenthood/family, political rights, access to court-of-law, the right to privacy and to property rights. The following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling, financial security, employment, independent living and participation in decisions affecting themselves. According to the Government, the benefits of employment and participation in decisions affecting themselves are not guaranteed by law.

No new legislation concerning disability has been enacted, since the adoption of the Rules.

Accessibility

There are rules to ensure the accessibility in the built environment requiring that public places, the outdoor environment, means of public transportation and housing are made accessible. Accessibility in the built environment is observed by local governments. The Government states that accessibility in the built environment is also observed by a national authority. The following measures have been promoted by the government in order to facilitate accessibility in the built environment: levelling off pavements, marking parking areas, installing automatic doors, lifts and accessible toilets, ensuring

access to public places, improving accessibility in housing, providing financial incentives/support for accessibility measures in housing, installing special lighting and using contrast colours for visually impaired and providing specially adapted motor vehicles. There are special transport arrangements for persons with disabilities, available for medical treatment, education, work and recreational purpose. The most difficult obstacles, when planning to build accessible environments are attitudinal factors, economic/budgetary factors, lack of planning and design-capacity and lack of enforcement mechanism.

Sign language for deaf people is recognized as the main means of communication between deaf persons and others. According to the Government, sign language for deaf people is also recognized as the official language for deaf people and is used as the first language in education of deaf people. There are government measures to encourage media and other forms of public information to make their services accessible to persons with disabilities. According to the Government, there are no measures to encourage media and other forms of public information to make their services accessible. The following services are provided in order to facilitate information and communication between persons with disabilities and others: literature in Braille/tape, sign language interpretation, being available for any purpose and easy readers for persons with mental disabilities.

Organizations of persons with disabilities

There is a national umbrella organization in which all different organizations are represented. There are legal provisions mandating the representatives of persons with disabilities to participate in policy making and to work with governmental institutions. Organizations of persons with disabilities are *always* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at both the national, regional and local level. The government financially supports existing or new organizations of persons with disabilities. Persons with disabilities participate to some extent in judicial authorities and political parties but to a great extent in government, legislatures and NGOs. The role of organizations of persons with disabilities is to advocate rights and improved services, mobilize persons with disabilities, identify needs and priorities, participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, contribute to public awareness, provide services and promote/organize income generating activities.

Co-ordination of work

The co-ordinating committee is reporting to the Parliament. The committee includes representatives of the Ministries of Health and Social Affairs, as well as Education and of organizations of persons with disabilities. The government expects the co-ordinating committee to participate in policy development but not to perform other tasks. According to the Government, the council is also expected to perform other tasks. The establishment of the committee has had the following effects: improved co-ordination of measures/programmes, improved legislation, improved integration of responsibility, a better dialogue in the disability field and more accurate planning. The establishment of the committee has not led to a more effective use of resources or improved promotion of public awareness.

The adoption of the Rules has not led to a rethinking of the approach to disability policy. According to the Government, the adoption of the Rules has provided a new instrument to carry out the disability policy.

REHABILITATION FOUNDATION, FINLAND (30)

General policy

The officially recognized disability policy in Finland is, according to the Rehabilitation Foundation, expressed in law and in guidelines adopted by a National Disability Council. According to the Government, the disability policy is also expressed in policy adopted by political parties and by NGOs. The emphasis in this policy - in descending scale - is on individual support, rehabilitation, accessibility measures, anti-discrimination law and prevention.

Since the adoption of the Standard Rules, the government has not done anything to initiate or support information campaigns, conveying the message of full participation. The Government states that the National Council on Disability, in co-operation with the Ministry of Social Affairs and Health, has published an easy reader version of the Standard Rules in Finnish and Swedish.

Legislation

The rights of persons with disabilities are protected by general legislation, applicable to all citizens. According to the Government, the rights of disabled people are protected by a combination of special legislation and general legislation. The judicial mechanism adopted to protect the rights of persons with disabilities is due process (legal remedy through courts), while administrative and other non-judicial bodies include an Ombudsman and a governmental body (administrative).

General legislation applies to persons with different disabilities with respect to education, employment, the right to marriage, the right to parenthood/family, political rights, access to court-of-law, the right to privacy and property rights. The following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling and financial security. According to the Government, even the benefits of independent living and of participation in decisions affecting themselves are guaranteed by law.

No new legislation concerning disability has been enacted, since the adoption of the Standard Rules. The Government states that, since the adoption of the Rules, the Constitution has been amended (1995). The clause on equality was included in the Constitution Act (section 5 §2) and the clause (section 14 §3) according to persons using sign language and persons in need of interpretation and translation services because of disability, will be protected by law.

Accessibility

There are laws and regulations to ensure accessibility of the built environment requiring that public places, the outdoor environment and land, sea and air transportation are made accessible. Accessibility in the built environment is observed by local governments. The following measures have been promoted by the government in order to facilitate accessibility in the built environment: levelling off pavements, marking parking areas, installing automatic doors, lifts and accessible toilets, ensuring access to public places, improving accessibility in housing, providing financial support for the costs of adapting private buildings to the needs of persons with disabilities and providing specially adapted motor vehicles. According to the Government, even special

lighting and contrast colours for visually impaired are provided. The special transport arrangements include low floor buses. This special transport is available for medical treatment, education, work and for recreational purpose. The most difficult obstacles, when planning to build accessible environments, are attitudinal factors, lack of knowledge, research and information, lack of user participation and lack of enforcement mechanism. A disability awareness component is not incorporated in the training of planners, architects and construction engineers. According to the Government, there is a disability awareness component incorporated in the training of planners, architects and construction engineers, but the issue, whether this is taken into account, depends on the professors at the Architectural Universities.

Sign language for deaf people is recognized as the official language of deaf people and is used as the first language in education of deaf people. There are government measures to encourage media (The Broadcasting Corporation) to make their services accessible to persons with disabilities. The following measures are provided in order to facilitate information and communication between persons with disabilities and others: literature in Braille/tape and sign language interpretation being available for any purpose. A sign language news bulletin is also being provided on television. According to the Government, even easy readers for persons with mental disabilities are provided.

Organizations of persons with disabilities

There is a national umbrella organization in which practically all organizations are represented. There are no legal provisions mandating the representatives of persons with disabilities to participate in policy-making or to work with governmental institutions. According to the Government, there are legal provisions mandating the representatives of persons with disabilities to participate in policy-making and to work with governmental institutions. Disability organizations are *often* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at both the national, regional and local levels. The government financially supports the existing and new organizations of persons with disabilities. Persons with disabilities participate to a very limited extent in legislatures and judiciary, to some extent in government and political parties and to a great extent in NGOs. The role of disabled persons' organizations is to advocate rights and improved services, mobilize needs and priorities, contribute to public awareness and to provide services. According to the Government, organizations also participate in the planning, implementation and evaluation of services and measures concerning disabled persons.

Co-ordination of work

The national co-ordinating committee is reporting to the Ministry of Health and Social Security. The committee includes representatives of the Ministries of Health and Social Affairs, of Employment, of Transport, of Housing, of Education, of Culture and of Planning, and of other NGOs. The co-ordinating committee is expected to participate in the planning and policy development. The establishment of the co-ordinating committee has had the following effects: improved co-ordination of measures/programmes in the disability field, improved legislation, a better dialogue in the disability field, more accurate planning and improved promotion of public awareness.

The adoption of the Standard Rules has not yet led to a rethinking of the approach to disability policy.

HELLENIC SOCIETY FOR DISABLED CHILDREN, GREECE (53)

General policy

The officially recognized disability policy is expressed in law, in guidelines adopted by the government, in policy adopted by political parties and in policy adopted by NGOs. In addition, Article 21 of the Constitution makes reference to disability and constitutes a mandate for legislative and administrative action. The emphasis in this policy - in descending scale - is on individual support, rehabilitation, prevention, accessibility measures and anti-discrimination law.

Since the adoption of the Rules, the following has been made in order to convey the message of full participation: relevant spots on T.V. and various events relating to the International Day of Disabled Persons. A recent Law (1995) prescribes T.V. and radio time to be allocated to awareness raising messages. Proposed legislation recognizes the International Day of the Disabled.

Legislation

The rights of persons with disabilities are protected by a combination of special legislation and general legislation. The judicial mechanism adopted to protect the rights of persons with disabilities is due process (legal remedy through courts). The non-judicial mechanism is a governmental body (administrative).

General legislation applies to persons with different disabilities with respect to education, employment, the right to marriage, the right to parenthood/family, political rights, access to court of law, the right to privacy and to property rights. However, the right of privacy is constrained by accessibility barriers and the resultant overprotection/dependency. The following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling and financial security. According to the Government, even the benefits of employment, independent living and participation in decisions affecting themselves are guaranteed by law.

Since the adoption of the Rules, the Law for raising time in the mass media has been enacted as well as a special law, dealing with the conditions and overseeing the mechanisms for the provision of organized welfare services, some of which apply to facilities and services for disabled persons.

Accessibility

There are rules to ensure accessibility of the built environment which establish national design standards requiring that public places and the outdoor environment are made accessible. According to the Government, there are rules to ensure the accessibility in the means of public transportation. No responsible body exists to ensure accessibility in the built environment. The following measures have been promoted to ensure accessibility in the built environment: levelling off pavements, marking parking areas, installing lifts and accessible toilets, ensuring access to public places and providing specially adapted motor vehicles. Special transport arrangements include accessible buses, urban transportation being free for commuters, and discounts, existing for long distance travel. Special transport is available for medical treatment, education and for recreational purpose. The most difficult obstacles, when planning to build accessible

environments, are economic/budgetary factors, lack of planning and design-capacity, lack of user participation, lack of co-operation from other organizations/institutions and lack of enforcement mechanism. The Government does not regard economic/budgetary factors as an obstacle for building accessible environments. There is no disability awareness component incorporated in the training of planners, architects and construction engineers.

Sign language for deaf people has no officially recognized status, is not used as the first language in education of deaf people and is not recognized as the main means of communication between deaf persons and others. There are government measures to encourage media to make their information services accessible to persons with disabilities, but no government measures to encourage other forms of public information to make their services accessible to persons with disabilities. The following services are provided in order to facilitate information and communication between persons with disabilities and others: literature in Braille/tape, news magazines on tape/Braille and sign language interpretation being available for major events only.

Organizations of persons with disabilities

There is a national umbrella organization. There are legal provisions mandating the representatives of persons with disabilities to participate in policy-making and to work with governmental institutions. Organizations of persons with disabilities are *often* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at both the national, regional and local level. The government gives financial support to existing or new organizations of persons with disabilities. Persons with disabilities participate to some extent in government, political parties and NGOs. The role of organisations of persons with disabilities is to advocate rights and improved services, mobilize persons with disabilities, identify needs and priorities, participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, contribute to public awareness, provide services and promote/organize income generating activities.

Co-ordination of work

There is no national co-ordinating committee or any similar body.

The Standard rules have been helpful when organizing new services and are taken into account when preparing new legislation. The Rules have certainly strengthened demands of the organizations concerned.

NATIONAL FEDERATION FOR THE AID OF THE HANDICAPPED, ICELAND (153)

General policy

The officially recognized disability policy is expressed in law, in guidelines adopted by a national disability council and in policy adopted by NGOs. The emphasis in this policy is on individual support, accessibility measures, rehabilitation, prevention and anti-discrimination law.

In order to convey the message of full participation the Ministry of Social Affairs has translated the Rules to Icelandic.

Legislation

The rights of persons with disabilities are protected by a combination of special legislation and general legislation. The judicial mechanism adopted to protect the rights of persons with disabilities is recourse procedure by a special agency, dealing with anti-discrimination issues. The non-judicial mechanism is a government body (administrative). According to the Government, no judicial mechanisms have been adopted to protect the rights of persons with disabilities, but there is an Ombudsman for that purpose.

General legislation applies to persons with different disabilities with respect to education and employment. According to the Government general legislation also applies with respect to the right to marriage, the right to parenthood/family and to political rights. The following benefits are guaranteed by law to persons with disabilities: training, rehabilitation and counselling, financial security, employment, independent living, participation in decisions affecting themselves. According to the Government, even the benefit of health and medical care is guaranteed by law.

No new legislation concerning disability has been enacted, since the adoption of the Rules.

Accessibility

There are rules to ensure accessibility of the built environment which establish national design standards requiring that public places, means of public transportation and housing are made accessible. According to the Government, there are no rules to ensure accessibility in the means of public transportation. Accessibility in the built environment is observed by a national authority and by local governments. The following measures have been promoted to facilitate accessibility in the built environment: levelling off pavements, marking parking areas, installing automatic doors, lifts and accessible toilets, ensuring access to public places, improving accessibility in housing, providing financial incentives/support for accessibility measures in housing, using contrast colours for visually impaired and providing specially adapted motor vehicles. Special lighting for visually impaired has not been promoted. Special transport arrangements include specially adapted cars, run and controlled by the local authorities. Special transport is available for medical treatment, education, work, recreational purpose. According to the Government special transport is not available for medical treatment or for recreational purpose. The most difficult obstacles, when planning to build accessible environments, are economic/budgetary

factors, lack of planning and design-capacity and lack of enforcement mechanism. There is no disability awareness component incorporated in the training of planners, architects and construction engineers.

Sign language for deaf people has no officially recognized status, but is used as the official language in education of deaf people and is recognized as the main means of communication between deaf persons and others. There are government measures to encourage media to make their information services accessible to persons with disabilities, but no government measures to make other forms of public information services accessible to persons with disabilities. The government states that there are measures to encourage media and other forms of public information to make their services accessible. The only service provided in order to facilitate information and communication between persons with disabilities and other persons is sign language interpretation for major events. According to the Government, even literature in Braille/tape and news magazines on tape/Braille are provided.

Organizations of persons with disabilities

There is a national umbrella organization of persons with disabilities. There are legal provisions mandating the representatives of persons with disabilities to participate in policy-making and to work with governmental institutions. Organizations of persons with disabilities are *often* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at the national, regional and local level. The government gives financial support to organizations of persons with disabilities. Persons with disabilities participate to a very limited extent in government, judicial authorities, political parties and to a great extent in legislatures and NGOs. The role of organizations of persons with disabilities is to advocate rights and improved services, mobilize persons with disabilities, identify needs and priorities, participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, contribute to public awareness, provide services and promote/organize income generating activities. According to the Government, organizations do not advocate rights or improved services, nor do they promote/organize income generating activities.

Co-ordination of work

The national co-ordinating committee is reporting to the Ministry of Social Affairs. The committee includes representatives of the Ministries of Social Affairs, of Employment, and of Housing, of organizations of persons with disabilities, of local authorities and of the budget committee. According to the Government, the committee includes representatives from the Ministry of Finance only. The government expects the national co-ordinating committee to participate in policy development and to perform other tasks. The establishment of the co-ordinating committee has had the following effects: improved co-ordination of measures/programmes, improved integration of responsibility, a better dialogue in the disability field, more accurate planning, more effective use of resources and improved promotion of public awareness. It is too early for an assessment whether the establishment of the co-ordinating committee has led to a rethinking of the approach to disability policy.

NATIONAL REHABILITATION BOARD, IRELAND (8)

No reply was received from the Government of Ireland.

Legislation

The rights of persons with disabilities are protected by general legislation. The following benefits are guaranteed, though only partially, by law to persons with disabilities: health and medical care, training, rehabilitation and counselling and financial security. No new legislation concerning disability has been enacted, since the adoption of the Rules.

Accessibility

There are rules to ensure accessibility of the built environment requiring that public places - only new buildings and major extensions in existing buildings - are made accessible. There are no standards requiring that the outdoor environment, means of public transportation or housing are made accessible. Accessibility in the built environment is observed by a national authority, by local governments and by the constructor. No measures have been promoted by the government in order to facilitate accessibility in the built environment. There are special transports for persons with disabilities, available for medical treatment and education. The most difficult factors, when planning to build accessible environments, are attitudinal factors, economic/budgetary factors, lack of planning and design-capacity, lack of co-operation from other organizations/institutions and lack of enforcement mechanism. There is no disability awareness component incorporated in the training of planners, architects and construction engineers.

Sign language for deaf people has no officially recognized status, is not used as the first language of deaf people and is not recognized as the main means of communication between deaf persons and others. There are no government measures to encourage media to make their information services accessible to persons with disabilities. The following services are provided in order to facilitate information and communication between persons with disabilities and others: literature in Braille/tape and sign language interpretation, being available for major events.

Organizations of persons with disabilities

There is no national umbrella organization. There are no legal provisions mandating the representatives of persons with disabilities to participate in policy-making or to work with governmental institutions. Organizations of persons with disabilities are *sometimes* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at both the national, regional and local level. The government gives financial support to existing or new organizations of persons with disabilities. Persons with disabilities participate to a very limited extent in government, legislatures, judicial authorities, political parties and to a great extent in NGOs. The role of organizations of persons with disabilities is to advocate rights and improved services, mobilize persons with disabilities, identify needs and priorities, contribute to public awareness and to provide services.

Co-ordination of work

There is no national co-ordinating committee or any similar body.

**JAPANESE SOCIETY FOR REHABILITATION OF DISABLED PERSONS,
AND THE JAPAN ASSOCIATION FOR EMPLOYMENT OF THE DISABLED,
JAPAN (162)**

General policy

The officially recognized disability policy is expressed in law, in guidelines adopted by the government, in guidelines adopted by the national disability council, in policy adopted by political parties and in policy adopted by NGOs. According to the Government disability policy is not expressed in policy adopted by political parties or in policy adopted by NGOs. The emphasis in this policy is on individual support, rehabilitation, accessibility measures, prevention and anti-discrimination law.

Since the adoption of the Rules, the government has conveyed the message of full participation through education programmes and other action.

Legislation

The rights of persons with disabilities are protected by a combination of special legislation and general legislation. The judicial mechanism available to protect the rights of persons with disabilities is due process (legal remedy through the courts). The non-judicial mechanisms include: a governmental body (administrative), independent expert bodies and a special arbitration/conciliation body. According to the Government, there are no judicial mechanisms to protect the rights of persons with disabilities while the non-judicial including only a governmental body (administrative).

General legislation applies with respect to persons with different disabilities to education, employment, the right to marriage, the right to parenthood/family, political rights, the right to privacy and access to court of law and property rights. The following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling, employment, financial security, independent living and participation in decisions affecting themselves.

New legislation concerning disability has been enacted since the adoption of the Rules.

1. Enactment of Disabled Persons' Fundamental Law (1993/12).
2. Enactment of the Act on Buildings Accessible and Usable for the Elderly and Physically Disabled (1994/4).
3. Amendment to the Law Concerning Mental Health and Welfare for the Mentally Disabled (1995/7).

Accessibility

There are rules to ensure accessibility of the built environment which establish national design standards requiring that public places, the outdoor environment, means of public transport and housing are made accessible. Accessibility in the built environment is observed by a national authority, by local governments and by the organizers/providers of services. The following measures have been promoted by the government to ensure accessibility in the built environment: levelling off pavements, marking parking areas, installing automatic doors, installing lifts and accessible toilets, ensuring access to public places, improving accessibility in housing, providing financial incentives/support for accessibility measures in housing, using contrast colours for visually impaired and providing specially adapted motor vehicles. In addition, measures such as providing

traffic sound signals for persons with visual disability, laying embossed titles for persons with visual disability have also been promoted. There are special transport arrangements for persons with disabilities, available for medical treatment, education, employment, for recreational purpose and personal purpose. The most difficult obstacles, when planning to build accessible environments, are attitudinal factors and economic/budgetary factors. The Government does not regard attitudinal factors to be an obstacle, when building accessible environments. There is a disability awareness component incorporated in the training of planners, architects and construction engineers.

Sign language is recognized as the official language of deaf people. According to the Government, sign language is recognized as the main means of communication between deaf persons and others. There are government measures to encourage media and other forms of public information to make their services accessible for persons with disabilities. The following services are provided in order to facilitate information and communication between persons with disabilities and others: literature in Braille/tape, news magazines on tape/Braille, sign language interpretation for any purpose and easy readers for persons with mental disabilities. According to the Government, easy readers for persons with mental disabilities are not provided.

Organizations of persons with disabilities

There is a national umbrella organization. There are legal provisions mandating the representatives of persons with disabilities to participate in policy-making and to work with governmental institutions. Disability organisations are *always* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at the national, regional and local level. The government gives financial and organizational/logistic support to existing or new organizations of persons with disabilities. Persons with disabilities participate to some extent in legislatures, judicial authorities and political parties and to a great extent in government and NGOs. The role of organizations of persons with disabilities is to advocate rights and improved services, mobilize persons with disabilities, identify needs and priorities, participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, contribute to public awareness, provide services and to promote/organize income generating activities.

Co-ordination of work

The national co-ordinating committee is reporting to the Ministry of Health and Welfare and to the Prime Minister's office. It includes representatives of many Ministries, of organizations of persons with disabilities, of other NGOs, of the private sector and of scholars and experts.

The government expects the committee to participate in policy development but not to perform other tasks. The establishment of the co-ordinating committee has led to: improved co-ordination of measures/programmes, improved legislation, improved integration of responsibility, a better dialogue in the disability field, more accurate planning and improved promotion of public awareness.

The adoption of the Rules, to a certain extent, has led to a rethinking of the approach to disability policy.

The Middle East and North Africa

KUWAIT SOCIETY FOR THE HANDICAPPED, KUWAIT (18)

No reply was received from the Government of Kuwait.

General policy

The officially recognized disability policy is expressed in guidelines adopted by the national disability council and in policy adopted by NGOs. The emphasis in this policy is on rehabilitation, prevention, accessibility measures, individual support and anti-discrimination law.

Since the adoption of the Rules, the government has not done anything to convey the message of full participation.

Legislation

The rights of persons with disabilities are protected by general legislation. The judicial mechanism available to protect the rights of persons with disabilities is due process (legal remedy through the courts). The non-judicial mechanism includes a governmental body (administrative) and independent expert bodies.

General legislation applies with respect to persons with different disabilities with respect to education, employment, the right to marriage, the right to parenthood/family, political rights and the right to privacy. The following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling, financial security, and participation in decisions affecting themselves.

No new legislation has been enacted, since the adoption of the Rules.

Accessibility

There are rules to ensure accessibility of the built environment which establish national design standards requiring that public places, the outdoor environment and means of public transport are made accessible. Accessibility in the built environment is observed by a national authority and by local governments. The only measures promoted in order to ensure accessibility in the built environment are marking parking areas, installing automatic doors, lifts and accessible toilets, ensuring access to public places, providing financial incentive/support for accessibility measures in housing and providing specially adapted motor vehicles. There are special transport arrangements available for medical treatment, education, and for recreational purpose. The most difficult obstacles, when planning to build accessible environments are attitudinal factors, geographical and climatic factors, lack of legislation and regulations, lack of knowledge, research and information, lack of user participation, and lack of enforcement mechanism. There is a disability awareness component incorporated in the training of planners, architects and construction engineers.

Sign language is recognized as the official language of deaf people, is used as the first language in education of deaf people and is recognized as the main means of communication between deaf persons and others. There are government measures to encourage media and other forms of public information to make their services accessible

for persons with disabilities. The following services are provided in order to facilitate information and communication between persons with disabilities and others: literature in Braille/tape, news magazines on tape/Braille, sign language interpretation for any purpose and easy readers for persons with mental disabilities.

Organizations of persons with disabilities

There is no national umbrella organization. There are no legal provisions mandating the representatives of persons with disabilities to participate in policy-making or to work with governmental institutions. Disability organizations are *always* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at the national level. The government gives financial support to existing or new organizations of persons with disabilities. Persons with disabilities participate to a great extent in government, legislatures and NGOs. The role of organisations of persons with disabilities is to advocate rights and improved services, identify needs and priorities, participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, contribute to public awareness, provide services and to promote/organize income generating activities.

Co-ordination of work

The national co-ordinating committee is reporting to the Ministry of Social Affairs. It includes representatives of many Ministries, of organizations of persons with disabilities, of other NGOs and from the private sector. The government does not expect the committee to participate in policy development or to perform other tasks. The establishment of the co-ordinating committee has led to improved co-ordination of measures/programmes, improved legislation, improved integration of responsibility, a better dialogue in the disability field, more accurate planning, more effective use of resources and improved promotion of public awareness.

The adoption of the rules has, to a certain extent, led to a rethinking of the approach to disability policy.

Countries in transition

ASSOCIATION OF DISABLED PERSONS IN THE CZECH REPUBLIC, RI, CZECH REPUBLIC (62)

General policy

The officially recognized disability policy is expressed in guidelines adopted by the government and in guidelines adopted by a national disability council. According to the Government, disability policy is also expressed in law and in policy adopted by NGOs. The emphasis in this policy is on rehabilitation, accessibility measures, individual support and prevention.

The government has conveyed the message of full participation, through information in TV and other media.

Legislation

The rights of persons with disabilities are protected by general legislation. According to the Government, the rights of persons with disabilities are protected by a combination of special and general legislation. There is no judicial mechanism available to protect the rights of persons with disabilities. The non-judicial mechanism available is a government body (administrative). According to the Government, the judicial mechanism available for that purpose is due process (legal remedy through the courts).

General legislation applies to persons with different disabilities with respect to education and employment. According to the Government, general legislation also applies with respect to political rights, access to court-of-law, the right to privacy and property rights. The following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling and financial security. According to the Government, even the benefits of employment and of participation in decisions affecting themselves are guaranteed by law.

The Pension Insurance law has been enacted, since the adoption of the Rules.

Accessibility

There are rules to ensure accessibility in the built environment requiring that public places, the outdoor environment and housing are made accessible. According to the Government, there are no rules to ensure accessibility of the built environment. Accessibility in the built environment is observed by a national authority and by the organization of persons with disability. According to the Government, local governments are reviewing the accessibility in the built environment. The following measures have been promoted to facilitate accessibility in the built environment: levelling off pavements, marking parking areas, installing lifts and accessible toilets, ensuring access to public places, improving accessibility in housing and providing specially adapted motor vehicles. Special transports include free public transport for persons with severe disability and a limited number of buses and trains adapted for wheelchairs. Special transport is available for medical treatment, education, work and for recreational purpose. The most difficult obstacles when planning to build accessible environments are economic/budgetary factors, lack of co-operation from other organizations/institutions and lack of enforcement mechanism. There is a disability

awareness component incorporated in the training of planners, architects and construction engineers.

Sign language for deaf people is recognized as the official language for deaf people. According to the Government, the right of deaf children to be educated by means of sign language is guaranteed by the law. There are government measures to encourage media and other forms of public information to make their services accessible to persons with disabilities. The Government states that there are no measures to encourage media and other forms of public information to make their services accessible to persons with disabilities. The following services are provided to facilitate information and communication between persons with disabilities and others: literature in Braille/tape, news magazines on tape/Braille and sign language interpretation being available for major events.

Organizations of persons with disabilities

There are three umbrella organizations, collaborating, in which organizations representing all kinds of disabilities are represented. There are legal provisions mandating the representatives of persons with disabilities to participate in policy-making and to work with governmental institutions. Organizations of persons with disabilities are *always* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at the national level. Organizations prepare projects, the larger part of the expenses being covered by the government. Persons with disabilities participate to some extent in government, legislatures, judicial authorities and to a great extent in NGOs. The role of organisations of persons with disabilities is to advocate rights and improved services, mobilize persons with disabilities, participate in the planning, implementation and evaluation of services and measures, contribute to public awareness and provide services.

Co-ordination of work

The co-ordinating committee is reporting to a government committee for persons with disabilities, chaired by the Prime Minister. The committee includes representatives of many Ministries and of organizations of persons with disabilities. The co-ordinating committee also includes representatives from the private sector, according to the Government. The government expects the committee to participate in policy development and to perform other tasks, e.g. to co-ordinate activities of NGOs and spread information. The establishment of the co-ordinating committee has had the following effects: improved co-ordination of measures/programmes, improved legislation and improved promotion of public awareness.

The adoption of the Rules has led to a rethinking of the approach to disability policy. According to the Government, the adoption of the Standard rules has not led to a rethinking of the approach to disability policy, due to the fact that the disability policy started one year before the adoption of the Rules, as a new attitude in this field. All aspects concerning full participation of disabled people were involved in the Resolutions of the Czech Government.

General policy

The officially recognized disability policy is expressed in law, in guidelines adopted by the government, in guidelines adopted by a national disability council, in policy adopted by political parties and in a national policy adopted by the parliament. According to the Government disability policy is not expressed in guidelines adopted by a national disability council or in policy adopted by political parties. The emphasis in this policy is on individual support, accessibility measures, rehabilitation, anti-discrimination law and prevention.

Since the adoption of the Rules, the government has not done anything to initiate or support information campaigns conveying the message of full participation. The Government states that it has initiated and supported information campaigns, conveying the message of full participation.

Legislation

The rights of persons with disabilities are protected by a combination of special legislation and general legislation. The judicial mechanism adopted to protect the rights of persons with disabilities is due process (legal remedy through courts). Administrative and other non-judicial bodies include an Ombudsman, a governmental body (administrative), and independent expert bodies. According to the Government there are no administrative or other non-judicial bodies available for that purpose.

General legislation applies to persons with different disabilities with respect to education, employment, the right to marriage, the right to parenthood/family, political rights, access to court of law, the right to privacy and property rights. The following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling, financial security, employment, independent living, participation in decisions affecting themselves. According to the Government, the benefits of independent living and of participation in decisions affecting themselves are not guaranteed by law.

New legislation concerning disability has been enacted since the adoption of the Rules. According to the Government, no new legislation concerning disability has been enacted since the adoption of the Rules.

Accessibility

There are laws and regulations to ensure accessibility of the built environment requiring that public places, the outdoor environment and housing are made accessible. According to the Government, there are rules to ensure accessibility only for public places. Accessibility in the built environment is observed by the constructor and by the organizers/providers of the activity. The following measures have been promoted by the government in order to facilitate accessibility in the built environment: levelling off pavements, marking parking areas, installing automatic doors, lifts and accessible toilets, ensuring access to public places, improving accessibility in housing, providing financial support for accessibility measures in housing, installing special lighting for visually impaired and providing specially adapted motor vehicles. According to the

Government, the only measures promoted to facilitate accessibility in the built environment are marking parking areas, installing automatic doors and installing special lighting for visually impaired. Special transport arrangements include free transport, special services and adapted buses. Special transport is available for medical treatment, education, work and for recreational purpose. According to the Government, special transport is not available for recreational purpose. The most difficult obstacles, when planning to built accessible environments, are attitudinal factors, technical factors, lack of planning and design-capacity, lack of knowledge, research and information, lack of user participation, lack of co-operation from other organizations/institutions and lack of enforcement mechanism. According to the Government, economic/budgetary factors is also a main obstacle for building accessible environments. There is a disability awareness component incorporated in the training of planners, architects and construction engineers.

Sign language for deaf people is recognized as the official language of deaf people and is recognized as the main means of communication between deaf persons and others. According to the Government, sign language for deaf people is not recognized as the official language of deaf people, but used as the first language in education of deaf people. There are no government measures to encourage media to make their services accessible to persons with disabilities, but government measures to encourage other forms of public information to make their services accessible to persons with disabilities, e.g. informational services for the deaf and the blind. According to the Government, there are not even measures to encourage other forms of public information to make their services accessible. The following services are provided in order to facilitate information and communication between persons with disabilities and others: literature in Braille/tape, news magazines on tape/Braille and sign language interpretation being available for any purpose. According to the Government, even easy readers for persons with mental disabilities are provided.

Organizations of persons with disabilities

There is a national umbrella organization in which 11 organizations are represented. There are legal provisions mandating the representatives of persons with disabilities to participate in policy-making and to work with governmental institutions. According to the Government, there are no legal provisions mandating the representatives of persons with disabilities to participate in policy-making or to work with governmental institutions. Organizations of persons with disabilities are *often* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at the national, regional and local level. According to the Government, consultations occur only at the national level. The government financially supports existing or new organizations of persons with disabilities. Persons with disabilities participate to a very limited extent in judicial authorities, to some extent in political parties, and to a great extent in government, legislatures and NGOs. The role of disabled persons organizations is to advocate rights and improved services, mobilize persons with disabilities, identify needs and priorities, participate in the planning, implementation and evaluation of services and measures, contribute to public awareness, provide services and promote/organize income generating activities.

The adoption of the Rules has not yet led to a rethinking of the approach to disability policy.

Latin America and the Caribbean

REHABILITATION INTERNATIONAL, ARGENTINA (39)

No reply was received from the Government of Argentina.

Legislation

The rights of persons with disabilities are protected by special legislation, applicable to all citizens. The judicial mechanism adopted to protect the rights of persons with disabilities is recourse procedure by a special agency, dealing with anti-discrimination issues. The non-judicial mechanisms include an ombudsman and a governmental body (administrative).

General legislation applies to persons with different disabilities with respect to education, employment, the right to marriage, the right to parenthood/family, political rights, access to court of law, the right to privacy and property rights. The following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling.

No new legislation concerning disability has been enacted, since the adoption of the Rules.

Accessibility

There are rules to ensure accessibility of the built environment which establish national design standards requiring that public places, the outdoor environment, means of public transport and housing are made accessible. Accessibility in the built environment is observed by a national authority and by local governments. The following measures have been promoted by the government in order to facilitate accessibility in the built environment: levelling off pavements, marking parking areas, installing automatic doors and providing specially adapted motor vehicles. Special transport is available for medical treatment, education, work and for recreational purpose. The most difficult obstacles, when planning to build accessible environments, are attitudinal factors, economic/budgetary factors, and lack of enforcement mechanism. There is a disability awareness component incorporated in the training of planners, architects and construction engineers.

Sign language is recognized as the main means of communication between deaf persons and others. There are no government measures to encourage media and other forms of public information services to make their services accessible to persons with disabilities. The following services are provided in order to facilitate information and communication between persons with disabilities and others: literature in Braille/tape and news magazines on tape/Braille.

Organizations of persons with disabilities

There is a national umbrella organization. There are no legal provisions mandating the representatives of persons with disabilities to participate in policy-making or to work with governmental institutions. Organizations of persons with disabilities are *often* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at both the national, regional and local level. The government gives

organizational/logistic support to organizations of persons with disabilities. Persons with disabilities participate to a very limited extent in judicial authorities and political parties, to some extent in government and legislatures and to a great extent in NGOs. The role of organizations of persons with disabilities is to advocate rights and improved services, and to contribute to public awareness. Organizations, however, do not mobilize persons with disabilities, identify needs and priorities, participate in the planning, implementation and evaluation of services and measures, provide services or promote/organize income generating activities.

Co-ordination of work

The co-ordinating committee is reporting to the Prime Minister's office. The committee includes representatives of many Ministries and of organizations of persons with disabilities. The government expects the co-ordinating committee to participate in policy development and to perform other tasks. The establishment of the co-ordinating committee has led to improved co-ordination of measures/programmes and a better dialogue in the disability field. It has not led to improved legislation, improved integration of responsibility, more accurate planning, more effective use of resources or to improved promotion of public awareness.

The adoption of the Rules has not led to a rethinking of the approach to disability policy.

ASOCIACION DOMINICANA DE REHABILITATION, RI, DOMINICAN REPUBLIC (73)

No reply was received from the Government of the Dominican Republic.

General policy

The officially recognized disability policy is expressed in policy, adopted by NGOs. The emphasis in this policy is on prevention, rehabilitation, accessibility measures and individual support.

Since the adoption of the Rules, the government has not done anything to convey the message of full participation.

Legislation

The rights of persons with disabilities are protected by a combination of special legislation and general legislation. There is no judicial mechanism to protect the rights of persons with disabilities. However, there is a special body to defend the rights of persons with mental disabilities.

General legislation applies to persons with different disabilities with respect to education and employment. The following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling and employment.

New legislation concerning disability has been enacted, since the adoption of the Rules.

Accessibility

There are rules to ensure accessibility of the built environment requiring that public places, the outdoor environment, and housing are made accessible. Accessibility in the built environment is observed by a national authority. The following measures have been promoted by the government in order to facilitate accessibility in the built environment: levelling off pavements, marking parking areas and ensuring access to public places. There are no special transport arrangements for persons with disabilities. The most difficult obstacles, when planning to build accessible environments, are attitudinal factors, economic/budgetary factors and lack of enforcement mechanism. There is no disability awareness component incorporated in the training of planners, architects and construction engineers. There are no government measures to encourage media or other forms of public information to make their services accessible to persons with disabilities.

Organizations of persons with disabilities

There is no umbrella organization. There are no legal provisions mandating the representatives of persons with disabilities to participate in policy-making or to work with governmental institutions. Organizations of persons with disabilities are *sometimes* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at the national level. Persons with disabilities participate to a very limited extent in government, legislatures, judicial authorities, political parties and NGOs. The role of organizations of persons with disabilities is to mobilize persons with disabilities, provide services and to promote/organize income generating activities.

Co-ordination of work

The co-ordinating committee is reporting to the Ministry of Health and Social Affairs. The committee includes representatives of Ministries, of organizations of persons with disabilities and of other NGOs. The co-ordinating committee is expected to participate in policy development but not to perform other tasks. It is too early for an assessment about the effects of the co-ordinating committee.

The adoption of the Rules has led to a rethinking of the approach to disability policy.

South, East Asia and the Pacific

REHABILITATION INTERNATIONAL, HONG KONG (87)

No reply was received from the Government of Hong Kong.

General policy

The officially recognized disability policy is expressed in law and in guidelines adopted by the government. The emphasis in this policy is on rehabilitation, anti-discrimination law, prevention and accessibility measures.

Since the adoption of the Rules, the government has conveyed the message of full participation, through education programmes and other action.

Legislation

The rights of persons with disabilities are protected by a combination of special legislation and general legislation. The judicial mechanism available to protect the rights of persons with disabilities is due process (legal remedy through the courts). The non-judicial mechanisms include: a governmental body (administrative), and a special arbitration/conciliation body (equal opportunities commission).

General legislation applies with respect to persons with different disabilities with respect to education, employment, the right to marriage, the right to parenthood/family, political rights, the right to privacy, access to court of law and property rights. No benefits are guaranteed by law to persons with disabilities.

New legislation concerning disability has been enacted, since the adoption of the Rules. (Disability Discrimination Ordinance and Amendments to the Mental Health Ordinance.)

Accessibility

There are rules to ensure accessibility of the built environment requiring that public places, the outdoor environment, means of public transport and housing are made accessible. Accessibility in the built environment is observed by a national authority. The following measures have been promoted by the government to ensure accessibility in the built environment: levelling off pavements, marking parking areas, installing lifts and accessible toilets, ensuring access to public places, improving accessibility in housing, installing special lighting and using contrast colours for visually impaired. There are special transport arrangements for persons with disabilities available for medical treatment, education, employment and for recreational purpose. The most difficult obstacles, when planning to build accessible environments are attitudinal factors, economic/budgetary factors, lack of legislation and regulations and lack of enforcement mechanism. There is no disability awareness component incorporated in the training of planners, architects and construction engineers.

Sign language is recognized as the main means of communication between deaf persons and others. There are government measures to encourage media and other forms of public information to make their services accessible for persons with disabilities. The following services are provided in order to facilitate information and communication

between persons with disabilities and others: literature in Braille/tape, news magazines on tape/Braille and sign language interpretation for major events.

Organizations of persons with disabilities

There is no national umbrella organization. There are no legal provisions mandating the representatives of persons with disabilities to participate in policy-making or to work with governmental institutions. Disability organizations are *often* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at the national level. The government gives financial support to existing or new organizations of persons with disabilities. Persons with disabilities participate to a very limited extent in government, legislatures, judicial authorities and political parties and to some extent in NGOs. The role of organizations of persons with disabilities is to advocate rights and improved services, mobilize persons with disabilities, identify needs and priorities, participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, contribute to public awareness, provide services and promote/organize income generating activities.

Co-ordination of work

The national co-ordinating committee is reporting to the secretary of Health and Welfare. It includes representatives of the Ministries of Health and Social Affairs, and of Education, of organizations of persons with disabilities, of other NGOs, and from the private sector. The government expects the committee to participate in policy development and to perform other tasks. The establishment of the co-ordinating committee has led to improved co-ordination of measures/programmes, improved legislation, improved integration of responsibility, a better dialogue in the disability field, more accurate planning, more effective use of resources and improved promotion of public awareness.

The adoption of the Rules has implicitly but not directly, led to a rethinking of the approach to disability policy.

MALAYSIAN LEPROSY RELIEF ASSOCIATION 46

No reply was received from the Government of Malaysia.

General policy

The officially recognized disability policy in Malaysia is expressed in guidelines, adopted by the government. The emphasis in the disability policy - in descending scale - is on individual support, rehabilitation, prevention, accessibility measures and anti-discrimination law.

The Association states that the government has initiated and supported information campaigns, conveying the message of full participation, failing, however, to specify what these campaigns included.

Legislation

The rights of persons with disabilities are protected by general legislation.

None of the following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation, and counselling, financial security, independent living or participation in decisions affecting themselves. Regarding the benefit of employment, 1% of persons with disabilities is being guaranteed employment in the public sector.

Accessibility

There are laws and regulation to ensure the accessibility of the built environment requiring that public places are made accessible. Accessibility in the built environment is observed by local governments. The following measures have been promoted by the government to facilitate accessibility in the built environment: levelling off pavements, installing automatic doors, lifts, accessible toilets, ensuring access to public places, improving accessibility in housing and installing special lighting for the visually impaired. There are special transport arrangements - no specification is provided - for persons with disabilities available for recreational purpose. Special transport is not available for medical treatment, education or work. The most difficult obstacles, when planning to build accessible environments, are attitudinal factors and economic/budgetary factors.

Sign language for deaf people has no officially recognized status, is not used as the first language in education of deaf people or recognized as the main means of communication between deaf persons and others. There are government measures to encourage media to make their information services accessible for persons with disabilities. The following services are provided in order to facilitate information and communication between persons with disabilities and other persons: literature in Braille/tape and sign language being available for any purpose.

Organizations of persons with disabilities

There is a national umbrella organization. There are no legal provisions mandating the representatives of persons with disabilities to participate in policy-making or to work with governmental institutions. Disability organizations are *often* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at the

national level. Persons with disabilities participate to a very limited extent in government but to a great extent in NGOs. The role of organizations of persons with disabilities is to advocate rights and improved services, mobilize persons with disabilities, contribute to public awareness and provide services.

Co-ordination of work

The co-ordinating committee is reporting to a particular Ministry. No specification is given. The committee includes representatives of the Ministries of Employment, and Education, as well as of organizations of persons with disabilities, of other NGOs and from the private sector. The co-ordinating committee is expected to perform other tasks, for instance, to organize seminars, exhibitions etc. The establishment of the co-ordinating committee has had the following effects: improved co-ordination of measures/programmes, improved legislation, a better dialogue in the disability field and improved promotion of public awareness.

NATIONAL COUNCIL OF SOCIAL SERVICE, SINGAPORE (170)

No reply was received from the Government of Singapore.

General policy

There is no officially recognized disability policy.

Legislation

The rights of persons with disabilities are protected by general legislation.

General legislation applies to persons with different disabilities with respect to education, employment, the right to marriage, the right to parenthood/family, political rights, access to court of law, the right to privacy and property rights. In the case of marriage and parenthood/family, the guardian has the right, not the individual, in making such decisions. None of the following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling, financial security, employment, independent living or participation in decisions affecting themselves.

No new legislation has been enacted, since the adoption of the Rules.

Accessibility

There are rules to ensure accessibility of the built environment requiring that public places are made accessible. There are no standards requiring that the outdoor environment, means of public transportation or housing are made accessible. Accessibility in the built environment is observed by a national authority. The following measures have been promoted by the government in order to facilitate accessibility in the built environment: levelling off pavements, marking parking areas, installing automatic doors, lifts and accessible toilets and ensuring accessibility in public places. There are special transport arrangements available for medical treatment, education, for work and recreational purpose. The most difficult obstacles, when planning to build accessible environments are attitudinal factors. There is a disability awareness component incorporated in the training of planners, architects and construction engineers.

Sign language is used as the first language in education of deaf people and is also recognized as the main means of communication between deaf persons and others. There are no government measures to encourage media or other forms of public information to make their services accessible for persons with disabilities. The following services are provided in order to facilitate information and communication between persons with disabilities and others: literature in Braille, and sign language interpretation being available for any purpose.

Organizations of persons with disabilities

There is a national umbrella organization. There are no legal provisions mandating the representatives of persons with disabilities to participate in policy-making or to work with governmental institutions. Disability organizations are *always* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at the national level. The government gives financial support to existing or new

organizations of persons with disabilities. Persons with disabilities participate to a very limited extent in government, legislatures, judiciary, political parties but to a great extent in NGOs. The role of disabled persons organizations is to advocate rights and improved services, identify needs and priorities, participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, contribute to public awareness, provide services and to promote/organize income generating activities.

Co-ordination of work

The national co-ordinating committee is reporting to the Ministry of Education. It includes representatives of the Ministries of Health and Social Affairs, of organizations of persons with disabilities and from the private sector. The government expects the co-ordinating committee to participate in policy development but not to perform other tasks. The establishment of the committee has led to improved co-ordination of measures/programmes, improved legislation, improved integration of responsibility, a better dialogue in the disability field, more accurate planning and more effective use of resources.

The adoption of the rules has led to a rethinking of the approach to disability policy.

NATIONAL COUNCIL ON SOCIAL WELFARE OF THAILAND, THAILAND (160)

General policy

The officially recognized disability policy is expressed in law and in guidelines, adopted by the government. The emphasis in this policy is on prevention, rehabilitation, accessibility measures, individual support, and anti-discrimination law.

Since the adoption of the Rules, the government has conveyed the message of full participation, through various actions (mass media, posters, brochures etc.).

Legislation

The rights of persons with disabilities are protected by a combination of special legislation and general legislation. The judicial mechanism adopted to protect the rights of persons with disabilities is due process (legal remedy through the courts). There are no administrative or other non-judicial bodies.

General legislation applies with respect to persons with different disabilities with respect to education, employment, the right to marriage, the right to parenthood/family, political rights, access to court of law, the right to privacy and property rights. The following benefits are guaranteed by law to persons with disabilities: health and medical care, training, rehabilitation and counselling, financial security, employment, independent living and participation in decisions affecting themselves.

Since the adoption of the Rules, the "Rehabilitation and Disabled Persons Act" has been enacted.

Accessibility

There are rules to ensure the accessibility of the built environment which establish national design standards, requiring that public places are made accessible. Accessibility in the built environment is observed by a "sub-committee for rehabilitation of disabled persons on accessibility". The only measures promoted in order to ensure the accessibility in the built environment marking parking areas and providing financial support for accessibility measures in housing. There are no special transport arrangements. The most difficult obstacles, when planning to build accessible environments are attitudinal factors. There is a disability awareness component incorporated in the training of planners, architects and construction engineers.

Sign language has no officially recognized status. There are government measures to encourage media and other forms of public information to make their services accessible for persons with disabilities. The following services are provided in order to facilitate information and communication between persons with disabilities and others: literature in Braille/tape and sign language interpretation being available for any purpose.

Organizations of persons with disabilities

There is national umbrella organization. There are legal provisions mandating the representatives of persons with disabilities to participate in policy-making and to work with governmental institutions. Disability organizations are *always* consulted, when laws and regulations with a disability aspect are being prepared. Consultations occur at

the national level. The government gives financial support to existing or new organizations of persons with disabilities. Persons with disabilities participate to a very limited extent in judiciary, to some extent in government and political parties and to a great extent in legislatures and NGOs. The role of disabled persons organizations is to advocate rights and improved services, identify needs and priorities, mobilize persons with disabilities, participate in the planning, implementation and evaluation of services and measures concerning the lives of persons with disabilities, contribute to public awareness, provide services and promote/organize income generating activities.

Co-ordination of work

The national co-ordinating committee is reporting to the Ministry of Health Highways and Social Services. It includes representatives of many Ministries, of organizations of persons with disabilities and of other NGOs. The government expects the co-ordinating committee to participate in policy development and to perform other tasks. The establishment of the committee has led to improved legislation, improved integration of responsibility, a better dialogue in the disability field, more accurate planning, more effective use of resources and improved promotion of public awareness.

The adoption of the Rules has confirmed that "our policy is on the right track".

The reply sent by the Government of Thailand is identical with that of the National Council of Social Welfare of Thailand.

CONFIDENTIAL VERSION - BEFORE EDITING

Determined NOT to be
National Security Classified Marking
By MB (NLGB) on 7/28/16

Monitoring the implementation of the Standard Rules
on Equalization of Opportunities for Persons with
Disabilities

Final report on the three-year mission, 1994-1997

by

Bengt Lindqvist
Special Rapporteur on the Commission for Social Development

"In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms and making it difficult for them to participate fully in the activities of their societies. It is the responsibility of States to take appropriate action to remove such obstacles."

(Standard Rules, Introduction, para. 15)

TABLE OF CONTENTS

PREFACE

I. BACKGROUND AND THE FRAMEWORK FOR THE ACTIVITY

1. Background
2. The monitoring mechanism
3. Meetings of the Panel of Experts
4. Guidelines by the Commission for Social Development

II. ACCOUNT OF THE UN AGENCIES

1. UN Disability Statistics Programme
2. UNICEF
3. ILO
4. UNESCO
5. WHO
6. Human Rights Entities

III. ACCOUNT OF NGO'S ACTIVITIES

1. Activities by the NGO's

IV. ACCOUNT OF RAPPORTEUR'S ACTIVITIES

1. Promoting the implementation of the Standard Rules
 - 1.1. Meetings with Governments
 - 1.2. Conferences
 - 1.3. Correspondence
2. Surveying the progress
 - 2.1. First survey
 - 2.2. Second survey
 - 2.2.1 General policy questions
 - 2.2.2 Questions on legislation
 - 2.2.3 Questions on accessibility
 - 2.2.4 Questions on organizations of persons with disabilities
 - 2.2.5 Questions on coordination of work
3. Rule 6 on education
 - 3.1. Legal regulation of the right to special education
 - 3.2. Parents' role
 - 3.3. Education forms and the issue of integration
 - 3.4. Special education legislation
4. Rule 7 on employment
 - 4.1. Summary of Rule 7
 - 4.2. ILO Convention 159

V. GENERAL DISCUSSION AND CONCLUSIONS

PREFACE

In my capacity as Special Rapporteur for monitoring of the implementation of the Standard Rules on Equalization of Opportunities for Persons with Disabilities I have the honour to deliver my final report to this Commission. It has been a privilege and a stimulating task to act as Special Rapporteur in this area. I want to express my sincere appreciation to the UN Secretary-General for showing confidence in me by appointing me to this important task. I also would like to thank all those Governments, which have contributed financially to this project, including the Swedish Government, which has provided me with office resources throughout the whole exercise.

From the beginning and during the whole monitoring activity I have enjoyed full support by Undersecretary-General, Mr. Nitin Desai, and excellent professional advice by Mr. A. Krassowski and his group at the UN Department of Policy Coordination and Sustainable Development. I also want to express my appreciation for the excellent work performed by my colleagues in my Swedish office.

One key element in this monitoring exercise has been the Panel of Experts, established by six major international NGO's in the disability field. The Panel members, five men and five women with different experiences of disability, have provided valuable guidance. They have also been very understanding, when limited resources have made it impossible to pursue all good ideas and initiatives.

Finally I want to thank all those Governments and NGO's who have provided information to my work.

I have chosen to describe the whole monitoring exercise, but, as I have delivered an interim report to the Commission for Social Development already to its 34th session, I summarize activities during the first year. To illustrate how widely spread the Standard Rules have become, I have included brief information about activities undertaken by UN Specialized Agencies and NGO's in the disability field. The main emphasis in the report is on recent activities and on the second and large survey, which has been a main activity during 1996. In the final section of the report - General Discussion and Conclusions - I have presented the observations, which I have made during the work with this most stimulating task.

I. BACKGROUND AND THE FRAMEWORK FOR THE ACTIVITY

1. Background

To fully understand the importance of the Standard Rules it is necessary to go back to the events, which started with the proclamation of 1981 as the International Year of Disabled Persons (IYDP). Of particular importance in this context was the adoption by the UN General Assembly of the theme of the year - "full participation and equality". This meant a recognition on the highest possible political level of the right to full participation of disabled people in the societies they belong to.

During the 15 years which have passed since the IYDP, "full participation and equality" has been widely accepted as the overall goal of all development efforts in the disability field. The World Programme of Action concerning disabled persons, which was adopted in 1982 by the

UN General Assembly, also made significant contributions to the clarification and understanding of policies, programmes and measures necessary to undertake, in order to obtain this goal. One such great contribution is the new chapter on equalization of opportunities, which brings a third dimension into the field of disability.

During the subsequent decade of disabled persons, 1983-1992, when the policies and programmes, outlined in the World Programme of Action should be implemented, some significant development was made. Generally, however, too little happened. This was the major concern of the group of experts who in 1987 evaluated the outcome of the first half of the decade.

Because of this the international disability community requested that the UN should assume a strong leadership role and give more concrete guidelines for development. In response to this request the Standard Rules were elaborated and unanimously adopted by the UN General Assembly in 1993 (Resolution 48/96).

There are mainly three things, which distinguish the Standard Rules in comparison with the World Programme of Action. The Rules are more concentrated and concrete in form; they directly address the issue of Member States responsibility and they include an independent and active monitoring mechanism.

2. The monitoring mechanism

One of the most significant features of the Standard Rules is that their implementation should be actively monitored. In chapter four of the Standard Rules document there is a fairly detailed description of the monitoring mechanism. The purpose of it is: "to further the effective implementation of the Rules. It will assist each State in assessing its level of implementation of the Rules and in measuring its progress. The monitoring should identify obstacles and suggest suitable measures that would contribute to the successful implementation of the Rules."

There are three actors involved in this monitoring task. The monitoring should take place within the framework of the sessions of the Commission for Social Development. A Special Rapporteur should do the actual monitoring work and report to the Commission. Finally, the non-governmental organizations in the disability field should be invited to establish among themselves a Panel of Experts, which should be consulted by the Special Rapporteur.

In March 1994 the Secretary-General, Boutros Boutros-Ghali, appointed me as Special Rapporteur. In September 1994 a Panel of ten Experts, five men and five women, all with personal experience of different disabilities and coming from different parts of the world, was established by the following six international organizations; Disabled Peoples' International, Inclusion International, Rehabilitation International, World Blind Union, World Federation of the Deaf, and World Federation of Psychiatric Users.

A precondition for the whole monitoring exercise was that extra-budgetary funding could be raised for the major part of the activities. Altogether eleven Governments have contributed financially to the project. The total amount of these contributions is estimated at USD 650,000. A special service agreement between the UN secretariat and the Special Rapporteur was signed in August 1994 for the period 1994 - 1997. It was agreed that the Special

Rapporteur should run his work from a small office in Sweden and that the UN secretariat would assist with advice and administrative services.

3. Meetings of the Panel of Experts

The Panel of Experts has held two meetings, in February 1995 and in June 1996. Both meetings were held at UN headquarters in New York. Through correspondence members of the Panel have continuously been informed and consulted by the Special Rapporteur.

During the first meeting in February 1995 all members of the Panel were present. The main purpose of the meeting was to give general advice concerning the monitoring task during the remaining two years. The Panel agreed on a set of concrete recommendations, which have been very useful for the Rapporteur.

Among the recommendations the following are of a more general importance:

* The Panel felt it necessary to clarify the relation between existing UN documents in the disability field: "In the global effort to implement the overall goal of full participation and equality the Panel of Experts considers it the most important task during the next few years to implement the Standard Rules. Panel considers the World Program of Action Concerning disabled persons providing an important framework for action in the fields of prevention, rehabilitation and equalization of opportunities for persons with disabilities. The long-term strategy, adopted by the General Assembly of the UN in 1994, should be regarded as a useful tool in the implementation of the Standard Rules."

* "The monitoring of the Standard Rules should be carried out in the spirit of cooperation and partnership on the international level between the UN and the international NGO's participating in the Panel of Experts and on the national level between Governments, the national NGO's and the UN."

* "Although the overall goal of the monitoring activity will be to fully implement all the 22 Rules, the Panel recommends that the monitoring efforts should be concentrated on the following six areas; legislation (Rule 15), coordination of work (Rule 17), organizations of persons with disabilities (Rule 18), accessibility (Rule 5), education (Rule 6), employment (Rule 7)."

* "Efforts should be made by the UN secretariat and the Rapporteur to involve the specialized agencies and the regional commissions in the implementation of the Rules."

* "The Panel considers it necessary to take further action to increase awareness in Governments, NGO's and the UN system."

The second Panel meeting was held in June 1996. Nine Panel members attended. During the preceding months the Special Rapporteur had distributed a comprehensive questionnaire to all UN Member States and to national NGO's in the disability field. One major task for the Panel this time was therefore to discuss the outcome of this survey. Despite the fact that the final date for replies had expired ten weeks earlier, replies were still coming in at the time of the panel meeting. A broad analysis of the results had therefore not yet been started.

The Panel gave advice on issues of special interest for the analysis and concerning the structure of the report. It noted with great satisfaction the high response rate in this questionnaire, which should provide the UN with extensive information in essential policy areas.

In view of the fact that only one year remained of the monitoring period the Panel started to discuss what should follow after 1997. Panel members were of the opinion that three years is a very short time for a worldwide monitoring of the implementation of such extensive policy guidelines as the Standard Rules. The Panel therefore decided to recommend to its organizations that they should advocate a prolongation of the monitoring task.

The Panel of Experts also discussed how the disability component could be integrated into the implementation of the five year follow-up plan to the World Summit for Social Development, recommended by the Commission for Social Development to the Economic and Social Council. It is in this context urgent to raise the issue of how disability measures can be included into such programmes. With reference to the Commission resolution the Panel decided to make the following statement: "The Panel noted with some alarm the tendency to disregard the specific needs of individuals with disabilities within Governments, the UN, and professional groups. This signifies the continued low priority status assigned to the individuals with disabilities on the ladder of progress. It is necessary to build the disability dimension into the existing models of Government and the UN in order to make laws and policies specific to the needs of individuals with disabilities."

4. Guidelines by the Commission for Social Development

At its 34th session in April 1995 the Commission for Social Development received a first report by the Special Rapporteur. In a resolution, 34/2, the Commission expressed its support for the approach to monitoring by the Special Rapporteur to place emphasis on advice and support to States concerning implementation of the Standard Rules. Furthermore the Commission;

- * encouraged the Special Rapporteur to focus his monitoring efforts in the forthcoming two years on an appropriate number of priority areas, bearing in mind that the overall goal of the monitoring activity is to implement the Rules in their entirety;

- * called upon the Department for Policy Coordination and Sustainable Development of the Secretariat, as the UN focal point on disability issues, the UN development programme and other entities of the UN system, such as the regional commissions, the specialized agencies and inter-agency mechanisms, to cooperate with the Special Rapporteur in the implementation and monitoring of the Rules;

- * strongly urged States and intergovernmental and non-governmental organizations to continue to cooperate closely with the Special Rapporteur and respond to his second questionnaire on the implementation of the Rules;

- * called upon States to participate actively in international cooperation concerning policies for equalization of opportunities and for improvement of living conditions of persons with disabilities in developing countries.

II. ACCOUNT OF THE UN AGENCIES

In paragraph seven of chapter IV in the Standard Rules the Specialized Agencies and other UN entities are requested to cooperate with the Special Rapporteur in implementing the Rules. The following agencies have responded positively to this request and taken special initiatives in connection with the monitoring of the Rules.

1. UN disability statistics programme

The Standard Rules draw attention to the importance of statistical data on the living conditions of persons with disabilities and that such data collection should be undertaken at regular intervals as part of the official statistical system of countries.

The work is concentrated on three main issues:

- 1) Together with States and others, improve the methodology for collection of data by standardizing concepts of disability and by establishing new and more effective procedures for the collection of data
- 2) the compilation of already existing data into a database (Distat)
- 3) cooperation with the growing numbers of users of data on disability, such as planning agencies, research institutes and NGO's.

2. UNICEF

UNICEF headquarters took an active role in dissemination of copies of the Standard Rules to over 150 UNICEF regional and country offices in English and other available languages. In addition to the Convention on the Rights of the Child and Unicef policy paper on "Children in Need of Special Protection Measures" UNICEF officials have also used the Standard Rules in their promotion of Human Rights and improved conditions for the children of the world.

3. ILO

As the Special Rapporteur, in consultation with the Panel of Experts, had decided to study employment policies as one of six selected Rule areas and as it was considered important to bring up the issue of employment in the final report of the monitoring, ILO offered to make available the data on the monitoring of the ILO Convention 159, ratified by 56 countries. The material contains Government reports and communication between Governments and ILO experts concerning the practical application of the various articles of the convention. For our analysis, 6 articles in the Convention were selected, which all have corresponding sections in Rule 7 on employment. For a summary of results see III, 4, in this report. In addition, the ILO will carry out beginning in 1996, a general survey of the law and practice of member States which have not ratified Convention 159. The results of this extensive survey will be presented to the International Labour Conference in 1998.

4. UNESCO

Since 1980, UNESCO has collected information on practice in special education. The latest Review concerns 1993-1994 and was published in 1995. A great deal of the collected information is highly relevant for the monitoring of Rule 6 on education. According to UNESCO, this study is to be seen as a UNESCO contribution to the monitoring of the Standard Rules.

Furthermore, UNESCO carried out a study on Legislation Pertaining to Special Needs Education, the information was compiled in 1994 and was published in 1996. It represents information from fifty-two countries.

In 1994 UNESCO organized a World Conference on Special Needs Education in Salamanca, Spain. More than 90 countries were represented. The conference adopted The Salamanca Statement and Framework for Action, which builds on and develops the guidelines in Rule 6 of the Standard Rules.

In 1995 the issue of special needs education was on the agenda of the UNESCO General Conference. In my capacity as UN Special Rapporteur on Disability I had the opportunity to address the Conference. In my statement I emphasized the importance of implementing the guidelines presented in the Standard Rules and the Salamanca Statement, which in all essential areas are in harmony with each other.

5. WHO

As a WHO contribution to the monitoring of the Standard Rules, the Special Rapporteur and the members of the panel of experts, coming from developing countries were invited to participate in the meeting of WHO regional advisers for rehabilitation, which took place in Geneva in January 1996. The meeting discussed the role of WHO towards the implementation of the UN Standard Rules. Among the recommendations made at the meeting, the following can be mentioned:

- * That WHO should promote the general spirit and direction towards human rights as stated in the United Nations Standard Rules, taking responsibility for surveying Rules 2, 3 and partially Rule 4
- * That WHO should promote a multi-sectoral approach for the analysis of the disability situation in the developing countries so that appropriate national policies to guide programme planning can be developed
- * That WHO should promote the inclusion of organizations of persons with disabilities in the development, implementation, monitoring and evaluation of CBR programmes
- * That there should be increased collaboration at the national, regional and international levels to intensify the fight and to end discrimination against persons with disabilities
- * That a media campaign about disability issues and the Standard Rules should be promoted with the collaboration of different public sectors, NGO's and organizations of persons with disabilities

6. Human Rights Entities

Since the publication in 1992 of the report, entitled Human Rights and Disabled Persons, by Special Rapporteur Leandro Despouy, several activities have been initiated within the UN Human Rights Administration. Among these the following might be mentioned.

The World Conference on Human Rights, held in Vienna in 1994, in its Vienna Declaration and Program of Action stated that "special attention need to be paid to ensuring non-

discrimination, and the equal enjoyment of all human rights and fundamental freedoms by disabled persons, including their active participation in all aspects of society."

The Sub-Commission on Prevention of Discrimination and Protection of Minorities in resolution 1995/17 requested the Secretary-General to report in 1996 to the Sub-Commission regarding coordination endeavours, which affect persons with disabilities, with emphasis on activities by other UN organizations and bodies that deal with alleged violations of human rights.

In May 1996 the following three committees had reported activities in the field of human rights and disability: Committee on the Rights of the Child, Committee on Economic, Social and Cultural Rights and Committee on the Elimination of Discrimination against Women.

In all these areas the analysis concerning the protection of the human rights of persons with disabilities has been started. Of particular interest, in my opinion, is the General Comment No. 5 (1994) issued by the Committee on Economic, Social and Cultural Rights. In its analysis the Committee also relates the situation of disabled people to the general trends of development and discusses necessary means for the protection of the rights of persons with disabilities.

Finally, it should be mentioned that the Commission on Human Rights, in its resolution 1996/27, entitled "Human Rights of persons with disabilities" urged all Governments to implement, with the cooperation and assistance of organizations, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities.

III. ACCOUNT OF NGO'S ACTIVITIES

The major international non-governmental organizations in the disability field were, from the very beginning, actively involved in the elaboration of the Standard Rules. Even though some parts of the Rules were agreed upon through compromise it is important to note that the international NGO's fully supported the adoption of the Rules.

The unique form of cooperation, where NGO's upon the invitation by UN established a panel of experts to serve as part of the monitoring exercise, meant a direct involvement of these organizations in the actual monitoring process.

The six international NGO's, represented in the panel and a considerable number of other organizations have organized many different activities to support the implementation of the Rules. Many organizations have made users' guides and information kits to assist member organizations in the utilization of the Rules. These materials are being extensively used both on a national and regional level.

The Rules have been presented in articles in many of the organization magazines. In some cases series of articles have been published.

At practically all important events organized by the major NGO's, the issue of implementing the Standard Rules has been part of the programme.

The major NGO's have worked together at all the recent world conferences, organized by the UN, including the Social Summit, to ensure that the implementation of the Standard Rules was included in declarations and reports from these conferences.

The following quotation from para 75, section k, in the report from the Social Summit, may serve as an example of what was obtained through these activities: "Promoting the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities and developing strategies for implementing the Rules. Governments, in collaboration with organizations of people with disabilities and the private sector, should work towards the equalization of opportunities so that people with disabilities can contribute to and benefit from full participation in society. Policies concerning people with disabilities should focus on their abilities rather than their disabilities and should ensure their dignity as citizens."

The NGO's have brought up the issue of integrating the disability component, built on the Standard Rules, into the mainstream activities of the various UN agencies.

IV. ACCOUNT OF RAPPORTEUR'S ACTIVITIES

1. Promoting the implementation of the Standard Rules

In accordance with the purpose of the monitoring - "to further the effective implementation of the Rules" - I have endeavoured to use all available opportunities to present the Rules, their background, message and function. During the 30 months of monitoring, since I started in August 1994, I have had discussions with 20 individual Governments, of which 15 are developing countries or countries in transition. On all these occasions I have also involved the national organizations of disabled people. I have participated in about 35 international conferences. I have had meetings with all the major UN agencies with responsibilities in the disability field. During the whole monitoring exercise I have had extensive correspondence and communication with a great number of people, who in different ways have been involved in my monitoring task.

1.1. Meetings with Governments

Meetings with individual Governments have been initiated mainly in two ways. In many cases I have been directly invited by Governments, who have been interested in discussing various aspects of the implementation of the Rules. In some cases I have suggested to Governments that we should meet as I have been attending a conference in the country or in a neighbouring one.

The talks have had different character due to the situation in the country. In some cases Governments wished to present their new initiatives in the disability field with me and discuss various aspects in the implementation - Japan, China, Mexico, India. Other visits have been to countries in transition, where Governments have wanted to discuss how the disability issue could be integrated in the reconstruction or reorientation of Government policy - South Africa, the Palestinian Authority, Estonia, Macedonia, the Czech Republic.

In some cases my visit has resulted in written recommendations for future measures - Macedonia, the Czech Republic.

During all these visits I have established contacts with existing organizations of disabled people and also tried to involve other organizations and agencies in the disability field. The representatives of organizations of disabled people have, in some cases, been invited by their Governments to participate in my deliberations with various Ministries. My general impression is that my visits often have vitalized the dialogue between Governments and organizations. In some cases I have been able to suggest new initiatives to the organizations, in a few cases I have functioned as a mediator suggesting a compromise. As then often concerned the establishment of a coordinating council, the composition and function of such a body.

1.2 Conferences

In view of the great importance of the NGO's in the disability field in advocating the implementation of the Standard Rules, I have given high priority to my participation in important events organized by such organizations. In fact I have attended almost all world congresses and assemblies arranged by the six organizations constituting the Panel of Experts. I have also attended a great number of other international conferences. Some of these conferences have been jointly organized by Governments, specialized agencies and NGO's. One very useful form of conference for promoting the implementation of the Standard Rules has been regional conferences with participation from both Governments and organizations. One such regional conference, organized in Abidjan, Cote d'Ivoire, was of particular interest as it was organized jointly by the three specialized agencies, ILO, UNESCO and WHO, in collaboration with UNDP. Participants came from Governments, organizations and these agencies.

My participation has usually consisted in a general presentation of the Standard Rules, often followed by a workshop or a seminar where various aspects in the implementation work have been discussed. Through my participation at such a great number of international meetings, I have reached a great number of persons with different functions from a large number of countries with my message. At some of the world congresses organized by the international NGO's more than 100 countries have been represented. Finally, I have also been invited to speak at universities, county councils, research seminars and seminars on development cooperation.

1.3. Correspondence and communication

The correspondence in connection with my various activities has been extensive. I have been asked to send written statements, which have been used in various texts. I have written a number of articles for magazines for the international NGO's, WHO and EU. I have provided advice concerning various implementation aspects and in some cases people have raised individual issues with me. Due to the extensive network of contacts we have developed during this monitoring task, we have often handled requests for speakers on the Standard Rules for various meetings and conferences.

2. Surveying the progress

2.1. First survey

In November 1994 a first letter from the Rapporteur to Governments was distributed to member states. The letter contained four general questions concerning the reception of the Rules by Governments and other interested entities in the countries.

A summary country by country of all the replies was made and attached to the first report to the Commission. The following information might be noted as highlights.

- * Most Governments indicated either that they already acted in the spirit of the Rules or that they are drafting new policies in accordance with the Rules.

- * Many countries had translated the Rules into the native language even in countries with more than one language.

- * Many countries already had National Coordination Committees. In others such a body was being created. Throughout the replies there was strong emphasis on the active participation by organizations of disabled persons in forming policies and programmes in the disability field.

- * Many countries expressed the wish to receive more information, especially about the activities in the disability field in other countries.

- * Some countries already had adopted, or were drafting, legislation or other documents using the principles of the Rules.

- * In some countries the Rules were used in awareness-raising campaigns.

- * One country was planning to develop an E-mail forum for the Rules.

- * Several new bodies or institutions were created with various functions but with the common purpose of supporting the implementation of the Rules. Examples of such new bodies were: A High Commissioner on Disability (Morocco), a Disability Ombudsman (Sweden), an Equal Opportunities Centre (Denmark), a Special Committee of State Secretaries (Norway) and a Foundation to promote the development in the disability field (with an income from taxation on gambling, Estonia).

The first letter was distributed through the regular UN channels. Member states were asked to reply before February 15, 1995. A reminder to Governments was sent out by the Secretariat shortly before the final date for replies. In addition to this the international non-governmental organizations, constituting the Panel of Experts, were asked by the Rapporteur to distribute the letter to their national members. A total number of 38 replies was received from Governments. Only 4 replies came from NGO's.

38 replies only is of course a very disappointing result. The questions were of such a kind that it would not take much time to formulate a reply. Such a low response rate seems, however, to correspond well with earlier experience within the Secretariat concerning questionnaires to Member States on disability matters. Bearing this experience in mind, we decided to extend the efforts to make Governments and NGO's reply, by using reminders to all concerned and by using the contacts we already had. As can be seen from the response rate in connection with the second survey, the efforts were successful.

2.1. Second survey

In order to move towards a more accurate assessment of the world-wide implementation of the Standard Rules I decided, in consultation with the Panel of Experts, to make a second survey among the Member States and national NGO's in the disability field. The purpose of the survey was threefold: a) to assess the level of implementation; b) to identify main changes and accomplishments in the field of disability; c) to identify major problems and obstacles encountered during the implementation process.

The preparations started in August 1995 and the report on the survey was completed in December 1996. A questionnaire was elaborated, which requested information on five areas: general policy, legislation (Rule 15), accessibility (Rule 5), organizations of persons with disabilities (Rule 18) and coordination of work (Rule 17) (questionnaire, Annex I). Given the variations that exist between Member States in economic, political and cultural conditions, it was a rather complicated task to make the questionnaire and it is hardly surprising that certain questions require a broad interpretation.

The questionnaire was delivered in December 1995 to all Governments and to the approximately 600 national member organizations of the six internationals, constituting the Panel of Experts. Information was enclosed that the objective was to identify the official policy of the country. It was pointed out that the questionnaire "focuses specifically on the nature and scope of the implementation of the Rules undertaken principally through legislative action, administrative rules or regulatory measures".

By August 1996 the survey had resulted in 83 responses from Governments which might be considered as a high score of replies.

<u>Replies</u>	<u>Number</u>	<u>Response rate per cent</u>
Governments	83	45
NGO's: Total	163	27
Countries	96	n/a

It may be noted that replies were received from the Government of 30 countries from which there was no NGO response. Conversely, NGO replies were received from 43 countries whose Governments did not reply. In total, 126 countries are covered by the survey.

It is encouraging to note that our survey has resulted in extensive and essential disability data, which will be of great importance to understand the progress in the area of disability policy. In the following we present some selected findings from the analysis of Government replies. Due to a constant flow of incoming replies, the analyses of the data could not be started until late August 1996. Therefore, time has not permitted us to analyze the material in its entirety. We intend to continue the work and to publish a report including both Government and NGO replies and comparative studies between them.

2.2.1. General policy questions

An officially recognized disability policy is essential for the attainment of equality of opportunity. The aim of this part of the questionnaire was to identify the existence of such policy

and its form. The existence of a disability policy can be measured by the extent to which relevant legislation has been enacted, information campaigns undertaken etc.

In the first question the respondents were asked to indicate whether there is an officially recognized disability policy. In the majority of countries, i.e. 70 of 82 providing information on this issue, there is an officially recognized disability policy. Only 11 Governments reported that they do not have an officially recognized disability policy. Ten of them are developing countries.

In ten countries the officially recognized disability policy is not expressed in law but in guidelines and/or in different policy documents.

In question two the respondents were asked to indicate where the emphasis in the national disability policy lies. The aim was to find out whether disability policy focuses on a welfare approach, on accessibility or on anti-discrimination measures. When individual support is given more emphasis, our interpretation is that the disability policy is of a more traditional welfare-oriented type. When accessibility or anti-discrimination law gets the main emphasis, we consider the disability policy more human rights oriented. As our survey indicates, the highest ranking among countries, was on rehabilitation and prevention (i.e. a welfare approach), while less emphasis was on accessibility measures and anti-discrimination law. This could be considered an indication that many countries have not yet implemented the Standard Rules. It could also be explained by greater difficulty to organize and finance this kind of measures. Unquestionably, it is clear that the more traditional welfare approach to disability is still very widely spread.

In the third question on general policy, respondents were asked to indicate, if the Government since the adoption of the Rules, has done anything to initiate and support information campaigns, conveying the message of full participation for persons with disabilities: 64 Governments of 79 providing information reported that they through various methods have conveyed this message.

Of course, the actions taken by the Governments vary. The most frequent measures mentioned are translation of the Rules, translation and publication into an easy reader version, development of educational materials in order to raise the awareness of the public, television and radio programmes conveying the message of full participation, support to research projects, support to NGO's advocating the message of full participation, advertisements in newspapers, donations in order to support the work of the Special Rapporteur. As much as 15 Governments reported that they have not done anything in this area since the adoption of the Rules. This is rather astonishing three years after the adoption of the Rules. To make the Rules known is after all the easiest and the least costly measure of all.

2.2.2. Questions on legislation

In order to present a broad picture of national legislation concerning the rights of persons with disabilities, the present survey reviewed general aspects of legislation. Question 4 aimed at finding out whether the Government has enacted rights legislation to protect individuals and groups from discrimination on the basis of disability. This can be done either by general legislation, special legislation or a combination of these two types. The provisions in general legislation are intended to apply equally to all persons, regardless of disability. Special legislation draws the attention to the particular needs of persons with disabilities and creates

specific protections. Special legislation is often advocated, when general legislation fails to provide sufficient protection. It can be maintained that special legislation is a stronger piece of legislation, since it specifically refers to the needs and rights of persons with disabilities.

As the results indicate, the most common type of legislation is to use both special and general legislation or a combination of these two types. 56 Governments replied that there are specific amendments, referring to disabled persons rights within general legislation. 10 Governments reported that the rights of persons with disabilities are protected only by special legislation and 17 Governments that these rights are protected only by general legislation. The great diversity among these countries indicates that the level of social and economic development or law tradition cannot play an essential role in the choice of legislation.

In question 5 the aim was to find out, whether there are mechanisms to protect disabled people's citizenship rights. Judicial mechanisms as well as administrative and other non-judicial bodies are the institutional arrangements, through which citizenship is protected. The protection of the rights of disabled people depends, to a large extent, on the enforcement mechanism built into the legislation. Unless objections can be raised through judicial mechanisms or non-judicial bodies, laws remain ineffective. As the results show, the status of persons with disabilities in relation to the enforcement mechanisms is not always clear.

In the majority of the 81 Governments providing information, mechanisms have been adopted to protect the rights of persons with disabilities. The most common judicial mechanism is legal remedy through the courts, while the most common non-judicial mechanism is a Governmental body (administrative). 16 Governments reported that they do not have any judicial mechanism. In two countries there is neither any judicial nor any non-judicial mechanism/arrangement to protect the rights of disabled people. This is a serious infringement of their human rights. (See International Covenant on Civil and Political Rights Article 2, §3, and Articles 16 and 26)

In question six the aim was to find out, whether general legislation applies to persons with disabilities and their right to equal protection under the law, or if disability is a cause for differential treatment. The result showed that in 27 countries of 80 providing information, persons with disabilities are not considered as fully fledged citizens in a number of areas within the general legislation, i.e. the right to vote, the right to property, right to privacy etc. In 55 countries disability is not used as a basis for differential treatment.

The results indicated that disabled people in 10 countries of 80 providing information are not guaranteed by law the right to education and the right to employment. In 17 countries the right to marriage is not guaranteed by law; in 16 countries the rights to parenthood/family, access to court-of-law, privacy, property are not guaranteed by law, and in 14 countries persons with disabilities have no political rights. As regards exclusion from the right to marriage, to parenthood/family, access to court-of-law, property and political rights, they are all examples of the factual discrimination, which occurs through legislation and regulations. Legislation may actually prevent disabled people (in particular those with mental disabilities) from exercising these rights. For instance, in some countries laws governing property exclude disabled persons from owning property. There may also be legal provisions which prevent disabled persons from entering into contracts in their own names. This seems to be a legally sanctioned discrimination, which these Governments have established in their legislation. (See Article 23, §12, Articles 17 and 25 in the International Covenant on Civil and Political Rights).

In question 7 the aim was to study the existence of legislation concerning a number of benefits, such as health services, social security, rehabilitation, and employment. In 4 countries of 82 providing information, no benefits at all are guaranteed by law to persons with disabilities. In 33 countries all of the mentioned benefits are guaranteed by law, while for the remaining 49 countries one or more of these benefits are not guaranteed by law. In 10 countries the right to health/medical care is not guaranteed. In 14 the right to training, rehabilitation and counseling is not guaranteed by law. In 24 the right to financial security, in 27 the right to employment, in 34 the right to independent living and the right to participation in decision-making are not guaranteed by law. Thus, in most countries one or more of these social security and welfare services are not within the legal framework, guaranteed to all citizens.

When comparing the information in questions 6 and 7, it can be noted that Governments are more advanced in establishing laws which guarantee civil and political rights than social and economic rights. Persons with disabilities are significantly disadvantaged in many societies. Many of the social and economic conditions they experience, reflect a basic lack of equality which can be traced back to a weak legal basis.

When comparing questions 6 and 7 with question 4, it can be concluded that a correlation exists between general legislation and a weaker protection of citizenship rights for persons with disabilities. When the rights of persons with disabilities are protected only by general legislation there are several citizenship rights (political rights, the right to marriage, the right to parenthood/family) as well as several social and economic rights (financial security, employment, independent living), which are not guaranteed by law. This tendency could be found in 13 countries of a total of 17, reporting only general legislation. Only in four countries exceptions could be noticed from the tendency that general legislation is sufficient to protect the citizenship rights of persons with disabilities.

In question 8 the aim was to find, whether new legislation concerning disability has been enacted since the adoption of the Rules. In the majority of the countries - 44 of 83 providing information - no new legislation concerning disability has been enacted since the adoption of the Rules. However, several Governments (47%) have recently adopted legislation, which protects persons with disabilities against discrimination and other forms of unjust treatment.

2.2.3 Questions on accessibility

In the area of accessibility, two major aspects must be considered - access to the physical environment and access to information and communication. Accessibility is taken for granted by the general population in areas such as housing, transportation, education, work and culture. Without an accessible physical environment and access to information, it becomes difficult to exercise both political and social rights. Accessibility is therefore a prerequisite for achieving the goal of full participation for persons with disabilities.

Questions 9 and 10 aim at finding out, whether there are laws and/or regulations concerning the built environment. 23 of 83 Governments providing information reported that there are no standards which require accessibility to the built environment.

In most countries there are standards which ensure accessibility in public places. But, only in 42% of the countries there are means of public transportation, accessible to persons with

disabilities. Thus, the accessibility to public places is in practice much lower, since without transportation it is difficult to utilize the accessibility of buildings.

In question 12 the aim was to determine what measures have been promoted by Governments in order to facilitate accessibility in the built environment. As our study shows, providing special parking lots and installing automatic doors, lifts and accessible toilets for persons with physical disabilities are the most frequently promoted measures. The measures least frequent are the use of special lighting and contrast colours for visually impaired. 18 Governments of 81 providing information reported no measures at all facilitating accessibility in the built environment.

In question 13 the aim was to see if there are any special transport arrangements for persons with disabilities and for what purposes special transport is available. In 26 countries of 82 providing information, there are no special transport arrangements, not even reduced prices in public transport in urban areas. Special transport arrangements vary to a great extent. Our survey indicated that special transport, when available, is most often provided for the purpose of education, while less frequent for recreational purposes.

Question 14 aimed at determining impediments, when planning to build accessible environments. A number of obstacles were listed and Governments were asked to rate the most difficult ones. The results indicate that the three main obstacles to an adaptation of the built environment to the needs of disabled people are; economic/budgetary factors, attitudinal factors and the lack of enforcement mechanism. Surprisingly, attitudinal factors are considered by many as a major obstacle to accessibility measures.

Question 15 aimed at determining, whether there is a disability awareness component incorporated in the training of planners, architects and/or construction engineers. The findings indicated, that in the majority of the countries - in 42 of 78 providing information - there is no such awareness component incorporated in training programmes.

The information and communication rights of persons with disabilities are addressed specifically by the questions 16, 17, 19. Of particular importance is to create measures which make information and communication accessible to deaf, deaf-blind and visually impaired people.

In question 16 the aim was to find out the status of the sign language in Member States. Our survey indicated that in 26 countries of 80 providing information, sign language is neither used in education of deaf people nor as the main means of communication between deaf people and others. In 15 countries it is used as the first language in education of deaf people and in 15 countries it is used as the main means of communication between deaf persons and others, but not used as the first language in education of deaf people.

Questions 17 and 18 concerned measures taken by Governments to encourage media and other public information providers to make their services accessible for persons with disabilities. Such services include text on TV, news in sign language, interpretation in sign language of other programmes, newspapers in easy reading language, text telephones for deaf people, interpretation of theatre plays in sign language, etc. The findings indicated that about 50% of the countries providing information, have not taken any measures to encourage media to make their services accessible. Likewise ca 50% of the countries reported that no measure had been taken in order to encourage other public information providers to make their services accessible.

Question 19 should determine which services are provided in order to facilitate information and communication between persons with disabilities and others. The results showed that 71 countries of 81 providing information provide literature in Braille/tape and 45 countries provide news magazines on tape/Braille. 34 countries provide sign language interpretation for any purpose and 25 countries provide easy readers. It is noticeable that services vary considerably to different groups of persons with disabilities. Services to blind and visually impaired people get the most attention, while services to deaf and persons with mental disabilities are more limited.

2.2.4 Questions on organizations of persons with disabilities

According to Rule 18 the activities concerning the implementation of the Standard Rules should be carried out in cooperation between national authorities and organizations of persons with disabilities. It is an important principle of democracy that individuals should be involved in decision-making concerning themselves. In this context organizations of persons with disabilities represent the experiences and aspirations of their members. Such organizations can provide decision-makers with insight into and knowledge of the problems, needs and requirements of people with disabilities.

Question 20 concerned the existence of an umbrella organization, i.e. a joint organization of different organizations of persons with disabilities. 63 countries of 81 providing information reported that a national umbrella organization exists. 18 countries reported that there is no umbrella organization. In the countries where the umbrella exists, most organizations of persons with disabilities are represented.

Regarding the existence of legal provisions, which mandate the representatives of these organizations to participate in policy-making and to work with Governmental institutions (question 21) the results were as follows: In 31 countries (39%) of 80 countries providing information, there are no legal provisions. In 49 countries (61%) there are such legal provisions.

Question 22 aimed at finding out, if and how often the views of organizations of persons with disabilities are taken into account. In 37 countries of 80 providing information, organizations are *always* consulted when preparing laws, regulations and/or guidelines with a disability aspect. In 24 countries, their views are *often* taken into account. In 18 countries, their views are *sometimes* taken into account and in one country the views of the organizations are *never* taken into account.

As the results of question 23 showed, consultations take place most often at the national level, less often at the local level and least often at the regional level.

Question 24 aimed to find out, whether the Government gives any support and what kind of support is given. In 65 countries of 80 providing information, organizations of persons with disabilities receive financial support from their Governments. In 9 countries organizations receive only organizational/logistic support, while in 5 countries organizations do not receive any support at all.

Question 25 tried to measure the extent, to which persons with disabilities participate in political and public life. Respondents were asked to evaluate in a scale, ranging from 1 to 5, the extent to which, persons with disabilities participate in five different areas of public life: Government,

legislatures, judicial authorities, political parties and NGO's. The level of participation could be evaluated on a scale ranging from very limited extent to great extent.

The results showed that persons with disabilities participate to a very limited extent in Government, legislatures and judicial authorities, but to a great extent in NGO's. It is interesting to note that participation in political parties scored next after NGO's.

Question 26 aimed at pointing out what role the organizations of persons with disabilities have. The organizations most often contribute to public awareness, to mobilize persons with disabilities and to advocate rights and improved services. Least often their role is to promote/organize income generating activities.

2.2.5. Questions on coordination of work

Disability is a multidisciplinary and multidimensional issue, which concerns all spheres of society. There is therefore a constant need for coordination between all parties concerned in developing disability policy and programmes.

In questions 27 and 28 the aim was to find out, whether there is a national coordinating committee or similar body and to whom it is reporting. 62 countries of 84 providing information, reported that a coordinating committee or similar body has been established, while 22 countries (26%) report that they do not have a national coordinating committee or a similar body.

Regarding the authority to which the coordinating committee is reporting, 39 of 57 providing information, the coordinating committee is reporting to the Ministry of Social Affairs or other Ministry. In 12 countries the coordinating committee is reporting to the Prime Minister's Office, while in 6 countries the coordinating committee is reporting to other authorities.

In question 29 the aim was to find, what organizations and/or authorities are represented in the coordinating committee. Organizations of persons with disabilities are represented in the coordinating committees in a majority of the countries. Less common is that representatives of the private sector are included in the coordinating committees.

With questions 30 and 31 the aim was to find, whether the coordinating committee is expected by the Government to participate in policy development and to perform other tasks, for instance to be involved in evaluation, provide services etc. In 51 of 55 providing information, the coordinating committee is expected to participate in policy-development. In 42 of 53 countries providing information, the coordinating committee is expected to perform other tasks. In only 11 countries of 53 providing information, the coordinating committee is not expected to perform other tasks.

Question 32 asked for the effects of the establishment of the coordinating committee. It has had great effects in; improving coordination of measures/programmes and an improved dialogue. The establishment of a coordinating committee has not, according to the results, led to more accurate planning or more effective use of resources. 8 countries of 59 providing information on this issue reported that it is too early for assessment.

The last question asked for the effects of the Rules on the approach to disability policy. 50 countries of 59 providing information (i.e. 85%), reported that the adoption of the Rules has led to rethinking in disability policy. 9 Governments reported that the adoption of the Rules has not led to any rethinking. 23 countries did not answer the question and 3 countries reported that it is too early for an assessment of the effects of the Standard Rules.

When a Government answers that the adoption of the Rules has not led to rethinking, this does not necessarily mean that the approach to disability is in conflict with the philosophy expressed in the Rules. It can also mean that the guidelines in the Standard Rules are very similar to the guidelines in the country's disability policy.

3. Rule 6 on education

The fact that persons with disabilities live a more or less segregated life depends to a major extent on the shortcomings of social systems. One of the most important of these is the education system. There is a close relationship between the level of education and integration into society. Education lightens the burden of various forms of social disadvantage and opens the door towards better living conditions. Education of persons with disabilities is consequently one of the most essential target areas of the Standard Rules.

To understand the contents of the Rule on education it is necessary to consider it in the context of three other important documents, which preceded the Standard Rules and the one which followed after the adoption of the Rules. These other documents are: The UN Convention on the Rights of the Child (1989), The World Programme of Action Concerning Disabled Persons (1982), World Declaration on Education for All (1990), and the Salamanca Statement and Framework for Action on Special Needs Education (1994).

The Salamanca Statement, the most recent of these documents, builds upon and develops further the ideas formulated in Rule 6 and makes them more precise. The Salamanca Statement is a powerful instrument proclaiming *inclusive education* as the leading principle in special needs education. It states that: "those with special educational needs must have access to regular schools which should accommodate them within a child-centred pedagogy capable of meeting these needs". Inclusive education is regarded as the most effective means of combating discriminatory attitudes and moreover to "provide an effective education to the majority of children and improve the efficiency and ultimately the cost effectiveness of the entire education system."

Many countries are now taking steps to implement the guidelines in the Standard Rules. One major problem, is the maintenance of a segregated system of education; one "regular" education system for the non-disabled and one separate system of special education for persons with disabilities.

UNESCO has, since 1980, collected global information on practice in the field of special education. In 1993-1994 the latest UNESCO review was presented, entitled *Review of the Present Situation of Special Education*. This review covers issues on policies, legislation, administration, organization, teacher training, financing and provisions for special needs education. The material is very useful in measuring the implementation of Rule 6 on education in the Standard Rules. In our monitoring of Rule 6 on education we have studied the findings of

this Review. We have also had access to a previous UNESCO review on special education legislation (1991). In the following we have selected some results and observations based on these two Reviews, which are of importance to understand the situation in the field of education.

The 1993-1994 Review is built on information, collected through a questionnaire, which was sent to 90 governments. 63 countries responded. (In the case of Australia and Canada two separate replies were received. This explains the total of sixty-five.)

3.1. Legal regulation of the right to special education

The right to education is denied millions of children with special educational needs, who either are receiving inadequate and inappropriate public education, or are being excluded from the public school systems. Although many developing countries have recognized the right to education, it has in many cases not been applied to persons with special educational needs.

65 countries provided information on legislation. 44 countries reported that general legislation applies to the children with special educational needs. 34 countries reported that children with severe disabilities were excluded from education. In 18 of the 34 countries reporting exclusion, these children were by law excluded from the public education system. In 16 countries the exclusion was the result of other, non-legal factors. The most common reason given for excluding some children from the public education system was the severity of the disability, lack of facilities and trained staff, long distances to schools, and that regular schools did not accept pupils with special educational needs. Ten countries reported that no legislation on special education exists.

3.2. Parents' role

One question in the UNESCO questionnaire tried to find out what formal rights parents have in assessment procedures and decision-making with respect to placement of children with special educational needs. In 22 of the 53 countries providing information, the parents' role is fully recognized in decision-making concerning placement. In seven countries parents only have the right to appeal against decisions concerning their child's placement. In 24 countries, however, parents' involvement in decision-making and their right to choose placement in special education is severely limited.

3.3. Education forms and the issue of integration

From the information collected by the *Review* our tentative conclusion is that schooling for the children with special educational needs is still predominantly provided in a segregated educational system and that the rates of attendance in schools of persons with special educational needs is very low in a great number of countries. It was found, for instance, that thirty-three countries of forty-eight supplying information have fewer than one per cent of pupils enrolled in special educational programmes. Thus, in most countries integration represents an aspiration for the future. The UNESCO *Review* indicates, when compared to a *Review* made in 1986-1987 that some progress towards the goal of integration into regular education has been achieved.

3.4. Special education legislation

In 1991 UNESCO requested governments to report on the position of their law concerning special education. The request for information for this study, was sent to 70 countries, of which 52 responded.

The aim was to identify the kind of existing special education legislation and what it covers. We have here selected a few important findings from this study.

- * In sixteen out of fifty-two countries providing information, special education is financed totally by the state and/or local authorities.

- * Only in ten countries of fifty-two, disabled children in regular schools are expected to follow the regular school curriculum, using the learning methods suitable for their individual needs.

- * In the majority of the countries, the Ministry of Education is responsible for the organization of special education services

In an increasing number of countries, the Ministry of Education is responsible for the organization of the special education, while the responsibility for the implementation and evaluation is borne by Federal States or local authorities. In some countries the responsibility for the organization is shared between several Ministries. In one country, there is a division of responsibility between the Ministry of Education, for children with moderate disabilities, and the Ministry of Welfare, for those with severe disabilities.

4. Rule 7 on employment

4.1. Summary of Rule 7

One of the most important fields for action in disability policy is to create equal job opportunities. Without success in this area it will not be possible to obtain the overall goal of full participation. The essence of Rule 7 on employment is that persons with disabilities should be empowered to exercise their right to gainful employment and that it is the responsibility of States, to remove all remaining obstacles to employment. "The aim should always be for persons with disabilities to obtain employment in the open labour market. For persons with disabilities whose needs cannot be met in open employment, small units of sheltered or supported employment may be an alternative."

To further illustrate the contents of Rule 7, the following quotations should be mentioned:

"Laws and regulations in the employment field must not discriminate against persons with disabilities and must not raise obstacles to their employment"

"States should actively support the integration of persons with disabilities into open employment"

"States, worker's organizations and employers should cooperate with organizations of persons with disabilities concerning all measures to create training and employment opportunities"

The text also contains several examples of various technical measures, which could be taken by Governments, in order to obtain these objectives.

Equal opportunities and the integration of disabled people into the community is also the objective of the Convention adopted by ILO in 1983. It complies with the provisions of Rule 7 on employment in the Standard Rules. In fact, Rule 7 is created on the basis of this Convention.

4.2. ILO Convention 159

The Convention provides for vocational rehabilitation measures for all categories of disabled persons and for promotion of employment opportunities and equal treatment of disabled men and women. The Convention also requires that member countries, when formulating and implementing policies should consult organizations of disabled persons.

When the survey was made, at the beginning of 1996, 54 countries had ratified the Convention.

The regional distribution of these countries is as follows:

14 industrialized countries

5 Middle East and North African countries

11 countries in transition

13 in the Latin American and the Caribbean region

8 from Sub-Saharan Africa

3 countries in South Asia, East Asia and the Pacific

In accordance with article 22 of the ILO Constitution the ratifying Member State must supply the International Labour Office with an annual report. In this report the Member State must give information about all the measures it has taken for the purpose of giving effect to the Convention.

A Committee of Experts on the Application of Conventions and Recommendations is appointed by the Governing Body of ILO. The Committee's main task consists of examining the reports supplied by Governments. ILO, may write to Governments and request them to supply additional information.

In order to assist me in monitoring Rule 7 on employment, ILO made country reports and communication between Governments and the Committee of Experts available for our analysis. We have studied six articles of the Convention which are close to the contents of Rule 7 on employment. We will in this report only present some general observations concerning the compliance with requirements in some articles by ratifying countries.

- 11 of the 54 countries have not yet supplied any Government report

- 11 countries, mainly industrialized countries have given effect to the Convention by various measures based on legislation. In these countries the Convention is considered by the ILO to be applied in its entirety.

- In 7 countries measures concerning consultations and co-operation with representative organizations of disabled persons have not been ensured.

- In 3 countries there were no measures to enable disabled persons to gain and maintain employment

- In 10 countries measures concerning vocational rehabilitation and employment services in rural areas and remote communities have not been ensured

- In 8 countries measures to provide qualified vocational rehabilitation staff, have not been taken yet

In 16 countries the legislation is insufficient to guarantee the full application of the Convention, or the Convention is deemed to be applied to a very limited extent. In 1 country the Convention is deemed not to be applied. In 1 country the information supplied is insufficient to assess the compliance of national policy and practice with the requirements of the Convention. In 1 country the existing legislation is insufficient to serve as a framework for national policy.

To sum up, the measures which are less implemented are vocational rehabilitation in rural areas, cooperation with organizations of persons with disabilities and availability of qualified staff. This implies that a great number of disabled people do not receive appropriate training. The role of organizations of persons with disabilities to represent their groups in an advisory capacity has not yet been recognized in many countries. The lack of training of staff in vocational rehabilitation is a serious short-coming in many countries. This leads to less quality in training programmes.

The measure which is implemented in almost every country is anti-discrimination provisions in the employment field i.e. the same principles apply relating to equal treatment of disabled workers and workers generally.

V. GENERAL DISCUSSION AND CONCLUSIONS

The purpose of the UN Standard Rules is to provide guidance to Member States concerning policies and measures to achieve the goal of "full participation and equality". This goal brought a new dimension into disability policy, when it was launched 15 years ago. It drew the attention towards the surrounding society and it inevitably brought up the human rights aspect of disability policy.

The recommendations in the Standard Rules document are very progressive and in my opinion there is no country, not even among the most advanced, which has fully implemented the Rules. On the other hand there is no doubt that the Rules, in the short time since their adoption, have been widely accepted and are being used as the main policy guidelines in the disability field both by Governments and NGO's.

I have seen mainly three ways, in which the Rules have been used by Governments - as a basis for new legislation, as guidelines to national plans of action, and for evaluation of policies and programmes. One important and encouraging signal concerning the use of the Rules is the fact that so many Governments (83) and NGO's (163) replied to our second survey.

Our survey shows that a majority of Governments (85% of those providing information) indicate that the Rules have led to rethinking of policies. We must not forget that the majority of Governments in Member States, as far as we know, may not yet have started to use the

Rules. Among the International NGO's the Rules are being widely used for advocacy, for new initiatives and in training programmes. On the national level the use of the Rules varies to a great extent among organizations.

In summary this indicates that **measures to make the Rules known must continue and be strengthened both on the national and international level.**

On the international level it is obvious that those specialized agencies with involvement in the disability field are familiar with the Standard Rules. ILO, UNESCO and WHO have cooperated with me in my monitoring task. These specialized agencies, however, have their own guidelines in the disability field, which of course play a more visible role in their development work. Generally, it can be said that there are no conflicting ideas or approaches between the Standard Rules and these other documents. **The role of the UN Secretariat as focal point in support of the implementation of the Standard Rules should be further developed. The cooperation between the UN Secretariat and the specialized agencies in efforts to guide Member States in their policy development should be better coordinated. A form of inter-agency mechanism should be established, which could improve coordination and identify areas for cooperation and joint action.**

In the area of development cooperation I find the situation less satisfactory. I have not found any serious effort, neither in UNDP nor in inter-governmental institutions for development cooperation, to integrate disability measures into their mainstream activities. This is also true concerning international financial institutions like the World Bank, Regional Banks etc. Due to this lack of commitment, there is a great risk that disability measures ones again will be left out or marginalized in those development programmes, launched in response to the UN follow-up plan to the Social Summit. It would, for instance, be extremely discouraging, if programmes for poverty eradication now are being launched without measures to support persons with disabilities. **To strengthen and integrate disability measures into the mainstream of technical cooperation - including UNDP, the World Bank, and other financial institutions - is one of the most urgent measures of all in the future implementation of the Standard Rules.**

My talks with Governments and organizations and my participation in international conferences together with the extensive information received through our second survey, makes it possible for me to make a number of observations concerning how far the implementation of the Rules have advanced. According to our second survey 85 % of Governments providing information, state that they have an officially recognized policy. A majority of countries put the main emphasis on rehabilitation and prevention. This seems to indicate that in most countries, having an officially recognized policy, the Standard Rules have not yet led to broadening of their policies to also include accessibility and participation measures. **Advisory services and support to Governments in their efforts to develop disability policies, based on the Standard Rules should be strengthened. This should be done both through the specialized agencies within their mandates and the UN Secretariat.**

One striking result is the weak protection of the human rights of persons with disabilities that occurs in many countries. Our results indicate that violations of these rights on account of disability occur in a number of human rights areas. The situation seems somewhat better in

the area of civil and political rights than concerning economic, social and cultural rights. Therefore, **the activities initiated by different entities within the UN human rights sector, and the cooperation between them and the NGO's in the disability field should be continued and developed further.**

In the field of education, UNESCO has adopted the Salamanca Statement and Framework for Action, after the adoption of the Standard Rules. This document together with Rule 6 on education provides excellent guidance for educational policies in the disability field. The major thrust in UNESCO's action continues to be in the area of policy development and teacher education. One main reason for the marginalization of persons with disabilities is lack of or inappropriate education. UNESCO studies show that in many countries less than one per cent of children with special educational needs receive education. In nearly 50 % of the countries providing information, these children were excluded from education, either by law or for other reasons. Such other reasons were severity of disability, lack of facilities, long distances and refusal by the regular schools to accept children with special educational needs.

When children with special educational needs receive education, they most often get it through a separate system of special education. An integrated approach, providing adequate support and accessibility in regular schools, seems far away in many countries. **As the right to education is a fundamental human right, it is necessary for all Governments to provide appropriate education for children and adults with special educational needs. Conditions should be created for UNESCO to give more vigorous support to Governments in this area.**

The most telling confirmation of success in disability policy would be to reach employment rates, similar to those for the general population. This does not occur in any country in the world. On the contrary, also States with advanced welfare systems report employment rates for persons with disabilities far below those for the labour force generally.

Rule 7 on employment and ILO Convention 159, adopted already in 1983, give clear guidance for measures to create job opportunities. It is a disheartening fact that only 56 countries (End of 1996) so far have ratified the ILO Convention, adopted 13 years ago. Our study unfortunately also shows that many Governments, having ratified the Convention, fail to comply with important parts of the requirements. **Governments, which have not yet ratified the ILO Convention, should do so in order to strengthen their policies and get professional assistance from the ILO. Governments, which have ratified the Convention, should make further efforts to reflect the provisions of the Convention in their national law and practice.**

In 1996-1997, the ILO is dedicating its biennial general survey to disability and labour market policies. The results will be reported in 1998. This ILO survey could provide a basis for a new and more effective labour market policy in the disability field. The situation in employment indicates that the present policies throughout the world fail to create equal job opportunities. **ILO should in cooperation with Governments and inter-governmental bodies like OECD, EU etc., take the lead in assisting member States to formulate national policies and strategies which could work towards equal job opportunities.**

One important dimension of disability policy, which cuts right across all spheres of society, is accessibility. In our second survey we have studied this aspect. Most countries have adopted some standards for access to the physical environment. 23% of countries providing information, have no such standards at all. In 32% of the countries there are no kind of special transport arrangements. Only about 54% of the countries providing information, have included a disability component in the training of architects and building engineers.

In the area of access to information and communication much remains to be done. The most established form here is obviously providing Braille and talking books to visually impaired people. Sign language for the deaf is gaining ground. In 19% of countries providing information, sign language is the first language in education. In an equal number of countries sign language is the main language used in communication between deaf people.

In order to achieve the goal of full participation it is necessary for all Governments to continue the development of all kinds of accessibility measures. As some industrialized countries have considerable experience in this area, international exchange of information and concrete cooperation should be encouraged.

The Standard Rules clearly recognize the advisory role of organizations of persons with disabilities. A strong and cooperating movement of persons with disabilities is probably the best possible guarantee for progress. In our second survey we found that 78% of countries providing information, have so called umbrella organizations of persons with disabilities, through which the various disability groups cooperate. In 62 % of countries these organizations have a legal mandate to cooperate with Governments.

In 74% of countries providing information, there are national coordinating committees/councils, through which Governments, organizations of persons with disabilities and often others, cooperate. In almost all cases these coordinating bodies are expected to participate in policy making.

In many countries there is a pattern of cooperation between Governments and organizations, which is of great importance for the development in the disability field. **Governments should develop further this pattern of cooperation at all levels. They should also strengthen their support to the work of organizations of persons with disabilities.**

One obvious weakness in Government handling of disability matters is the common lack of monitoring and evaluation procedures (Rule 20). This also is the situation in many industrialized countries. **The UN should, as part of the follow-up activities to this monitoring exercise, take measures to assist Governments to build their own monitoring and evaluation mechanisms.** This could be done as a task for the national coordinating councils or through separate bodies. It is important, however, that it is done in cooperation with the organizations of persons with disabilities.

Finally, I should like to make some general observations about the Standard Rules as an instrument for development and change. There is no doubt that the UN Standard Rules have proved to be a useful tool in international efforts towards full participation and equality. It is true that the Rules are not legally binding, but the way they were elaborated in close cooperation between a great number of Governments and the major international NGO

*copy made for travel*

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Date: 27 November 1997

Dear Panel Members,

Let me first of all tell you that from now on my letters to you will be copied to the secretariats of your six organizations. It has been a busy few months since I last wrote to you. This letter will be a mixture of information about activities we have had and planning new initiatives for the future.

1) Contract for second period signed

In the middle of October I visited the UN secretariat in New York. We discussed our draft work programme and the draft budget and were able to finalize the contract for the second period. My contract runs from August 1997 to July 2000. This also means that this is the time of mandate for the panel. So far we have not heard from any of the INGO's about changes in the composition of the Panel. I know, however, that at least one organization, the newly formed World Deaf Blind Union, will approach us to discuss how they could be involved in the monitoring of the Standard Rules.

2) UN announcement of second period

The decision to continue the monitoring for another three years was taken in July this year by ECOSOC (res. 1997/19). As you know the whole monitoring activity has to be funded through extra-budgetary means. Therefore the UN must write formally to Member States and announce that this decision has been taken and that Member States are invited to support the activity financially. Unfortunately, and for reasons I do not know, this letter has not yet been circulated. This is, of course, causing problems as there are Governments who are interested and as we know of Governments which should be approached

concerning their support. It seems therefore, that the next step has to be to approach Under-Secretary Nitin Desai, who in my opinion is the one who should make the announcement, to urge him to take this initiative immediately. The letter from the UN is a prerequisite for funding and therefore we will have no money until this letter has been circulated and also approaches to Governments must have this letter as a formal basis to have any chance of success.

3) Activities September - November 1997

The last few months have been full of activities. In September I participated in a pan-Arab symposium on the Standard Rules, organized in Jordan together with ESCWA. More than a hundred representatives of Governments and NGO's from 12 Arab countries participated in the symposium. At the end a statement was adopted. (Under separate cover I send you the English translation which does not do full justice to the original text.) The conference was a great success but as usual it must be followed up. 39 national NGO's participated from the 12 countries and especially among them (most of them members of your organizations) the enthusiasm was great.

Later on I made a stop-over in Thailand where I paid a visit to the ESCAP office to discuss how the Standard Rules could be a tool of support in implementing the ESCAP agenda for action. We also prepared my participation in the high-level ESCAP meeting, which was to take place in Seoul a few days later. The organizations of disabled people of Thailand had invited to a conference on the Standard Rules, while I was there. It turned out that there was a great interest in this initiative. The conference was attended by more than 100 people, mainly from the organizations, but also from four different Ministries. At the conference a permanent secretary promised that there will be a Government seminar on disability policy based on the Standard Rules.

The '97 Seoul International Conference on Disability, organized by RI, Korean Government and ESCAP turned out to be a large and important event for the region. I delivered papers at the conference and at the special ESCAP meeting to evaluate the second decade. I made a lot of new and interesting contacts during my stay in Seoul. I also got the impression that the Korean Government may be interested in supporting our monitoring efforts.

On the 6th of October the UN Committee on the Rights of the Child had invited to an open meeting on the situation of disabled children. I was invited to speak

on the subject. I will mail you a copy of my statement. Hopefully, all the many interesting interventions will be summarized a report. The Committee will consider the various suggestions for follow up activities. In my statement I clearly expressed my wish to cooperate closely with the Committee in monitoring the situation of disabled children. I anticipate an interesting discussion on how this could be arranged. Just recently I have been informed that the Committee on the Rights of the Child at its next meeting will consider a proposal to set up a special working group for following up all the suggestions put forward at the conference.

Recently the IPWH - "the International organization for the provision of work for people with disabilities and who are occupationally handicapped" - which is an association of employers in various forms of sheltered and supported employment, held a conference in Kyoto, Japan. I was invited to speak on the Standard Rules and especially on Rule 7 on employment. 34 countries were represented and the discussions which followed my statement and other contributions were interesting. I told them that the world needs their experience and that they should play a more active role in the debate on employment of persons with disabilities.

Last week I participated in a national conference in Dublin, Ireland. The main reason for holding the conference was that one year had passed since the presentation of a very important report from the Commission on the Status of Disabled Persons. It was encouraging to learn that this report was to a large extent built on the UN Standard Rules. This Commission report has created a lot of activity in Ireland. Several new laws are on the way based on a clear human rights perspective. If Ireland adopts these new laws this country will be in the forefront when it comes to this kind of legislation. At a meeting with the responsible Minister I got the impression that Ireland could be prepared to support our monitoring.

4) Further activities during 1997

Before the end of this year I will participate at another three activities. On 4 December, the ILO Committee of Experts will meet to analyze the outcome of the general survey on labour market policies and disability. I will participate as an observer and I am just now preparing for that. During the period 8-11 December I will visit Iceland on the invitation by the Icelandic Government. The purpose is to analyze the Icelandic disability policy and to give lectures on

the Standard Rules. Finally, I have been invited by the national council on disability in Finland to take part in a discussion on the Finnish situation.

If you study all these activities during the latest months you see that there are very few activities directly concerning developing countries. A serious problem is that I get very few invitations from that part of the world. On the other hand I want to add that practically all activities of which I have given an account here, have been funded from other sources than the UN budget.

4) Human Rights Commission

As you know I have been invited to speak at the meeting of the UN Commission on Human Rights next year. The meeting will take place 23 March - 18 April 1998. So far I have not had any definite information about the time of my appearance at the Commission. One representative of the Human Rights Center made the guess that it would be during the 3rd or 4th week of the meeting. As soon as I know more about this important meeting I will inform you. It would be very good if your organizations used their NGO status to participate in this meeting in order to emphasize the great importance that we all attach to this event. Also for this reason it is highly desirable to know more definitely about times.

I have started a dialogue with the Irish delegation which will be chairing next years meeting and with the Danish delegation, where Holger Kallehauge is active. We will discuss about the possibility to have a resolution passed on human rights and disability and about the contents of such a resolution. Of course I will involve you in this discussion when I get more information from the parties concerned.

5) NGO reports on survey

As you remember we have drafts of five different reports (based on the five INGO's). Due mainly to lack of funds we have not been able to process this material further, but now things are moving. We will have finalized drafts in January 1998, and the question is how to handle the printing. My original plan has been to hand the originals over to the respective INGO's and to ask them to use the material in the way they find suitable. On the other hand there is a general interest in reading these reports and therefore I am now looking for a solution where the reports could be printed in a small number which could be distributed to the UN family, all interested INGO's etc. After that each report

could be handed over to each organization for further printing and distribution. I welcome all views on this matter from you.

6) World Disability Report

As you may know already, the International Disability Foundation has plans for the issuing of a "World Disability Report", which would be distributed in July/August next year. The whole project seems well organized and the funding of it is already there. In my contacts with IDF and the project manager, George Reid, I have emphasized that the six organizations of our panel should be directly involved in this project. Concretely I have suggested that there should be a group of editorial advisors, which I think the IDF have received favourably. The report will profile the work to implement the Standard Rules and will bring up many interesting issues in connection with modern disability policy. Provided that we can create an active relation between the organizations and this project, I now think that the world disability report is a worthwhile and promising project. As the basic subject is Standard Rules I hope you will keep informed about your organizations involvement and contributions. If you want the already existing documents please contact the IDF.

7) Cooperation with Disability Awareness in Action, DAA

As you know DAA is issuing a magazine with a lot of short and interesting stuff on the disability field. I and Victor have met Rachel Hurst and discussed the idea of using DAA as a vehicle to inform more directly about our efforts to make States implement the Standard Rules in various ways. Rachel is interested but also says that if we want a guaranteed space in every issue we have to find a financial arrangement for it. We have only had preliminary discussions on this, but I have the impression that we are not talking about big sums of money. On my behalf Victor will continue the discussion with Rachel during December.

8) Next Panel meeting

As we have discussed, it would be highly desirable that the Panel could meet in connection with the meeting of the Human Rights Commission and its discussion on human rights and disability. However, there are two reasons for not choosing this option. One is that it has up to now been impossible to get definite information about when the disability item will be treated by the Commission. The other is that in March/April 1998 we may not yet have received money enough for a Panel meeting. This, as you understand, is due to the fact that we have not yet been able to start this fund-raising activity. My proposal therefore is that we do what we can to make your organizations send

observers to the Human Rights Commission and that we choose another time for the Panel.

There are certain things we should discuss and decide on as early as possible. Let me only remind you that we have not yet decided definitely in what areas we will make global surveys during this second period. Such a decision must be taken as soon as possible during 1998. I would from this perspective like to have a Panel meeting in May or June. From my point of view, the following three weeks would be possible: 11-14 May, 25-28 May and 8-11 June 1998. Concerning venue I would choose either New York or Geneva but I am open to other suggestions. One possibility we have discussed is to meet in Bangkok at ESCAP headquarters in order to get more information about activities there. Please give me your advice concerning next panel meeting before 15 January 1998.

Well, friends, this is all for now. I am very much looking forward to hearing from you on the various matters above. Eva and I would also like to use this opportunity to convey Seasonal Greetings to all of you and to wish you a happy and prosperous 1998!

Yours sincerely,

B. L.
Bengt Lindqvist

By mail:

- Statement from pan-Arab seminar
- Speech on children
- Speech on labour market policy
- Speech on human rights issues



Rehabilitation International

a worldwide network of people with disabilities, service providers and government agencies working to improve the quality of life of people with disabilities

Activity on UN Standard Rules for Equalisation of Opportunities for People with Disabilities

Introduction

Rehabilitation International's (RI) internal and external work in the implementation of the **Rules** began early in 1994, first at the international and then the national levels. Preceding all activity was the ratification of RI's first strategic plan in October, 1993, (**RI 2000 The Way Forward**). Goal 7 "Equalization of Opportunities" has as its objective (p. 16) "Promote the UN **Standard Rules on Equalization of Opportunity for People with Disabilities**."

The RI Executive identified Goal 7 (above) as a high priority objective. RI's new Secretary General's first significant international meeting was participation in the UN's first Preparatory Committee to the World Summit for Social Development (WSSD), convened on January 31, 1994. This was a meeting of all UN Member States to create strong policy statements able to lead to viable action by Member States after the March, 1995, WSSD. The WSSD's three goals: (1) lessening of poverty; (2) reduction in unemployment; and (3) inclusion of marginalized populations into the economic mainstream, all highly relevant to global disability policy and programme implementation, generated interest from RI Members who were able to call their governments' attention to the need for implementation of the **Rules**.

Accordingly, from January, 1994, onwards, RI used UN events - (1) the WSSD (March '95) and (2) the Commission on Social Development (April '95) and our own scheduled Regional Conferences (Budapest, September '94, Jakarta, September '95) and the quadrennial World Congress (Auckland '96) as opportunities to promote the **implementation of the Standard Rules**.

RI has one representative on the Panel of Experts advising the Special Rapporteur on Disability of the UN's Commission for Social Development - RI President (1992-1996) John Stott of New Zealand.

United Nations Collateral Events

As mentioned above, the UN's WSSD preparatory meetings provided the chance to reference the **Rules** in the draft texts being created by UN Member States. We also developed draft language for insertion into the working documents. This was accomplished in two ways: (1) suggested language was faxed to the about 20 RI Members willing and able to work with their governments to develop policy positions; and (2) submission for the formal UN record **RI Statements** made on behalf of the organization and its president. Statements were made as an officially registered WSSD NGO in 1994 (February, October, and August) and in 1995 (January and March). RI voluntarily took on the task during the period of the WSSD policy preparation the dissemination to her sister NGOs of key policy language. In January, 1995, we convened representatives of five of the six NGOs on the Panel of Experts for the purpose of uniting and speaking with a single voice at the final PREPCOM prior to the March Summit. Together we ensured that the references to the **Rules** held, as did several dozen references to disability which now appear in the duly ratified **Copenhagen Declaration**.

RI Member Countries involved in the UN WSSD and the UN Commission on Social Development include: Australia, Austria, Brazil, China, Denmark, Egypt, Finland, France, Germany, Japan, Iceland, Norway, Saudi Arabia, Sweden, and the USA. The organizational base built during the 1994-1995 period is still in use as the Special Rapporteur ends the first three year phase of work and is now being utilised in the "Call to Action" mentioned below.

Country Level, 1994, 1995, and 1996

With the September, 1994, Budapest Regional European meeting, RI began vigorous circulation of the **Rules** document. The Special Rapporteur delivered a plenary address at the Budapest Conference to over 600 people, the majority from Europe, including a significant representation in attendance from the Newly Independent States of Eastern Europe.

In September, 1995 (Jakarta) RI Members were requested to lobby their respective governments with regard to the implementation of the **Standard Rules**, also to facilitate their countries' contribution of funds towards the work of the Special Rapporteur and the Panel of Experts. Building upon the collaborative UN WSSD work with the USA, RI was able to facilitate that country's financial contribution. At both the Jakarta and Auckland Assemblies, RI Members reported their country-level **Standard Rules'** promotional activities. Members had also been asked to coordinate their country activities with the other NGO members of the Panel of Experts.

In September, 1995, the countries reported out as follows: (1) Netherlands: lobbying Government; (2) Australia: development of disability strategy based on **Standard Rules** and standard for compliance; (3) Sweden: information and education budget set aside; (4) Germany: German version of the **Rules** made widely available; (5) Norway: tasking their Government to give implementation of the **Rules** to Council for Disabled; (6) New Zealand: introduction of strategic plan for Government agencies based on **Standard Rules**; (7) Indonesia: comprehensive legislation introduced; (8) Japan: promotion of rights through Asia Pacific Decade of Disabled Persons; (9) India: disability rights legislation to be adopted by December, 1995.

The Auckland RI 18th World Congress provided the Special Rapporteur the chance to present a Keynote Address on his vision of the future for disabled people to achieve quality to participants from 75 countries. He also delivered the critical "**Summary Comments**" to the Congress' "Vision Track" on the final day. Several of the Members on the Panel of Experts addressed a special workshop of the **Standard Rules**. Congress organizers raised funds assisting the Special Rapporteur and some of the Panel Members to travel to New Zealand.

Summary

In October and November, 1996, RI's leadership issued a "Call to Action" to its global membership, asking that each member contact its government, calling for support for the work of the Special Rapporteur to continue.

In response to the "Call," the USA on October 18th in a UN General Assembly meeting, indicated its support for continuation of the important work of the Special Rapporteur and the Panel of Experts. RI is convinced that the effects of the Special Rapporteur's and the Panel of Experts' work are just beginning to be felt at the country level. Accordingly, the first three year term should be extended for at least another three year term beyond 1997.

John W. Stott
Immediate Past President
Rehabilitation International
Member, Panel of Experts



**Special Rapporteur of the Commission for Social Development on
Disability**

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UN Commission on Human Rights, 54th session
agenda item 15

Statement by Mr. Bengt Lindqvist, Special Rapporteur of the UN Commission for
Social Development

Mr. Chairman,
Distinguished Delegates,

It is a great honour for me as UN Special Rapporteur, monitoring the Standard Rules, to have the opportunity to speak before this Commission. May I begin with a quotation, which is a contribution by the disability community to the ongoing debate concerning the concept of equality.

"The principle of equal rights for the disabled and non-disabled implies that the needs of each and every individual are of equal importance, that these needs must be made the basis for the planning of societies, and that resources must be employed in such a way as to ensure, for every individual, equal opportunities for participation."

You find this statement both in the World Programme of Action (adopted in 1982) and in the Standard Rules (adopted in 1993). When we relate this statement to the situation of disabled people around the world, it becomes extremely relevant. The needs of disabled people are not taken into account in the "planning of societies" and the resources are not employed to ensure "equal opportunities for participation".

Mr. Chairman,

If I, after thirty years of work in the international disability field, were to choose one word to describe the situation of disabled people, I would without any hesitation say "exclusion". By international standards of classification there are at least 500 million disabled people in the world. Due to several factors, the number is expected to rise. Millions and millions of disabled people in developing countries lack access to education, have poor health conditions, are poverty stricken and socially isolated. It is a well-known fact that there is a close link between disability and poverty. Disability leads to poverty; poverty leads to disability.

What is being done is often achieved by voluntary organizations, while Governments in many cases fail to assume their responsibilities. Concerning countries in transition the situation is similar. One great problem in many of these countries is that it has been an accepted public policy throughout the years to put disabled people - children and adults - in institutions, where they spend their whole lives. Of course, there is a link between the general economic situation of the country and the living conditions of disabled people. Exclusion also seriously limits progress and development.

Even though the situation of persons with disabilities in industrialized countries is much better, the goal of full participation will not be possible to attain without a considerable improvement of the situation. It is clear that economic progress alone is not a guarantee for the equalization of opportunities. Especially, I would like to point to the area of employment, where the employment rates for the different groups of disabled people are dramatically lower than for those of the general population. In most industrialized countries, access to programmes, services and activities, generally available to non-disabled people, is still limited.

Mr. Chairman,

The Standard Rules on the Equalization of Opportunities for Persons with Disabilities were adopted by the UN General Assembly in 1993. They were elaborated on the basis of the World Programme of Action and the experiences gained during the UN Decade of disabled persons (1983-1992). The purpose of the Rules is to provide guidance for Member States in their efforts to work towards full participation and equal opportunities for persons with disabilities. To illustrate the core message of the Standard Rules, let me quote the following two sentences from the Introduction:

"In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms and making it difficult for them to participate fully in the activities of their societies. It is the responsibility of States to take appropriate action to remove such obstacles."

As is made clear in this statement, the Standard Rules apply a human rights perspective as a basis for its recommendations. In addition, the Standard Rules document could be described both as a code of conduct for Governments and as an implementation tool.

The Standard Rules document contains a rather detailed description of the monitoring mechanism. The purpose of the monitoring is to "further the effective implementation of the Standard Rules". There are three actors within the monitoring mechanism. The results of the monitoring shall be reported to the UN Commission for Social Development. A Special Rapporteur has the responsibility for the actual monitoring. A panel of experts serves in a consultative capacity. This panel has been formed by six

international organizations, representing the interests of disabled people, having a powerful network of national affiliates in more than 160 States.

I have reported twice to the Commission for Social Development. Both my reports have been circulated as documents before the General Assembly (A/50/374 and A/52/56). Our collection of information has been done by extensive traveling and through two global surveys which have been reported. In a highly condensed form I should here like to summarize our findings.

The adoption of the Standard Rules and the activities within the monitoring mechanism have created a momentum, which is very important to keep alive. In our second survey 85% of the responding Governments stated that the Rules have led to rethinking or strengthening of their disability policies. A considerable number of Governments have adopted new legislation, made plans of action or otherwise initiated a further development of their policies, based on the Standard Rules. There are good examples of such initiatives in all regions of the world. The Economic and Social Council of the Asian and Pacific Region (ESCAP) has formed an "Agenda for Action" for a second decade (1993-2002), which in spirit comes very close to the Standard Rules. All the UN agencies with key-roles for disability policy have taken new and interesting initiatives during the 1990's. There is an obvious need for more effective co-ordination and co-operation between these agencies and the UN secretariat. I have suggested that the previously used inter-agency mechanism should be re-established to meet this need.

To approach the goal of full participation, nations must learn how to integrate disability measures into all kinds of development and to do this at an early stage. One obvious area, where we up to now have failed to do this, concerns development co-operation. Unfortunately, we in this way waste a lot of opportunities to include the needs of disabled people in programmes and services, which would have a decisive effect on the living conditions of disabled people. This neglect or omission is not in harmony with the Standard Rules and in serious cases must be considered as discrimination. We should give top priority in future to finding effective ways to eliminate this discriminatory behaviour.

Several studies show that education is an area where the exclusion of disabled girls and boys in general school programmes is a very serious problem. Still a lot of large development programmes in the education field, launched by both national and international funding agencies, are run without paying any attention to the needs of disabled children. Like many others we found that employment is another problematic area. Without considerable improvement in the field of employment and other forms of income-earning activities it is impossible to approach the goal of full participation.

The description above may seem negative and pessimistic. The rule of exclusion prevails. There is little compliance with the Universal Declaration of Human Rights. We have, however, noticed growing awareness among Governments and there are good initiatives which will be of importance for the future. As is emphasized in the Standard Rules, a pre-requisite for development is that disabled people themselves and their organizations have an opportunity to influence the development on the basis of their experience. Governments should develop their co-operation with organizations of disabled people and other organizations in the disability field. One encouraging result of our surveys is that we found a "pattern of co-operation" between Governments and organizations, which is spreading and gaining importance. We found that 74% of the responding Governments have national councils on disability and that in 62% of countries, organizations of disabled people have a legal mandate to influence public disability policy.

Mr. Chairman,

As you know, my mandate as Special Rapporteur concerns the promotion and monitoring of policy development in the disability field. My observations are, of course, also relevant for the discussion of the human rights of disabled people. As I said initially, a state of "exclusion" prevails in the disability field. This is the result either of lack of access to important parts of the community or through sending disabled people away to live in institutions.

In the institutional environment it is, of course, impossible to create opportunities for social integration. We also know that many forms of degrading treatment, sexual abuse and various forms of violence occur in such secluded places.

The exclusion of disabled people in the open society has its roots in lack of knowledge and attitudinal barriers. It mainly leads to neglect of the needs of disabled people when designing and constructing environment, services and programmes, available to non-disabled people.

In our second survey we included a number of questions concerning legal provisions for participation and access. We also asked about various forms of enforcement mechanisms. Generally, we found that the protection of the rights and freedoms of disabled people is weak in many countries and in many areas. To our surprise we found that there were a number of legal provisions, Government regulations and practical routines, explicitly excluding various groups of disabled people from such fundamental rights as access to court-of-law, political rights, property rights and the right to parenthood and marriage. During the 1990's the international NGO's in the disability field have started to involve more directly in the human rights area. They have established committees on human rights and started to collect information on

problems and alleged violations. Their available information to a high degree confirms the findings of our survey.

Mr. Chairman,

During the drafting of the World Programme of Action the issue of human rights for disabled people was discussed. A section on human rights was included in the World Programme. On the basis of this analysis, Mr. Leandro Despouy was appointed Special Rapporteur to make a study on human rights and disabled people. His report (Human Rights and Disabled Persons, Study Series No. 6), published at the beginning of the 1990's, has stimulated a series of other activities within the human rights area, which are very encouraging. In particular, I should like to mention the General Comment No. 5 from 1994 by the Committee on Economic, Social and Cultural Rights; the increased attention to the situation of disabled children, given by the Committee on the Rights of the Child; the recently commenced work concerning disabled women by the Commission on the Status of Women, and the resolution 1996/27, adopted by this Commission. Together these initiatives signify important progress.

In addition to the above mentioned formal initiatives, a number of well-known specialists in the human rights area have written papers on various aspects of human rights and disability. I have studied these documents and I notice that human rights specialists have developed a deeper understanding of the problems involved and about how they relate to the protection and monitoring of the human rights.

During the 1990's some countries have adopted anti-discrimination legislation in the disability field. The concept of "reasonable accommodation" is obviously becoming the tool through which the different obstacles to participation for disabled people can be handled. After the presentation of the above mentioned General Comment No 5, I am convinced that more countries will consider taking new legislative initiatives. In my opinion - and I have not consulted with my panel in this - we should accept the concept of "reasonable accommodation" for the time being. It seems to be a politically and economically manageable approach. Let us see how far we can come on the basis of this method. Principally, however, it is important to emphasize that the human rights of disabled people must not be compromised.

Mr. Chairman,

Our monitoring of the Standard Rules indicates that the two areas of social development and human rights are communicating vessels. The more successful we are in removing structural barriers in social development, the more opportunities for persons with disabilities to enjoy their rights and freedoms. A stronger protection of the rights of disabled persons will also increase the pressure for social change. Let us

pursue this dual approach as the best way to meet the challenges of the next century. This means that we have to work both through social development channels and through the human rights entities of the United Nations. As the second period of the special monitoring mechanism in connection with the Standard Rules ends during the year 2000, the Commission for Social Development will have to find new forms for the promotion both of the Standard Rules and of other international guidelines.

Mr. Chairman,

Permit me also to comment on the future methods for the protection and monitoring of the human rights of disabled people. As you might know, it was suggested, ten years ago, that a convention on the rights of disabled people should be elaborated. This proposal was turned down by the UN General Assembly. However, this matter might be brought up again. My present position in this is that the further discussion on a special convention should be postponed for the next few years. Let us see how far we can get through already existing channels. What results will the further implementation of the Standard Rules bring? What can we achieve through a strengthened and more elaborate monitoring of the rights of disabled persons via the already existing instruments? My forecast, however, is that the request for a special convention will be brought back to the UN with much more force than ten years ago, if we do not obtain tangible results within the next few years.

To conclude I should like to make a few recommendations, the purpose of which would be to develop awareness, to increase efficiency and to create a closer co-operation between the UN human rights entities, the Standard Rules monitoring mechanism and the NGO's in the disability field.

1. A more distinct disability component should be elaborated to be included in all monitoring activities of the UN human rights entities.
2. Some of the international organizations of disabled people have for some years collected information on human rights issues. In my second survey I also got some information about discriminatory legislation and practice. I suggest that these various pieces of information should be compiled in a report, which I am sure would increase awareness and knowledge.
3. International disability NGO's, to whom the human rights field is new, should be invited to participate in the assistance and training, offered by the Office of the High Commissioner for Human Rights.
4. More efficient forms for communication and co-operation between the international NGO's in the disability field and the human rights entities should be developed.

5. Subject to finding a hosting country and funding, an international conference on human rights and disability should be organized. The purpose should be to stimulate the further development of ideas and methods and promote the exchange of information between human rights experts and representatives of the organizations in the disability field.

Thank you, Mr. Chairman.



Rehabilitation International

a worldwide network of people with disabilities, service providers and government agencies working to improve the quality of life of people with disabilities

Date: June 12, 1998

To: Members, RI Executive Committee

From: Susan Parker, Secretary General

Subject: Proceedings of the Rio de Janeiro Meeting, April 16 and 17, 1998

Dear Colleagues,

Enclosed are the Proceedings from our April meeting. This is the first time we have compiled Proceedings from an Executive Committee meeting; usually the format is to summarize decisions made. Due to the importance of the issues, we have decided to take the step of presenting the tone and content of the meeting to the maximum extent possible. Summaries of Decisions will also be done and distributed, as is the custom, to the Assembly Members.

Enclosures

Accompanying the Proceedings are the written reports of the four (4) Vice Presidents, the RI 1998 Personnel Policies as revised, the Proposal from JSRD through Mr. Matsui, an offer made during the April meeting, to establish an RI Home Page within established websites.

Latest RI/UNICEF Publications

You are also being sent one of the publications from the RI/UNICEF Collaboration, now in its 18th year. Volume 17 (English, French, and Spanish) of **One in Ten** and the **Video Catalogue** Are the last two products from the contract just ending (October '96 through May '98). We have agreed to compile, publish, and distribute Volumes 18 and 19 between July 1 and December 31, 1998, also in English, French, and Spanish. We are concerned about the distribution of these products - please suggest how to better place these field-relevant tools in the hands of those of could make the best use of them.

RI Un Activity: Human Rights and ILO

You heard in Rio about RI UN activity, including that done in collaboration with the UN Special Rapporteur on Disability. The Special Rapporteur's presentation is enclosed, along with the historic Resolution on Disability presented to the Member States of the Human Rights Commission. Ireland and Denmark co-chaired these meetings; as such, Ireland was responsible for the initial drafting of the above mentioned Resolution which drew 42 countries as co-sponsors.

RI collaborated with a sister international NGO, Inclusion International, to submit and deliver a strong Joint Statement on 5 June in Geneva. We are calling on the ILO's decision-makers to include disability in the all important Core Labor Standard named "Convention 111," linking the Convention to another Convention named '159" which suggests to member states that countries establish vocational rehabilitation and training. The Joint Statement is enclosed.

RI Members on E-mail

Please note that six (6) of you are on E-mail; accordingly, you have been placed on the RI address book, along with other members of the RI family. You have also received the above mentioned Joint Statement over the E-mail. Please advise if that transmittal did not arrive to you.

I look forward to working with you in Jerusalem. With best regards to all,

Susan

A handwritten signature in cursive script, appearing to read "Susan", written over the printed name "Susan".



**Special Rapporteur of the Commission for Social Development on
Disability**

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**For information: Headquarters of DPI, RI, Inclusion
International, WFD, WBU, WFPU, UN/Mr. Krassowski**

Stockholm, 25 May 1998

Dear Panel Members,

This letter from me will include both information about some new developments and items where I would like to have your input. I apologize for writing a long letter this time, but this has to do with the fact that we meet rather seldom at present.

1) *New Panel Member for RI*

A short time ago I received information from RI headquarters that the new member of the Panel for RI will be Mr. Lex Frieden, whom I am sure many of you already know. For your information we attach the updated list of Panel Members with relevant addresses. **May we use this opportunity to ask you to check your own address on the list and to add your e-mail address when appropriate.**

2) *Next panel meeting*

As you remember I informed you in my previous letter that the funding situation does not permit a meeting in June. I therefore suggested two alternative in October and November this year. It turns out that there is more support for 20-22 October and I therefore suggest that we fix this date as the date of the next panel meeting. Still one reservation has to be that we must solve the funding problem.

In my previous letter I also asked you to hold the days in June for a possible tele-conference. Those who have reacted to this suggestion have been rather negative to this form of communication within the panel. I therefore suggest that we skip the tele-conference and that we instead, on the basis of this letter, start to communicate on a number of subjects. One purpose of this communication would be to prepare for the panel meeting in October.

Among items that should be on the agenda in October, I can already identify the following:

- follow-up of human rights resolution by the UN Commission on Human Rights
- WHO involvement in the monitoring of the Standard Rules
- World Bank development concerning disability policy
- follow-up of ILO deliberations on the report of labour market policies in the disability field
- IDF Standard Rules project
- IDF World Disability Report

Concerning external participation there are indications that both the WHO and the World Bank would like to participate in items concerning them. Also IDF representatives have indicated a similar interest.

Please, consider carefully the items above. If you have comments and especially if you have additions, please, let me know. Even if many of the items have the character of reports, I am sure that we already have a full agenda. We will also have to consider if three days (20-21-22) is enough.

3) *Panel presentation*

It seems that the emphasis in my activities is moving from visits to countries and over to collaborating with the UN agencies. Both with regard to the World Bank, WHO and ILO, I think that the Panel of Experts could play a significant role in the future. It is true that the Panel was set up to be a consultative body within the monitoring of the Standard Rules. However, the mere fact that there is an expert group composed of these six international organizations is of great interest. The Panel could serve as an advisory body in relation to UN agencies on a more general basis.

I therefore think that there is a need to present the Panel of Experts in writing. It could be a very simple paper with the basic facts about the participating organizations and personal data on the participating experts. If such paper is to

be prepared I need your cooperation. **First of all I would like to have your reactions concerning the idea as such.** When you consider this I ask you to bring the reports below concerning UN agencies into account.

4) *Disability Awareness in Action - DAA*

As I am sure you know, DAA has a newsletter including a lot of valuable information and with a fairly wide distribution. Together with Victor Wahlström I have discussed with Rachel Hurst to find a form for more regular reporting through DAA on the progress in our monitoring. This has now started, which I hope you have noticed in the latest editions. I am sure that DAA would welcome input from you concerning both developments in your regions and in your organizations. If you consider this possibility you may either distribute your information through our office or directly to DAA in London (fax: +44 171 821 9539).

5) *IDF matters*

a) World Disability Report

Two weeks ago George Reid sent me the first draft of a lead article which is to be signed by me. We have, in other words, now started the process of dealing with texts for the World Disability Report. George told me that the volume of work has turned out to be much bigger than he originally thought. This is the main cause of delay. According to the present time schedule, the Report will appear in connection with the International Disability Day in December. This, of course, gives us much more time to complete a good job in this important project. As the Panel should be involved in the consultation process, I hope that you by now have heard from Mr. Reid and that you are in communication with him.

b) Report on IDF Standard Rules project

A few weeks ago I received a report from IDF to Danida, which is a presentation of the IDF activities during the first project year. I just want to inform you that this report exists and I hope that you also have received it. If not, I think it would be good if you ask for a copy from IDF in Geneva. The report gives a good summary of the activities during the first year and includes some useful information on which we can build.

6. Travel plan

I include a separate paper with a list of the travel activities which I will do from now until the end of this year. Some of the indicated events are

preliminary, and in some cases there are additional ones which I have not mentioned at all, as I consider them rather uncertain. As you can see from the list, there is a clear dominance for visits to Eastern European countries. Unfortunately, I must repeat the fact that I get very few invitations from developing countries. **Please, help me to change this.**

7) *Development within WHO*

As you remember, Dr. Pupulin of WHO, at our panel meeting last year informed us that he would apply for fund for a number of projects in the disability field. He has been quite successful in this and therefore a number of projects are now being started from his rehabilitation unit. Two of these projects concern us directly. I would therefore like to give you the following information, which is based on a visit I made to Geneva about a week ago.

a) Assistance in monitoring the Standard Rules

WHO has now received resources in order to assist us in monitoring the progress in the areas of Rules 2, 3, 4, and partially 19. This is exactly what we wanted to happen, when we discussed WHO involvement in Geneva.

Dr. Pupulin has employed Ms. Eva Sandborg, who will have this project as one of her main tasks. Eva is Swedish. Professionally she is a social counselor and administrator. She was for six years president of the Swedish National Association of Psoriasis. For some years she was an administrator at the Ministry for Social Affairs and she has now, for nearly four years, been the international relations officer at the Swedish handicap ombudsman. For those of you who participated in the drafting of the Standard Rules, she may be known as one of the participating delegates of the Swedish government.

Together with me, Eva will now prepare to make a survey on the situation in the above mentioned rule areas. The survey will concern both governments and NGOs. In this project she will work closely with me and with you in the panel. The WHO survey will be a major item on the agenda of our next panel meeting. Eva has just started to prepare for a questionnaire and she may contact you even before our meeting in October. If you on your side have ideas or comments you would like to pass on to her, you may, of course, contact her directly. In that case I would appreciate a copy of your letter. Her address is as follows: WHO, rehab.unit. CH-1211, Geneva 27, Switzerland.

b) Re-visiting CBR

I suppose you remember that we also discussed CBR at our meeting last year. As a result of our discussion it was concluded that a new evaluation of CBR

should be made from a user perspective. WHO has now received money to enter into such a project. The focus of this project will be to study the impact of CBR on the living conditions of disabled people. Also this project will be conducted in close cooperation with organizations of disabled people and other NGOs involved in CBR.

At our discussions a few days ago, Dr. Pupulin, Eva Sandborg and I agreed that priority should be given to the Standard Rules project during 1998. To be able to summarize the results in time for my final report to the UN, it is necessary to distribute the questionnaire during 1998. The CBR project will be prepared during 1998, but mainly carried out in the next year. A number of other projects are also being started now by Dr. Pupulin. I will ask him to prepare information about these for the panel meeting in October.

8) *Human Rights and disabled persons*

As I have stated before, I think that the discussion within the Commission on Human Rights in March/April this year, will prove to be an event of historical importance. I attach the final result of the deliberations, which is a rich and powerful resolution on the issue. I hope that you will all carefully study the contents and reflect on the possibilities that this resolution creates. One important issue for your organizations to decide will be; **should the six panel organizations work together to follow up this resolution?** My opinion is that such a cooperation would be most useful. If the organizations decide to work together, of course, the panel is a natural tool for this cooperation.

I suggest that you discuss this matter of responsibility for the follow up of the human rights resolution within your organizations. But, at the same time it would be bad to lose time. I therefore suggest that we within our group start thinking about what could be done. What activities should be created? One suggestion which was made among your representatives in Geneva, was that the organizations should develop common understanding both of the basic issue of human rights and disability, and of the implications of this resolution. It was suggested that one special seminar could be arranged to work towards such common understanding. In my speech I suggested a number of things, among which were training activities for officials within the international organizations of disabled people. My idea is that all members of your boards should have basic knowledge about how the UN system works with human rights, and what are our opportunities for influencing this system.

Of course all international activities must be based on what happens in the countries. I therefore also think that the national affiliates should take up the issue of human rights and plan for more systematic work in this field. Again this means building up competence, where this is needed. It also means a need to approach organizations working in the human rights area to seek cooperation and common action. Internationally there is certainly also a need for closer relations between your internationals and the main organizations working in the human rights area. There are many actors, but there is also a network and a kind of loosely composed forum to prepare major meetings within the United Nations system. All these things are matters that should be studied further. As we go along I will try to obtain more information which I will share with you. I would suggest that important things you find out, are also circulated within the panel. I hope you will find a way to bring this matter at your next executive meeting.

Again, let me repeat that there is a need for us to communicate on this matter, as it does not follow automatically that work in the human rights area is a natural duty for me as Special Rapporteur serving another Commission and for you as the panel of experts in the same area. As you can see in the resolution, the Human Rights Commission has decided to cooperate with me and with its sister Commission in the area of human rights of disabled people, and I think this is a wise decision for the moment.

9) *Future promotion of disability matters within the UN system*

Finally, in this long panel letter, I should like to bring up the question concerning what should happen when our mandate terminates in the year 2000. In my opinion there is a need both for the UN and for the responsible international organizations in the disability field to start this discussion now. As we, I as Rapporteur and you as panel members, have major role in the present system, I think we have the duty to start this discussion. I therefore make an attempt now and hope that you will respond and develop your views. Later on, when we have penetrated the matter a little further, we should approach our respective organizations for further deliberations. To start us off, here are some initial reflections:

- After six years of monitoring we will be able to look back on a period which has offered more progress than previous periods. A considerable number of countries will have reviewed their legislation towards a greater harmony with international guidelines as in the Standard Rules. The position of organizations of disabled people will have grown stronger in a number of

countries through their participation in national councils on disability and through a clearer mandate to represent their groups. We will see some indications of progress in our endeavour to include disability needs in development cooperation. The World Bank will in all probability play an important role in this development. UN Human Rights entities will start to develop a monitoring of the situation of disabled people and disability will have become a more established item on the agenda for them. Hopefully, this will also mean that questions and indicators will be included in requests for information from countries. These are examples of progress.

However, as we all know most things will remain to be done. There will be a clearly noticeable gap in countries between adopted new laws and the implementation of them in reality. There will also be a great need to transfer new policies into concrete programmes which can really change the conditions of life of disabled people. Our analyses of human rights will reveal conditions which cannot be accepted and which have to be dealt with.

In one way, the situation on the international level will change. It will be necessary to work both in the social development area and in the human rights area within the UN system. Another conclusion is that it will be necessary to continue the cooperation between international NGOs. Perhaps you will have to consider including a number of other organizations in your cooperation, but if this is done in a sensible way, it could only strengthen the cooperation.

Finally, I would like to reflect a little on the crucial issue on how to make sure that disability stays on the agenda in the world community. By what method or methods could we ensure that this will happen? To start our discussion I would here just like to mention some actions that may be of interest in this context.

- a) A separate monitoring mechanism continues in a way similar to what we have today
- b) The disability programme within the UN secretariat takes the full responsibility for the future monitoring of the Rules and for the promotion and coordination of development. This could perhaps be combined with an NGO participation in the same way as now.
- c) A function as international disability ombudsman is established. Such an ombudsman would be within the human rights sphere, but could also have a monitoring role within social development.
- d) A convention on the rights of disabled people is elaborated. It will have a monitoring mechanism attached to it in the same way as other conventions have it now. There are pros and cons with this solution. What would be the

actual contents of an agreed convention? Another issue concerns the time during which a convention is elaborated. It took ten years with the Convention on the Rights of the Child. What happens in the meantime?

- e) An interagency mechanism on disability is created within the UN system. This could, of course, include an NGO participation. It could have a secretariat of its own and it could be developed into an equivalent on the international level of national disability councils.

Well, dear panel members, these were some concrete ideas on how to proceed after the year 2000. I would welcome your comments and suggestions in this area and I could make sure that your contributions will be circulated to all panel members. I think it is important to start this discussion now, so that we can have a really constructive session on this topic when we meet in October.

10) *Economic situation*

I will end this long panel letter with information on our economic situation. As far as I know, no new contributions have arrived after Mr. Desai's letter to government. It is still early, but I must say that the situation frightens me a bit. According to my calculation we have less than USD 30 000 now, which is all for the whole three-year period. With my travel arrangements this sum will diminish quickly, even if I have the possibility to use other sources in many of the travel arrangements during this year. **I appeal to each one of you to assist in obtaining government contributions.** You can do it by acting directly towards your own governments, but you can also provide me with more ideas on how we could operate this matter. I have written to a large number of contacts and hope that there are activities going on just now around the globe. However, the silence is more or less complete.

Well, panel members, this is the end of my letter. I hope I will hear from you in all the different issues I have raised. Let us stay in touch!

Yours sincerely,



Bengt Lindqvist

Panel of experts - updated list of April 1998

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Transcription of Resolution adopted by the Commission on Human Rights, fifty-fourth session
Agenda item 15

1998.... Human rights of persons with disabilities

The Commission on Human Rights,

Mindful of the pledge made by States, under the Charter of the United Nations, to take action jointly and separately, in cooperation with the United Nations, in order to promote a better quality of life, full employment, and conditions for economic and social progress and development,

Recalling that all persons with disabilities have the right to protection against discrimination and to full and equal enjoyment of their human rights, as laid down inter alia in the provisions of the Universal Declaration of Human Rights, the International Covenant on Economic, Social and Cultural Rights, the International Covenant on Civil and Political Rights, the Convention on the Rights of the Child, the Convention on the Elimination of All Forms of Discrimination against Women and of the International Labour Organization Convention No. 159,

Recalling also the report of the Secretary-General, to the General Assembly on the third review and appraisal of the World Programme of Action concerning Disabled Persons (A/52/351).

Reaffirming the continuing validity and value of the World Programme of Action concerning Disabled Persons, adopted by the General Assembly at its thirty-seventh session, which provides a firm and innovative framework for promoting and protecting the human rights of persons with disabilities,

Mindful of the unreserved reaffirmation in the Vienna Declaration and Programme of Action, and by the Fourth World Conference on Women of the human rights and fundamental freedoms of persons with disabilities, as well as the recognition in the programme of Action of the International Conference on Population and Development and the Programme of Action of the World Summit for Social Development of a pressing need for, inter alia, the realization of the goals of full participation and equality for persons with disabilities,

Reaffirming its resolution 1996/27 of 19 April 1996 on the human rights of persons with disabilities,

Noting the report of the special Rapporteur of the Commission for Social Development on monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (A/52/56. annex),

Reaffirming Economic and Social Council resolutions 1997/19 on equalization of opportunities for persons with disabilities and 1997/20 on children with disabilities,

Recalling General Assembly resolution 48/96 of 20 December 1993, by which the Assembly adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities,

Recalling also General Assembly resolution 52/107 of 12 December 1997, in which the Assembly called for the full and equal enjoyment of all human rights and fundamental freedoms by children with disabilities,

Welcoming initiatives to hold international conferences relating to persons with disabilities, particularly the holding of the Fifth World Assembly of Disabled People's International at Mexico City in December 1998, on the theme "Towards an inclusive twenty-first century",

Re-emphasizing the responsibility of Governments for removing or facilitating the removal of barriers and obstacles to the full integration and participation of persons with disabilities in society, and supporting their efforts to develop national policies to reach specific objectives,

Recognizing the contribution of non-governmental organizations, especially organizations of persons with disabilities, in the global effort to bring about full participation and equality for persons with disabilities and to ensure the full enjoyment of human rights by persons with disabilities,

Noting the reports of Mr. Leandro Despouy, Special Rapporteur of the Sub-Commission on Prevention of Discrimination and Protection of Minorities, and the Office of the High Commissioner for Human Rights publication Human Rights and Disabled Persons, in which international mechanisms for the protection and promotion of the human rights of persons with disabilities, such as an ombudsman, are proposed,

Noting also the International Labour Organization survey of the law and practice of States parties to Convention No. 159,

Concerned at the extent of disabilities caused by the indiscriminate use of anti-personnel mines, particularly among civilian populations,

1. Recognizes that any violation of the fundamental principle of equality and any discrimination or other negative differential treatment of persons with disabilities inconsistent with the United Nations Standard Rules on Equalization of Opportunities for Persons with Disabilities is an infringement of the human rights of persons with disabilities;
2. Calls upon the Secretary-General to maintain the integrity of programmes within the United Nations system relating to persons with disabilities, including the United Nations Voluntary Fund on Disability, in order to promote the rights and the equalization of opportunities and full inclusion within societies of persons with disabilities;
3. Welcomes the renewal of the mandate of the Special Rapporteur on disability of the Commission for Social Development, and thanks him for addressing the Commission on Human Rights in the year of the fiftieth anniversary of the Universal Declaration of Human Rights;

4. Invites the Special Rapporteur of the Commission for Social Development to address the Commission on Human Rights at its fifty-sixth session;
5. Takes note of the global survey of government action on disability policy published in 1997 by the Office of the Special Rapporteur on disability;
6. Calls upon States to cooperate fully with the Special Rapporteur, to meet his requests for information and to provide relevant data to the Committee on Economic, Social and Cultural Rights;
7. Encourages non-governmental organizations active in the protection and promotion of the human rights of persons with disabilities to cooperate closely with each other, and to provide relevant information to the Committee on Economic, Social and Cultural Rights and to the Office of the High Commissioner for Human Rights;
8. Also encourages such non-governmental organizations to avail themselves of the technical assistance of the Office of the High Commissioner for Human Rights to assist them to function effectively in the human rights sphere;
9. Encourages Governments to support non-governmental organizations active in the promotion and protection of the human rights of persons with disabilities;
10. Recognizes the right of persons with disabilities, individually and collectively, to form and become members of organizations of persons with disabilities and the right of such organizations to speak for and act as legitimate representatives of their members;
11. Encourages all the human rights treaty monitoring bodies to respond positively to its invitation to monitor the compliance of States with their commitments under the relevant human rights instruments in order to ensure full enjoyment of those rights by persons with disabilities, and urges Governments to cover fully the question of the human rights of persons with disabilities in complying with reporting obligations under the relevant United Nations human rights instruments;
12. Invites all special rapporteurs, in the course of carrying out their mandates, to take into account the situation and human rights of persons with disabilities;
13. Urges Governments to implement, with the cooperation and assistance of relevant organizations, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, having particular regard for the needs of women, children and persons with developmental and psychiatric disabilities in order to guarantee their human dignity and integrity;
14. Invites Governments and the private sector to contribute to the United Nations Voluntary Fund on Disability, with a view to providing additional support for the implementation of the Standard Rules, within the context of the World Programme of Action concerning Disabled Persons;

15. Requests the Secretary-General to continue to ensure appropriate support for the effective functioning of the Long-Term Strategy to Implement the World Programme of Action concerning Disabled Persons to the Year 2000 and Beyond;

16. Expresses grave concern that situations of armed conflict have especially devastating consequences for the human rights of persons with disabilities;

17. Welcomes increased international efforts in various forums with respect to anti-personnel mines, and in this regard takes due note of the conclusion of the Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-Personnel Mines and on Their Destruction and its implementation by those States that become parties to it, as well as of the amended Mines Protocol of the Convention on Prohibitions or Restrictions on the use of Certain Conventional Weapons Which May be Deemed to be Excessively Injurious or to have Indiscriminate Effects

18. Calls upon all States and relevant United Nations bodies, including the United Nations Voluntary Trust Fund for Assistance in Mine Clearance, to contribute on an ongoing basis to international mine clearance efforts, and urges States to take further action to promote gender- and age-appropriate mine-awareness programmes and rehabilitation, thereby reducing the number and the plight of victims;

19. Encourages the development of programmes for persons with disabilities to enable them to develop their potential to fully participate in all aspects of society;

20. Requests the Secretary-General to report biennially to the General Assembly on the progress of efforts to ensure the full recognition and enjoyment of the human rights of persons with disabilities;

21. Also requests the Secretary-General to make available to the Commission at its fifty-fifth session the latest report of the Special Rapporteur on disability of the Commission for Social Development on his monitoring of the Standard Rules on the Equalization of Opportunity for Persons with Disabilities;

22. Calls upon the United Nations Development Programme and all intergovernmental institutions for development cooperation to integrate disability measures into their mainstream activities;

23. Requests that all United Nations organizations and specialized agencies address the problem that exist in creating equal opportunities for persons with disabilities at all levels;

24. Encourages Governments to work towards developing appropriate education policies and practices for children and adults with disabilities, to include persons with disabilities in strategies and plans aimed at eradicating poverty, promoting education and enhancing employment, and to take account of the right to persons with disabilities to housing, shelter, transport and supportive equipment;

25. Invites the International Labour Organization, in cooperation with governments and intergovernmental bodies, to take the lead internationally in formulating policies and strategies that will lead to equal job opportunities;

26. Invites Governments and non-governmental organizations to collect and collate appropriate information and data on persons with disabilities, to assist in the formulation of effective policies to address issues of equality;

27. Recommends that the Office of the High Commissioner for Human Rights take account of information on legislation affecting the human rights of persons with disabilities which has been collected by the Special Rapporteur on disability of the Commission for Social Development;

28. Reaffirms its commitment to ensuring that the human rights of persons with disabilities and their concerns for full participation in all aspects of society continue to be addressed in all of its work;

29. Decides to continue to consider the question at its fifty-sixth session under the agenda item entitled "Report of the Sub-Commission on Prevention of Discrimination and Protection of Minorities".

TRAVEL PLAN for Special Rapporteur
end of May - 15 December 1998

- 26-31 May Japan, participation in seminar concerning elderly and meeting of DPI Japan
- 9-11 June Russia, planning of national seminar on disability policy to take place in 1999
- 16-20 Aug. Armenia, participation at conference on disability policy and visits to government and organizations
- 26-27 Aug. The Netherlands, participation at Inclusion International World Assembly
- 5-10 Oct. Bulgaria, participation at seminar and talks with government
- 20-22 Oct. Panel meeting, either in New York or Geneva
- 26-30 Oct. Rumania, participation at a conference on disabled children and talks with government
- 2-6 Nov. South Africa, preliminary date for human rights conference
- 4-12 Dec. Mexico and Costa Rica, participation at DPI congress and at seminar on disability policy in Costa Rica

UNITED NATIONS



NATIONS UNIES

**Special Rapporteur of the Commission for Social Development on
Disability**

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Mr. Lex Frieden
TIRR
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USA

Date: 22 May 1998

Dear Lex,

Some weeks ago I received the pleasant information that you have been appointed member of my panel of experts, monitoring the Standard Rules. Naturally, I am delighted about this news.

For your information I attach a list of the panel members and the minutes from our meeting in May 1997. Of course, you are welcome to put questions and make comments in order to bring you update with what we are doing.

Once again, I am delighted to have you in the panel and I hope you will find the necessary time for participating actively.

Yours sincerely,

A handwritten signature in cursive script, appearing to be 'B. Lindqvist'.

Bengt Lindqvist

UN Standard Rules Monitoring Project

MINUTES

from meeting between UN Special Rapporteur on Disability and Panel of Experts, at International Disability Centre, Ferney-Voltaire, France
22-25 May 1997

Present: See attachment 1.

§1. Opening

In his opening remarks, Mr. Bengt Lindqvist wished all panel members welcome to the meeting. In particular Mr. Lindqvist addressed Ms. Leonie Manns and Ms. Carol-lee Aquiline, who were both deputized to participate in the panel meeting by their organizations. He also welcomed attending observers from three of the six panel organizations.

Mr. Lindqvist reminded the panel members that this meeting constituted the last meeting of the first period. It was therefore important to use the meeting for reflections and discussions concerning experiences by panel members during this first period. As the UN Commission for Social Development has recommended to ECOSOC a continuation of the monitoring mechanism, Mr. Lindqvist emphasized that considerable time during this meeting should also be used for making plans and preparations for a second monitoring period.

Mr. Hans Hoegh from the International Disability Foundation, IDF, warmly welcomed the participants to the International Disability Centre and emphasized that he was looking forward to the joint discussion to be held during the meeting and to future fruitful cooperation.

§2. Procedural matters

Under this heading the panel decided to consider the following three different items:

a) The chairing function of the meeting

The panel decided to have one person chairing each of the four days of the meeting. The following panel members were elected to chair:

Joshua Malinga - Thursday, 22 May

William Rowland - Friday, 23 May

Garé Fabila de Zaldo - Saturday, 24 May

Leonie Manns - Sunday, 25 May

b) Secretary of the meeting

Ms. Eva Sagström was elected to take minutes of the meeting.

In this context panel members expressed their appreciation to Ms. Sayeed for having taken minutes during previous meetings.

c) Approval of agenda

The draft agenda, circulated by Mr. Lindqvist, was adopted with the following additions;

- Follow-up of meetings in New York in February 1997
- The issue of providing good examples
- How to approach governments in countries with extreme poverty

d) Programme for the four days

The panel approved the suggested programme for the four days of meeting. Thursday should be dedicated to a meeting with WHO, Friday to meetings with ILO, the Human Rights Centre and the IDF, Saturday and Sunday used for the actual panel deliberations.

§3. Report by Rapporteur on present situation

Mr. Lindqvist started by summarizing the recommendations in the minutes from the previous panel meetings. He continued by pointing to the recommendations he had made to the Commission for Social Development in his final report. Finally he presented the Commission resolution (E/CN.5/1997/L.59), in which the Commission among other things recommends a continuation of the monitoring mechanism. The actual decision concerning a future monitoring activity will be taken by ECOSOC, holding its meeting in June/July this year. A draft of Mr. Lindqvist's report to the Commission had been circulated in November to panel members. The official, finalized report by Mr. Lindqvist together with the Commission resolution was handed out to panel members. It was found that most of the recommendations made by Mr. Lindqvist had been taken up and adopted by the Commission for Social Development.

Mr. Lindqvist reported that the Swedish government was initiating an activity to consider funding a second monitoring period in connection with the ECOSOC meeting in July.

Mr. Lindqvist reported on the situation concerning the publication of results from the large, second survey. The Rapporteur has applied for approval by the UN Publications Board to publish a book with government replies. In addition

to this he intends to issue five reports on NGO replies and comparisons between government and NGO replies. The Swedish government has promised to fund these publications. Mr. Lindqvist hoped that the permission from the Publications Board will be obtained in time to publish the book before the ECOSOC meeting in July.

After some discussion on various items the panel approved the report.

§4. Experiences of the first monitoring period

Both the Rapporteur, all panel members and observers reported on their experiences during the first monitoring period 1994-1997. Many valuable observations were made, of which the following may be noted as of a more general interest:

- * One difficulty during the first period had been to obtain invitations for discussions from individual governments
- * The cooperation with NGOs in connection with Rapporteur's activities should be further strengthened
- * An evaluative component for the whole process of monitoring should be established
- * The second resolution passed by the Commission for Social Development on disabled children should be observed and used during a second period
- * The integration of the Standard Rules guidelines into the ESCAP (Economic and Social Commission for Asia and the Pacific) agenda for action should be obtained
- * The World Federation of Psychiatric Users must be given more resources to be able to actively participate in a second monitoring period. A letter to the Australian government was drafted during the meeting.
- * In Africa further efforts should be made to establish disability policies on the agenda. Activities should build on cooperation with OAU (Organisation of African Unity) and ARI (African Rehabilitation Institute).
- * Rapporteur should write a position paper with reflections on experiences during the first period
- * Panel members must assume the duty to keep the Standard Rules on the agenda of their organizations
- * Generally, panel members should be utilized more in monitoring activities
- * Results of the second survey should be used as launching pad for initiatives during a second period
- * We must better learn how to capitalize on the powerful networks of the six organizations and their grassroots movements

- * It is important to take into account that we know very little about more than 50% of UN Member States
- * It is necessary to make both gender and child aspects more visible in future monitoring
- * Perhaps Disability Awareness in Action (DAA) and its information channels could be involved in future monitoring activities
- * The possibilities of using Internet for communication and information exchange should be considered

§5. Guidelines for work relations within the monitoring mechanism

Mr. Lindqvist handed out a second draft proposal for guidelines concerning work relations between Special Rapporteur, panel members and their organizations. All views and suggestions presented by panel members before the meeting had been incorporated. After a short discussion John Stott and Victor Wahlström were asked to edit the second draft and to incorporate the new suggestions.

The draft suggested by Stott and Wahlström was adopted by the panel (see attachment 2). It was decided that the guidelines concerning the Rapporteur and the panel members would be put into practice immediately on a provisional basis. The guidelines as a whole should be sent to the headquarters of the six organizations for their approval before the first of November.

§6. Draft work programme for 1997-2000

The panel considered the draft work programme made by the Special Rapporteur and decided to make the following recommendations for changes and additions:

- * References should be made to relevant documents like the Habitat 2 report, the Beijing report, resolutions by the Commission for Social Development at the appropriate places in the work programme
- * Under the item of special issues, items of special interest to different groups should be mentioned, like literature in Braille, sign language, easy reading versions, clear print and devices for speech impaired
- * Attitudes as an obstacle to participation should be considered
- * The area of housing and shelter should be brought into the monitoring. A good basis for guidelines will be found in the report from Habitat 2
- * The fact that there is no Rule on transport should be considered
- * As new items on the work programme access within the UN system and employment of disabled people within the UN should be added

§7. Draft cost plan for activities 1997-2000

The panel considered the proposal by the Rapporteur for a cost plan concerning activities during a second monitoring period. It was decided to recommend:

- * The honorarium for the Rapporteur should be increased and be USD 50 000 annually
- * Funding for three panel meetings should be included in the cost plan
- * Additional funding for regional seminars should be applied for through the UN Voluntary Trust Fund

§8. Selecting subject areas for future surveys

After an introduction by the Rapporteur, the panel discussed at length various alternative strategies for selecting subject areas. It was noted that the ILO general survey on disability policy in employment is of great interest and covers Rule 7 on employment, partly Rules 8, 15, 19 and 4. The planned joint activities with WHO will bring further information on Rules 2, 3, 4 and 19. The panel was of the opinion that UNESCO in addition to working with education should take increased responsibility for disability policy in the area of culture and information. Concerning the situation of children with disabilities the Rapporteur should cooperate both with the Committee monitoring the convention on the rights of the child and with UNICEF. Concerning the gender aspect cooperation should be initiated with the Commission on the Status of Women. It was agreed that the Rapporteur should send a letter to the Commission on the Status of Women asking for cooperation. Kicki Nordström should assist in drafting this letter. In addition to this it was agreed within the panel to make the following recommendations:

- * Rule 9 on family life and personal integrity should be considered for more in depth analysis
- * Culture and information (Rules 5 and 10) should be included in future surveys
- * One strategically important area is the position of organizations of persons with disabilities. It should be considered in future surveys
- * The outcome of human rights findings from the second survey should be followed up. The Rapporteur will make a paper with a summary of the findings from the second survey
- * Employment and CBR activities will be considered again after the final report by the ILO and the outcome of the evaluation of CBR by the WHO
- * The panel agreed to come back to the discussion on selecting subject areas for further surveys when having had access to the full report from the second survey
- * A number of "burning issues" were raised in connection with this discussion:

- eugenics, euthanasia and cochlea implants for deaf people are examples of such areas. Mainly these areas were identified as possible future areas for cooperation between the INGOs.

The panel further discussed the establishment of an evaluative component. It was agreed that such a component could be built on two dimensions: The establishment and strength of organizations of disabled people and the establishment of necessary government policies in the disability field.

§9. Rapporteur activities during 1997

The Rapporteur had presented a list of his travel activities during 1997. The panel discussed further activities to be put into this schedule. Visits to South Africa, the Caribbean and ESCAP were mentioned.

§10. Cooperation with the IDF Standard Rules project

As the panel of experts together with the Special Rapporteur serve as advisory board for the IDF Standard Rules project it was of particular importance for the panel to discuss issues of cooperation with Hans Hoegh and his colleagues. The results are recorded in attachment 3.

§11. Panel and NGO activities in support of the UN monitoring

Discussions related to this was referred to item 6: Draft work programme for 1997-2000. Consequently, the agenda item 11 was considered already dealt with.

§12. Other business

a) Follow-up of activities in New York in February 1997

The notes and minutes from the meetings held by INGOs in connection with the meeting of the Commission for Social Development were studied and discussed. It was noted that on the whole these activities by the INGOs had been highly successful. The highlight of these activities was the meeting with the new UN Secretary General, Mr. Kofi Annan. Correspondence following this meeting was found to be of great value.

William Rowland reported that a new ECOSOC resolution will solve the problem of obtaining consultative status within the UN system. All the international NGOs in the disability field will be organizations in special status with the UN system.

b) Good examples

It was agreed that there is a great need to distribute information about good examples and good practice around the world. The difficult question is to establish an activity of this kind and to find resources for it. It was agreed that the matter should be discussed with Rachel Hurst at the Disability Awareness in Action. Perhaps the network of this organization could be utilized in this context.

c) How to approach governments of countries with extreme poverty

After some discussion the panel expressed the view that there is no available good approach, especially designed for this situation. To a large extent the approach has to be formed from case to case. It was emphasized that the reception by governments to a large extent depends on how they perceive the role and importance of the representative.

§13. Next panel meeting

The panel discussed the time and venue of next panel meeting. No definite recommendations were made, but it was felt that a meeting should be held early 1998. One attractive possibility would be to hold the meeting in connection with the meeting of the Commission for Human Rights, at which the Special Rapporteur will be invited to speak. Another idea is to hold a forthcoming meeting in connection with one of the regional seminars.

§14. Closing

The Rapporteur thanked the panel members and observers for their very active participation during the four days of the meeting. He also thanked the interpreters and the staff of the IDF for providing excellent meeting facilities for the panel. After having promised that he and Eva Sagström will do their best to issue the minutes and all relevant documents as soon as possible, the Rapporteur declared the meeting closed.

June 1997

Eva Sagström / Bengt Lindqvist

Attachment 1.

Present at panel meeting in Ferney Voltaire, 22-25 May 1997

UN Special Rapporteur's office

Bengt Lindqvist

Eva Sagström

Panel of Experts

Monica Bartley, DPI

Joshua Malinga, DPI

Garé Fabila de Zaldo, Inclusion International

Victor Wahlström, Inclusion International

John Stott, RI

Penny Hartin, WBU

William Rowland, WBU

Carol-Lee Aquiline (deputized), WFD

Mohamad Sazali Shaari, WFD

Leonie Manns (deputized) WFPU

Sign language interpreters

Wan Zuraidah Abu

Amanda Lyons

Mindy Brown-Wagenaar

Observers

Kicki Nordström, WBU

Susan Parker, RI

Zuhy Sayeed, Inclusion International

**Monitoring the implementation of the Standard Rules
Second period - 1997-2000**

Guidelines for work relations between the Special Rapporteur, Panel Members and their organizations

Adopted by the panel in Ferney Voltaire, 22-25 May 1997

A - The Special Rapporteur will:

- 1) At the beginning of the period draft a work programme and a cost plan for the activities during the second monitoring period. Panel members will be consulted before adoption.
- 2) Consult with panel members before decisions are made in major issues.
- 3) Be responsible for the preparation of panel meetings. Panel members will be consulted about time, venue and items on the agenda for each panel meeting.
- 4) Send copies of his communication with the panel to the headquarters of the six internationals.
- 5) Use fax as the main channel of communication, until all panel members have access to e-mail.
- 6) Will cooperate on a regional basis with panel members in the promotion of the Standard Rules.
- 7) Will cooperate with NGO's when making visits to countries.
- 8) Will continuously keep panel members informed about his traveling and about the progress of the monitoring project.
- 9) Will consult panel members in his reporting on progress to the UN system.

B - Panel members will:

- 1) Represent their organizations in panel consultations.

- 2) Give advice to the Special Rapporteur and, when appropriate, to the UN Secretariat on various aspects of the monitoring project.
- 3) Inform their organizations of the work in the monitoring project.
- 4) As far as possible take initiatives to promote the implementation of the Standard Rules within their regions and their organizations.
- 5) Assist the Special Rapporteur in selecting countries for visits and in obtaining invitations from the governments concerned.
- 6) Send copies of their communication with the Special Rapporteur to their organizations.
- 7) Be in active communication with the Special Rapporteur and respond within given time-frames to requests for information.
- 8) On specific occasions represent the monitoring project at the invitation of the Special Rapporteur and when travel authorization has been obtained from the UN Secretariat.

C - International NGO's will:

- 1) Use available opportunities to promote the Standard Rules in their work, by providing opportunities within their meetings and conferences for discussion and information on the Standard Rules project and by supporting their member associations in influencing their governments nationally, regionally, and on the global level.
- 2) Involve their respective panel members in the promotion activities of the Standard Rules.
- 3) Support panel members with information and advice in their work as members of the panel.
- 4) Collaborate between the six INGOs, where possible, in promoting the implementation of the Standard Rules.
- 5) Facilitate monitoring activities by providing contacts with their national and regional affiliates.

6) Improve the communication between the INGO's by:

- Exchanging work programmes for the second monitoring period,
- Exchanging magazines and other information of interest

Notes from meetings between the Panel of Experts, UN agencies, and the International Disability Foundation

Discussions with WHO

Representative of WHO: Dr. Enrico Pupulin, Rehab Unit

Three items were discussed during this session:

- 1 - Participation at WHO regional workshops
- 2 - CBR evaluation
- 3 - Rethinking care

1. Participation at WHO regional workshops

* Dr. Pupulin will send dates for the different workshops to the Special Rapporteur's office, and the Rapporteur will try to find panel members, preferably in the respective regions. As decided by the meeting, the Rapporteur will ask Dr. Pupulin if Ms. Garé Fabila de Zaldo can be given the opportunity to participate in the first workshop in Venezuela in June 1997.

* Dr. Pupulin will send copies of the 4 workshop programmes to the Special Rapporteur's office.

* William Rowland and Monica Bartley will prepare questions to address the countries participating in the workshops and send the material to the Rapporteur's office before 15 June 1997.

* Victor Wahlström and Susan Parker will prepare a statement to be used as a basis for participation at the workshops. The material will be sent to the Rapporteur's office before the end of June, circulated for views to panel members and finalized before the end of August.

* The Rapporteur will send a letter to the Director-General of WHO, requesting cooperation in the implementation of the Rules of concern for WHO.

2. CBR evaluation

* Dr. Pupulin will circulate a draft evaluation design through the Rapporteur's office to the panel members.

* The panel members will give views before the end of September.

* Dr. Pupulin will circulate reports to panel members through the Rapporteur's office on the joint multisectorial CBR conference in Abidjan.

3. "Rethinking care"

* Dr. Pupulin will circulate a draft programme on a world conference on rethinking care.

* The panel members will give views on the programme and suggest background studies, title of study and name of performer/writer before 15 June 1997.

* The INGOs will be invited by Dr. Pupulin to present background papers with their philosophies and observed trends before the end of October.

* Dr. Pupulin will invite to a small working group (November 1997) preparing a background document before the conference on rethinking care, built on the background papers.

* Dr. Pupulin will invite the INGOs to suggest countries to organize preparatory seminars on rethinking care, provided that the countries can fund the activity. There will be two preparatory seminars in each region.

Discussions with ILO

Representatives of ILO: Gerd Jung and Marc Dupont

* ILO has distributed a questionnaire to all member governments on labour market policy and disability. The questions cover areas in rule 4, 7, 8, 15 and 19. 80 governments have replied up to now. More government replies are expected in connection with the ILO conference in June this year. A committee of experts will consider the first draft survey report in November 1997.

* ILO representatives will consider a proposal to involve the Rapporteur in the drafting of their survey report.

* ILO representatives will study the idea of holding an NGO seminar on the outcome of the survey during the drafting process.

* The INGOs holding consultative status with ILO can participate in the ILO conference in 1998, which will consider the survey report.

* ILO is holding an annual meeting with regional representatives. One person representing the Standard Rules project will be invited to participate in the forthcoming meeting.

* ILO representatives presented research and technical cooperation projects. GLADNET (Global Applied Disability Research Network) will become an independent association this year. Also NGOs can become members.

* ILO representatives will circulate a list of Gladnet activities.

* It was noted that the ILO (and UNESCO) should be involved in the WHO evaluation of CBR, as earlier discussed with the panel.

* Conference on return to work: ILO together with some governments is preparing a world conference on "Return to work" to be held in Washington in 1998. ILO will circulate information to panel members.

Meetings with representatives of the Human Rights Centre

* Mr. Ovsiouk, responsible for disability issues within the Human Rights Centre, informed the meeting about ongoing activities. Disability is integrated in general activities as there is no special mechanism for monitoring the human rights of disabled people.

* Mr. Ovsiouk drew the attention of the meeting to two instruments of particular interest - the Covenant on Economic, Social and Cultural Rights, and the Convention on the Rights of the Child. The General Comment No. 5, from November 1994, issued by the Committee monitoring the Covenant on Economic, Social and Cultural Rights, contains an interesting analysis on disability rights.

* The Committee monitoring the Child Convention has decided to make the rights of disabled children the theme of this year's meeting. The meeting will take place 6 October 1997.

* The Commission on Human Rights (main UN commission in the human rights area) has decided to invite the Special Rapporteur on monitoring the Standard Rules to speak at its meeting in 1998.

* The Commission on Human Rights has requested the Secretary General of the UN to report biennially to the General Assembly on human rights and disability.

* To get access to information and reports on the situation of disabled children, the Rapporteur will write to the Human Rights Centre and request permission to study the reports of the committee on the Child Convention.

* The organizations holding consultative status with ECOSOC may attend meetings of the Human Rights Commission.

* Mr. Ovsiouk indicated the following two major ways for NGOs in the disability field to feed the Human Rights Centre with information on the situation of disabled people; a) to participate actively in the meetings of the Commissions, b) to send written statements on the situation to the Human Rights Centre.

* Mr. Ovsiouk offered to make a fact sheet on human rights and disabled persons. The panel appreciated and welcomed the offer.

* It would be valuable if national affiliates of the six INGOs requested their governments to report on the human rights situation of disabled people to the various monitoring committees.

Meeting with acting High Commissioner on Human Rights, Mr. Ralph Zacklin

* Mr. Zacklin expressed his satisfaction that disability is finally on the human rights agenda of the UN. The task now is to elaborate this issue. The responsibility of the Human Rights Centre is to serve governments. However, if it gets the mandate from the Commission it may perform activities in the NGO field. Thus the Centre could involve in human rights activities in cooperation

with INGOs in the disability field. The participation by the Rapporteur in the next year's meeting of the Human Rights Commission is, according to Mr. Zacklin, of tremendous importance.

* Mr. Zacklin emphasized that this event should be followed up by a resolution.

* The Centre will distribute, through the office of the Rapporteur, a draft plan of activities to celebrate the 50th anniversary of the Human Rights Declaration. There will be opportunities for NGOs to participate.

* Finally, Mr. Zacklin advised the organizations involved in human rights activities to develop relations with the various monitoring and controlling mechanisms.

Discussions with the International Disability Foundation, IDF

Mr. Hans Hoegh and Ms. Ingrid Sickler presented the IDF Centre and the IDF Standard Rules programme entitled "Towards awareness and action". This project will create national structures in twelve countries in Africa and Asia to promote the implementation of the Standard Rules. The "TAA" project should in all countries be supplementary to government activities. The ultimate goal of the project is to make governments implement national policies and programmes built on the Standard Rules.

* It was pointed out that creating separate projects with a life of their own must be avoided.

* Concern was expressed about what will happen after the two years of the project.

* Concern was expressed that the project is an enormous task to be undertaken in two years.

* It is important that panel members in a region, involved in the project activities, should have equal status.

* The role of the panel as a whole will be to deliver views on general policies.

* Panel members in Africa and the Asia/Pacific region respectively will participate more directly in the "TAA" activities.

* The IDF will make a newsletter regularly on the progress of the project.

* Task force reports should be circulated as information to all panel members.

* It was emphasized that an evaluation mechanism should be established.

* Findings and observations from the UN monitoring of the Standard Rules should be made available for use in the IDF Standard Rules project.

Panel of experts - updated list of April 1998

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Child Convention and the Standard Rules

Speech by Mr. Bengt Lindqvist at the 6 October 1997 discussion day of the Committee on the Rights of the Child

Distinguished Participants,

"Not until the creation and maintenance of decent conditions of life for all men has been recognized and accepted as a common obligation of all men and all countries, not until then shall we, with a certain degree of justification, be able to speak about mankind as civilized." This was said by Albert Einstein in 1945, when the world was waking up from the nightmare of the second world war.

Today is 1997 and more than 50 years have passed. The world as a whole has become much richer in material resources, and we have scientific knowledge and technical means, which humanity could not even dream of 50 years ago. Still we can not speak about mankind as civilized, not with this absurd inequity in wealth distribution, not with the existing poverty and social deprivation in large parts of the world, not with this mad waste of both human and material resources on instruments of war and destruction.

One of the most urgent needs in the area of social development concerns our children. The adoption of the Convention on the Rights of the Child means a significant increase in awareness and a decisive reinforcement of tools and resources in the struggle for better conditions. In our efforts to improve the conditions of children generally, we must not forget those children with disabilities. We who are here today know, however, that this often happens. It is a sad fact that millions of disabled children are Excluded from development and progress.

For this reason I am extremely grateful for this opportunity to focus on the situation of disabled children, provided by the Committee on the Rights of the Child and the High Commissioner for Human Rights. It is our duty to use this important event for finding new ways of cooperation.

In my capacity as Special Rapporteur on disability, responsible for monitoring the implementation of the UN Standard Rules, I will use the time available for two things. I want to share with you some observations concerning similarities and differences in the approach used in the Convention on the Rights of the Child and the Standard Rules. I also want to suggest a few areas, where we could, and actually also should, cooperate.

To make my presentation understandable, I want to start by explaining the goals and main components of modern disability policy, such as it is outlined in recent UN documents.

The theme adopted for the International Year of disabled persons - Full Participation and Equality - has been established and recognized as the overall goal of disability policy. Throughout the years it has become more and more evident that we, to achieve this goal, must deal with obstacles to participation, "preventing persons with disabilities from exercising their rights and freedoms and making it difficult for them to participate fully in the activities of their societies" (Standard Rules, Introduction para 15). In other words it is apparent that we, in disability policy, deal with issues of fundamental human rights. This is, of course, extremely important, as it draws our attention to the responsibility and conduct of governing institutions in Member States.

It has also become evident that measures to combat exclusion and bad conditions, to be effective, must be taken in two main areas - support to the individual and measures to create accessibility in the surrounding society. To concentrate efforts in only one of these two areas will never lead to the realization of full participation. I will use an example to illustrate what I mean. To make it possible for a physically disabled child to participate in the activities at school, the child will need some special training and technical equipment, maybe a wheelchair. This in our terminology would be part of the "support to the individual". To make this meaningful, the building and playground of the school must be made accessible for the wheelchair user. Otherwise his or her participation at school will be very limited or even impossible. Both approaches must be used!

Ladies and Gentlemen,

The Standard Rules on the Equalization of opportunities for Persons with Disabilities were adopted by the UN General Assembly in 1993. Basically the

philosophy is the same as in the World Programme of Action, which was adopted in connection with the International Year. The Rules, however also build on the experiences made during the Decade of Disabled Persons (1983-1992). Generally one could say that the Standard Rules document is a more elaborated tool for implementation. In addition it should, however, be emphasized that the Rules put more weight on the human rights aspects and that, consequently, the role of the State is addressed more emphatically.

The Standard Rules document contains chapters on both various ways to support and empower the individual (Preconditions for Participation) and measures to create accessibility and availability in all main areas of society. (Target Areas for Participation). A third chapter deals with Implementation Measures, which are all necessary to create real and sustainable progress in the disability field. In a fourth chapter detailed guidelines for the monitoring of the implementation of the Rules are presented. One important feature of the Rules generally and in the monitoring mechanism is the close cooperation with the organizations of persons with disabilities. In the monitoring exercise, six International NGOs serve on a Panel of Experts, which is consultative to the Special Rapporteur and the UN Secretariat.

So far the Standard Rules. Let us now look at the Child Convention from a disability point of view. The adoption and broad acceptance of the Convention on the Rights of the Child means an enormous step forward in the struggle for better conditions for all children. All the general and main principles of the Convention - non-discrimination, the best interest of the child, the right to survival and development and participation in the decisions affecting themselves - are all highly relevant in the work for disabled children. When we relate the meaning of these high principles to the actual situation of disabled children, we see, with shocking clarity, how far we are from complying with them. I am convinced that the organizations, representing disabled children at this conference, will develop this observation further.

The most obvious article for our discussion is, of course, article 23, which deals with the special needs of disabled children. It contains four paragraphs. In para 1 the State recognizes that disabled children are entitled to a full and decent life. Dignity, self-reliance and active participation should be ensured. In para 2 States recognize the right of disabled children to receive special care and assistance. According to para 3 such assistance should, under certain

circumstances, be provided free of charge and designed to ensure effective access to education, training, health care, rehabilitation, preparation for employment and recreation. In the final 4th paragraph it is stated that the exchange of appropriate information shall be promoted by States in the above mentioned areas.

Naturally, there are many similarities in the contents of the Standard Rules and the Convention on the Rights of the Child. As far as I can see, there are no conflicting principles in the two documents. There are, however, significant differences. For obvious reasons the Rules, which is a whole document on disability policy, contain a much higher degree of specification and give more guidance concerning what should be done and how it should be done. This naturally also has to do with the fact that the two documents have different legal status and general purpose.

My most important observation concerns the difference in general approach to disability between the two documents. As I have said before, Disability policy must contain both programmes to support the individual and measures to make the surrounding society accessible. According to article 4 of the Convention, States Parties are called upon to undertake all appropriate legislative, administrative and other measures for the implementation of The rights contained in the Convention. However, the Convention indicates only one concrete remedy in article 23 - care and assistance to the disabled child and its parents. Indeed, this is important, but, at the same time, it is not enough. There is a general provision that access to education should be ensured, but there is no further indication how this should be done.

The principles of non-discrimination and the best interest of the child speak strongly in support of integration and mainstreaming, to make it possible for the disabled child to stay in the social context which is natural to him or her. To make this possible, the surrounding society must take the needs of that child into account. It means, among many other things, to adapt programmes in preschools and schools, to make playgrounds, toys, books and communication facilities accessible and available for disabled children.

Unfortunately, these things will not come automatically. The state must assume the responsibility for indicating and sustaining programmes and measures of various kinds, staff training, the development and production of aids, norms for accessibility etc.

I am not sure, what the absence of concrete support for accessibility measures in the Child Convention really means for the work of the Committee on the Rights of the Child. One obvious conclusion is, however, that there are strong motives for combining provisions given in these two UN documents, in order to create strong and effective programmes for disabled children.

Ladies and Gentlemen,

The entity within the UN system, which is responsible for the monitoring of the Standard Rules, is the Commission for Social Development. At its meeting earlier this year the Commission adopted two resolutions concerning disability issues. One of them deals solely with matters concerning children with disabilities. It contains a number of recommendations for measures, which would increase the level of international involvement. The final paragraph, para 12, requests the Special Rapporteur, monitoring the Standard Rules, to pay special attention to the situation of children with disabilities. In doing this, the Rapporteur should "pursue close work relations with the Committee on the Rights of the child". The Rapporteur should report his activities to the Commission. In my opinion this conference is an excellent opportunity to start our discussions on cooperation.

I want to end this presentation by suggesting a few areas, where we could start to work together.

1. The Committee must by now have collected a considerable number of reports from governments on their progress in implementing the Convention. Hopefully, these reports also include information on disabled children. Let us together make an analysis of this material to find out where we stand and to discuss further action.

2. As a first step in the continuous exchange of information between us, I will make sure that the Committee and its secretariat will have access to all my reports from the first monitoring exercise concerning the Standard Rules.

3. In consultation with the Panel of Experts I have decided to make further surveys on the situation with regard to the implementation of the Rules in certain areas. I should add that this is all provided that we get funds for our activities.

There are several alarming findings in our second survey concerning legislation and basic human rights. It is necessary to follow up this information with further studies. We also want to look into the conditions concerning Rule 9 on Family Life and Personal Integrity. In both these areas there are a number of child aspects, which should be included in our analysis. Naturally I should like to perform these activities in cooperation with the Committee.

4. One important commitment I have made, is to pursue the principle of inclusion in all forms of development cooperation. With great satisfaction I note that many projects within UN agencies like UNESCO, ILO, UNICEF and WHO work along the same lines. If we are really to achieve progress in this area, both the governments of developing countries and major funding institutions must learn how to integrate disability measures into mainstream programmes. To exclude measures to meet the needs of disabled children, when it would be possible to do the opposite, must be seen as an act of discrimination.

5. In our monitoring we have all come across the need to describe and disseminate information about good practice. At the same time it is my experience that this is a rather resource demanding activity, for which it can be difficult to find money. Perhaps this is an area where we could cooperate.

6. In the monitoring of the Standard Rules The major international NGOs in the disability field play an active role. The following six organizations . Disabled peoples International, Inclusion International, Rehabilitation International, World Blind Union, World Federation of the Deaf and the World Federation of Psychiatric Users - have established a Panel of Experts, five men and five women from different parts of the world, all with personal experience of disability. The Panel constitutes an enormous resource in our monitoring, both as a consultative body and because of the gigantic network of national disability organizations it provides. Maybe this Panel would be willing to serve also in cooperation with other entities within the UN system and why not as partner in our cooperation concerning disabled children?

7. In August, 1998, the UN will organize an International Youth Forum in Portugal. So far we have not discovered any sign of bringing the attention to youth with disabilities. Let us cooperate to ensure the active participation by young disabled persons. We must also obtain some visibility for matters

concerning young disabled people on the agenda and in the background material.

Well, these are some concrete suggestions for cooperation, which we could discuss. I am sure that more good suggestions will come during the day.

Ladies and Gentlemen,

The Convention on the Rights of the Child recognizes fundamental rights of all children. It gives us all tremendous support in our struggle. The way the world looks, it will, however, take very long, before we will see full compliance with all its provisions in all countries. No group could illustrate this better than children with disabilities. If we are ever to succeed in providing decent conditions of life for all disabled children, their needs (both general and special) must be respected and taken into account in the mainstream of development in all countries. The recognition of the principle of inclusion and its consequences for resource allocation is our greatest challenge in the disability field. Let us begin with the children!

Thank you for your attention!

Recommendations

We, the participants in the Pan Arab symposium on the Standard Rules of the U.N. regarding achieving equal opportunities for the handicapped held in Amman on 18 and 19 October 1997, representing government and non-government organizations in the Arab countries, confirm our unanimous agreement on the following recommendations, which we present to our governments and the organizations active with the handicapped in the Arab world in order to work on implementing them.

1. We appeal to the governments to proclaim their commitments to achieving the two principles of complete participation and equality for the handicapped since these two participants constitute the main goal that seeks to improve the living conditions of the handicapped. This will lead to achieving our desired final goal of equal opportunities.
2. Governments should adopt national, procedural work plans that result in implementing the standard rules through the ministries concerned and organizations that work with the handicapped, and experts. These plans will have a positive impact on all citizens and not only on the handicapped.
3. A legal umbrella must be established in each country that acknowledges the rights of the handicapped to complete participation and equal opportunities in all sectors of society. This will be in accordance with the constitution of the countries concerned or derived from their legislative corpus.
4. In order to activate the legislation, it must be linked to appropriate mechanism such as the formation of by-laws and regulations in different spheres.
 - Spreading awareness among the different strata of society about equal opportunities for the handicapped.
 - Allocating financial resources that will help to activate this legislation.
 - Strengthening awareness.
 - Broadening the medical care umbrella for the handicapped.
 - Rehabilitating the handicapped.
 - Providing them with compensatory assistance and equipment.
 - Seeking to increase their independence in their daily life, and upholding their rights.

All the above are pre-requisite measures to the implementation of the Standard Rules of the U.N.

5. Governments must recognize the right of organizations and institutions that work with the handicapped to be represented whenever issues related to the handicapped are discussed, in accordance with the provisions of the Standard Rules.

6. A national Council for the handicapped must be established in each country. This council will draw up policies, coordinate national efforts and monitor the implementation of plans by the bodies concerned. This will guarantee improving the condition of the handicapped, increasing their participation in their communities and exchanging experiences with similar councils across the Arab world.

7. In order to guarantee the proper function of the National Council for the handicapped, it must be chaired by the Prime Minister or the minister responsible for the coordination of the handicapped programs. The Council should include the ministries concerned, representatives of the institutions that are active with the handicapped and experts.

8. Governments should adopt the creation of a Central National Register for the handicapped. This register will provide an essential data base in order to plan services offered to the handicapped and to carry out studies and researches according to actual needs.

9. Governments and national organizations should recognize the Community Based Rehabilitation Program (CBR), adopt its plans, and support it since it will be of strategic importance to involve the local community in raising the standard of the handicapped, and expanding areas of social participation. This will guarantee equal rights and opportunities and the rehabilitation of the handicapped. All of the above will result in the activation of the Standard Rules.

10. The Community Based Rehabilitation Program in each country concerned must focus on educating the handicapped on their rights and their varied opportunities for participation, and on sustaining their capacities to manage their own daily affairs.

The participants in the Forum affirm that the implementation of these recommendations must take place through close coordination between the Arab governments represented in their national councils, through the Arab League and the United Nations organizations that focus on the Arab region according to their specialties.

**Special Rapporteur of the Commission for Social Development on Disability**

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Speech on the Standard Rules by Mr. Bengt Lindqvist, Former M.P. and Cabinet Minister, Sweden

Ladies and Gentlemen,
Dear Participants,

I am both honoured and delighted to have this possibility to speak to you on the philosophy and contents of the new United Nations instrument in the disability field, entitled Standard Rules on the Equalization of Opportunities for Persons with Disabilities. Before I do this, I would like to briefly comment on the events which led to the adoption of these Rules.

As you remember, 1981 was the International Year of Disabled Persons. This was an event of historical importance. The greatest contribution of this event was, in my opinion, the theme of the Year: Full Participation and Equality. This must be considered as a recognition on the highest possible political level of the right of persons with disabilities to full participation and equal opportunities in the society they belong to. This important achievement was followed by the adoption of the World Programme of Action concerning Disabled Persons, which outlines the policies in harmony with the theme of the Year.

As you know the idea was that these policies should be implemented during the subsequent Decade of Disabled Persons, 1983 - 1992. Some important achievements were made during this period, but already in the middle of the decade it was obvious that too little happened. The international disability community therefore requested that the United Nations should assume a stronger leadership role in the development of better living conditions for persons with disabilities. The response to this request was the elaboration of the Standard Rules, which took place between 1990 -1993, when they were adopted.

Ladies and Gentlemen,

"In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms and making it difficult for

them to participate fully in the activities of their societies. It is the responsibility of States to take appropriate action to remove such obstacles. "This is probably the two most important sentences in the whole Standard Rules document. You find them in the Introduction, paragraph 15. The process outlined in the Rules is to identify and remove obstacles to full participation. The Rules indicate that this should be done both by empowering persons with disabilities and by creating an accessible society. Governments of countries are responsible for taking action to remove such remaining obstacles.

Well, as you see, we now already know three important things about the Standard Rules. The objective is to achieve full participation and equal opportunities. The method to use is to identify and remove remaining obstacles and governments are responsible for the necessary measures.

The Standard Rules instrument summarizes the contents of the World Programme and also takes into account some new aspects, which were emphasized during the decade. Above all the stronger emphasis on the human rights perspective, which developed during the decade, has been incorporated. In comparison with the World Programme there are mainly three features which distinguish the Rules document. The language of the Rules is more concentrated in form. The message of the Rules is directly addressed to member states, i.e. the governments of countries. The third characteristic is that the Standard Rules will be monitored through a separate monitoring system.

The Standard Rules include an introduction, a preamble, 22 different Rules and a description of the monitoring system. The actual Rules are divided into three sections: preconditions for participation, target areas for equal participation and implementation measures.

The first section, dealing with the preconditions for participation, mainly presents Rules on different forms of support to the individual, medical care, rehabilitation and various forms of support services. The purpose of these services is to reduce the functional limitations and increase the independence of the individual.

The section on target areas deals with sectors of society, which are of general importance for the quality of life. There is an initial Rule on accessibility, which deals with all the various aspects of access to physical environment and activities and services generally available to non-disabled persons. There are Rules on how to make sectors like education, employment, social security, culture and

recreation accessible. The Rule on family life and personal integrity is new and has no corresponding chapter in the World Programme. It reflects an area, which has attracted considerable attention during the decade.

The third section of the Rules, the implementation measures, presents a number of important measures, which are well-known in social engineering. I should here like to draw your attention to three of these Rules. In the Rule on legislation (Rule 15) the message is that states should create a legal base for measures to achieve full participation and equality for persons with disabilities. Legislative action may also be needed to remove conditions which may adversely affect the lives of persons with disabilities.

In Rule 18 it is said that states should recognize the right of the organizations of persons with disabilities to represent their groups at all levels. States should encourage and support the formation and strengthening of such organizations.

The third measure I should like to point to concerns coordination (Rule 17). Disability involves all spheres of society and therefore it is necessary to use a multisectorial approach. This also means that there is a constant need for coordination. It is therefore stated in the Rule that states are responsible for the establishment and strengthening of national coordinating committees or similar bodies.

The chapter on monitoring among other things contains the following:

"The purpose of the monitoring mechanism is to further the effective implementation of the Standard Rules. It will assist each state to assess its level of implementation of the Standard Rules and to measure its progress. The monitoring should identify obstacles and suggest suitable measures which would contribute to the successful implementation of the Rules.

...The Rules shall be monitored within the framework of the sessions of the Commission for Social Development. A Special Rapporteur...shall be appointed...for three years to monitor the implementation of the Rules. International organizations of persons with disabilities having consultative status with the Economic and Social Council...should be invited to create among themselves a panel of experts, on which organizations of persons with disabilities shall have a majority...to be consulted by the Special Rapporteur and, when appropriate, the secretariat."

Ladies and gentlemen,

In the following I should like to present more in detail a few Rules as examples. I choose some Rules, which are of more general interest.

One key element in disability policy is accessibility. Rule 5 deals with this issue. The main principle is that "States should recognize the overall importance of accessibility in the process of the equalization of opportunities in all spheres of society." The Rule deals with both the physical environment and access to information and communication. States are requested to make programmes of action to make the physical environment accessible and to provide access to information and communication.

In the area of physical environment standards and norms should be developed and the enactment of legislation should be considered. Such norms could concern buildings, means of transportation, streets and other outdoor environment. Accessibility measures should be introduced at the earliest possible stage of designing and Groups like architects, town planners and construction engineers should in their professional training have access to information about disability measures.

States should make information services and documentation accessible to different groups of persons with disabilities. Appropriate technologies, braille, sign language interpretation, easy language versions etc, should be used to make information available. States should encourage media to make their programmes accessible. States should also ensure that new computerized information and service systems are either made initially accessible or are adapted to be made accessible.

In Rule 6 on education it is stated that Member States should recognize the principle of equal educational opportunities for persons with disabilities, in integrated settings. States should ensure that the education of persons with disabilities is an integral part of the educational system. Adequate accessibility and support services, designed to meet the needs of persons with disabilities should be provided. In States where education is compulsory, it should be provided to girls and boys with all kinds and all levels of disabilities, including the most severe. Integrated education and community based programs should be seen as complementary approaches in providing cost-effective education and

training. In situations where the general school system does not yet adequately meet the needs of all persons with disabilities, special education may be considered. It should be aimed at preparing students for education in the general school system. The quality of such education should reflect the same standards and ambitions as general education and should be closely linked to it.

The essence of Rule 7 on employment is that persons with disabilities should be empowered to exercise their right to gainful employment and that it is the responsibility of states, i.e. governments of countries, to remove all remaining obstacles to employment. As far as possible, and it is possible to a far greater extent than today, persons with disabilities should have jobs in the regular labor market. When this, despite all efforts, does not seem to be possible, jobs should be offered in more protected forms.

Let me quote the following paragraphs from the text:

“Laws and regulations in the employment field must not discriminate against persons with disabilities and must not raise obstacles to their employment“

“States should actively support the integration of persons with disabilities into open employment“

“States, worker's organizations and employers should cooperate with organizations of persons with disabilities concerning all measures to create training and employment opportunities“

The text also contains a list of various technical measures, which could be taken by governments, in order to obtain these objectives.

In the related area of income maintenance and social security it is, of course, difficult to establish global guidelines due to the fundamental differences in economic conditions existing in the world today. Still it has been possible for the UN General Assembly to agree on some universal principles, which should be observed by all. I should here like to quote the following parts of Rule 8, which outline the basic responsibility of governments:

“States are responsible for the provision of social security and income maintenance for persons with disabilities“

“States should ensure the provision of adequate income support to persons with disabilities who, owing to disability or disability related factors, have temporarily lost or received a reduction in their income or have been denied employment opportunities“

“In countries where social security, social insurance or other social welfare schemes exist or are being developed for the general population, states should ensure that such systems do not exclude or discriminate against persons with disabilities“

“Social security systems should include incentives to restore the income-earning capacity of persons with disabilities.“

Ladies and Gentlemen,

One question I often get concerns the Standard Rules and the gender dimension. I have four different comments to make in this context.

First of all, the general presentation is done with the understanding that the suggested guidelines and policies concern all people with disabilities, irrespective of race, gender, age etc. This interpretation follows the tradition from the field of human rights.

Secondly, there are a few direct references to the gender dimension. The most general one is the sentence in para. 15 in the Introduction, where the following is said: "The purpose of the Rules is that girls, boys, women and men with disabilities, as members of their societies, may exercise the same rights and obligations as others."

The gender perspective is mentioned in some other instances in the Introduction. In the Preamble we find support for the Convention on the Elimination of All Forms of Discrimination against Women, particularly the sections on disabled women. In Rules 4 on Individual Support, Rule 6 on Education and Rule 9 on Family Life and Personal Integrity special attention is drawn to the needs of girls and women with disabilities.

Thirdly, the Rules must always be related to the concrete situation in a country. In doing so, there is a need for interpretation and for putting the emphasis or focus on certain conditions or circumstances. It is, for instance, often necessary to

emphasize the need to include special measures for disabled women in adult education, medical care, rehabilitation and the provision of technical aids. This kind of exemplifying and concretization must also be used much more in future monitoring.

Fourthly, it is very important to combine the provisions of the Standard Rules and those contained in the Convention on the Elimination of All Forms of Discrimination against Women. This possibility must be further developed through cooperation between the appropriate bodies within the UN, the special agencies, international NGOs and all concerned entities on the national level.

Finally, in reply to the question on the gender dimension, of course, one would have wished for a more clearly spelt out gender dimension in the Rules document. However, by using all these different means, which I have pointed to, I am sure that we can make it a strong and useful tool also in the struggle for empowerment and full participation by disabled women in their societies.

Ladies and Gentlemen,

The Standard Rules document is not an international convention. Consequently it is not legally binding for member states. Formally the Rules are a UN declaration with some special features, which I pointed out earlier. How important and committing are the Rules then? Well, the mere fact that they have been unanimously adopted by the UN General Assembly after extensive preparations and as the consequence of the UN Decade of Disabled Persons, makes them a strong international document. However, more has been done to increase the strength of the Rules. At all five major World Conferences, organized by the United Nations from 1993-1996, on human rights in Vienna 1993, on population issues in Cairo 1994, on social development in Copenhagen 1995, on the situation of women in Beijing 1995 and on housing and shelter in Istanbul 1996, Strong statements have been adopted in support of the implementation of the UN Standard Rules. This remarkable achievement has been made thanks to the untiring efforts and determination by many representatives of the organized movement of persons with disabilities to make the most of this document and to convince governments to move from words to concrete action to improve the living conditions of persons with disabilities.

Ladies and Gentlemen,

I should now like to use the rest of my time to give you an account of what we have been doing during these three years of monitoring. If you study the purpose of the monitoring, indicated in chapter IV, para 1 of the Rules document, you find that there are two main tasks to be performed - to promote the implementation of the Rules and to monitor the progress made by Member States. In our work we have tried to take both these tasks into account.

It all started in 1994. I was appointed by the Secretary General, Boutros Boutros-Ghali, in March that year. A large international conference was organized in cooperation between the Icelandic government and the UN secretariat, the purpose of which was to launch the monitoring activity. I started my work in August. A Panel of Experts was established in September by the following six organizations: Disabled Peoples' International, Inclusion International, Rehabilitation International, World Blind Union, World Federation of the Deaf, and World Federation of Psychiatric Users. The Panel has consisted of 10 persons, five men and five women, all with personal experience of disability and coming from different parts of the world. In September I also opened my small office in Stockholm.

To promote the implementation of the Rules I have traveled extensively during these three years. I have participated at more than 35 international conferences. I have held meetings with governments and NGO's in 21 countries, mostly developing countries, but also some countries in transition. I have attended four regional seminars in Africa and Central America with representatives of both governments and NGO's. The Panel of Experts has held three meetings to provide advice on important aspects of the monitoring. One of the most important contributions by the Panel was to reach an agreement with me to concentrate the monitoring effort on certain Rules, in order to get a more in-depth understanding of the situation in these areas. The Rules areas, selected for analyses, were the following: Accessibility (rule 5), education (rule 6), employment (rule 7), legislation (rule 15), coordination of work (rule 17), and organizations of persons with disabilities (rule 18).

In the areas of education and employment we have cooperated with UNESCO and ILO. In the other four areas we have made a comprehensive survey, built on a questionnaire with more than 30 questions.

During the third meeting of the Panel the experiences of the first three-year period were discussed. The Panel also started a discussion of future tasks, built on

the assumption that the Economic and Social Council would decide to continue the monitoring for a second three-year period.

The Commission for Social Development has dealt with our monitoring activity twice. It has given strong support to our work and agreed with us to limit our more profound analyses to some selected areas. One important recommendation from the Commission is that I should mainly concentrate my monitoring activities to assisting developing countries.

During these three years we have circulated two global surveys. The first study consisted of a letter to all governments, asking them how they had received the Rules, what their plans were and if they had already taken any new initiatives based on the Rules. We got only 38 replies from the totally 185 Member States, which, of course, was a disappointment. The second survey consisted of a comprehensive questionnaire dealing with general policy, legislation, accessibility, the position of organizations and coordination issues. This time we also invited the national member organizations of the international NGO's in the panel. Even if the final date for replies was the end of March 1996, replies have kept coming in ever since. We have now (March 1997) received 88 replies from governments and 165 replies from NGO's. Totally we have received information from 130 countries. This time the response rate from governments is considered to be high by UN standards. We started our analysis of government replies in August 1996, when 83 government replies had arrived. A report on the results of this analyses will be published during the first half of 1997. The analysis of NGO replies started in January 1997 and will be reported during this year.

Ladies and Gentlemen,

Let us now proceed to deal with the substance of our monitoring. What are our findings? Did the Rules during this period have any effect on the conditions of life for disabled people? Let me first of all emphasize one thing: People with disabilities around the world are still being marginalized. Their needs are often not being taken into account in a proper way. There is no country in the whole world which has fully implemented the Standard Rules. In developing countries millions of disabled people live in extreme poverty, under bad health conditions and lack access to education and income earning activities. It will take a long time to change these bad conditions.

The UN Standard Rules is a policy document, a "code of conduct" for governments in the disability field. The most it can do is to change the thinking and acting of governments, to make them adopt an inclusive approach to disability, and in the end, to inspire them to launch new legislation and programmes to improve living conditions. When we promote the implementation of the Rules we try to obtain this change in behaviour. When we monitor the Rules we try to find out to what extent government measures exist and if they are oriented towards the philosophy of the Rules.

Well, let us come to our findings. The first thing I want to tell you is that there is a noticeable change in the behaviour of governments. A considerable number of countries have adopted, or are in the process of adopting, new legislation in the spirit of the Standard Rules. Such countries can be found in all regions of the world. There are also countries which have adopted plans of action, built on the Rules. In our second survey we found that 85% of governments, providing information, state that the Rules have led to rethinking. Another observation of great importance is that the "pattern of cooperation" between governments and NGO's is getting established. In 74% of countries, providing information, there are national councils on disability or similar bodies. In the vast majority of these councils organizations of persons with disabilities are represented. These organizations have a legal mandate to influence policy making in the disability field in 62% of countries.

In the area of accessibility much remains to be done in most countries. However, there are some good signs. In 54% of countries, providing information, a disability component has been included in the training of architects, community planners etc. Strong legislation to create accessibility has been adopted in some countries, including USA, Canada, Australia and the United Kingdom. These new laws demonstrate that it is possible to maintain tough regulations on accessibility also in the most liberal economies.

Sign language for deaf people is definitely gaining ground. In a number of countries sign language has been recognized as the first language of deaf people in education. In a greater number of countries sign language is recognized as the main means of communication between deaf and hearing people.

In the crucial area of education the situation is very bad. Unfortunately, we have evidence that the needs of disabled children continue to be neglected or

marginalized in most developing countries, due to lack of interest from both governments in developing countries and foreign funders.

In the employment field there is not one single country in the whole world, which can report real success. The employment rates for disabled people are generally dramatically lower than for the working age population. The situation in employment calls for new and strong initiatives and a much more active government intervention. In my opinion the situation will remain basically the same, until this happens.

One result of our studies, on which many have reacted strongly, is that a number of countries obviously have legislation, which violates fundamental human rights of certain groups of disabled people. This for instance concerns areas like the right to marriage, access to law courts, property rights and political rights. In some cases up to 25% of countries, providing information, exclude certain groups of disabled people from such rights. Generally, it seems that many basic human rights of disabled people are badly protected in many countries.

Well, ladies and gentlemen, I could go on and on telling you about the observations we have made. Unfortunately, time does not allow this. Our work has been summarized in two reports to the Commission for Social Development, in 1995 and in 1997. Furthermore, it is our intention to publish one book on the analysis of government replies to our second survey and a number of reports on NGO replies, including some comparative analyses also including government replies from the same countries.

Ladies and gentlemen,

The Commission for Social Development has recommended that the special monitoring activity, attached to the Standard Rules, should continue for another three-year period. A second monitoring period will offer new opportunities, opportunities for new initiatives in legislation and programmes, opportunities for improved cooperation between governments and NGO's and opportunities for bringing the disability component into the large programmes for development cooperation. My hope is that we, in the years to come, will be able to move away from the present exclusive behaviour towards a human rights based approach. Measures to achieve full participation for persons with disabilities must become an integral part of government responsibility. These principles must govern the behaviour of actors in both the public and the private sectors.

In the past we have proved that we can achieve a lot through cooperation. Together we are able to change the world into a society, designed and constructed for all citizens - a society for all! And remember: A society good for disabled people, is a better society for all!

Thank you.



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Speech on the Standard Rules by Mr. Bengt Lindqvist, Former M.P. and Cabinet Minister, Sweden

Ladies and Gentlemen,

Dear Participants,

First of all I want to thank the organizers for the opportunity to participate at this important conference. I am also delighted to be back in Dublin, which I visited some fourteen years ago as secretary of the newly formed Disabled Peoples International. Through Liam Maguire, representing the movement of disabled people in Ireland, we were all inspired and challenged at the same time. His contribution to the development of international disability policy was outstanding.

I am going to speak about disability and human rights. As my point of departure I will use the UN Standard Rules and some observations I have made during my monitoring of these Rules.

As you remember, 1981 was the International Year of Disabled Persons. This was an event of historical importance. The greatest contribution of this event was, in my opinion, the theme of the Year: Full Participation and Equality. This must be considered as a recognition on the highest possible political level of the right of persons with disabilities to full participation and equal opportunities in the society they belong to. This important achievement was followed by the adoption of the World Programme of Action concerning Disabled Persons, which outlines the policies in harmony with the theme of the Year.

The idea was that these policies should be implemented during the subsequent Decade of Disabled Persons, 1983 - 1992. Some important achievements were made during this period, but already in the middle of the decade it was obvious that too little happened. The international disability community therefore requested that the United Nations should assume a stronger leadership role in the

development of better living conditions for persons with disabilities. The response to this request was the elaboration of the Standard Rules, which took place between 1990 -1993, when they were adopted.

Ladies and Gentlemen,

"In all societies of the world there are still obstacles preventing persons with disabilities from exercising their rights and freedoms and making it difficult for them to participate fully in the activities of their societies. It is the responsibility of States to take appropriate action to remove such obstacles." This is probably the two most important sentences in the whole Standard Rules document. You find them in the Introduction, paragraph 15. The process outlined in the Rules is to identify and remove obstacles to full participation. The Rules indicate that this should be done both by empowering persons with disabilities and by creating an accessible society. Governments of countries are responsible for taking action to remove such remaining obstacles.

Well, as you see, we now already know three important things about the Standard Rules. The objective is to achieve full participation and equal opportunities. The method to use is to identify and remove remaining obstacles and governments are responsible for the necessary measures.

The Standard Rules instrument summarizes the contents of the World Programme and also takes into account some new aspects, which were emphasized during the decade. Above all the stronger emphasis on the human rights perspective, which developed during the decade, has been incorporated. In comparison with the World Programme there are mainly three features which distinguish the Rules document. The language of the Rules is more concentrated in form. The message of the Rules is directly addressed to member states, i.e. the governments of countries. The third characteristic is that the Standard Rules will be monitored through a separate monitoring system.

The Standard Rules include an introduction, a preamble, 22 different Rules and a description of the monitoring system. The actual Rules are divided into three sections: preconditions for participation, target areas for equal participation and implementation measures.

The first section, dealing with the preconditions for participation, mainly presents Rules on different forms of support to the individual, medical care, rehabilitation

and various forms of support services. The purpose of these services is to reduce the functional limitations and increase the independence of the individual.

The section on target areas deals with sectors of society, which are of general importance for the quality of life. There is an initial Rule on accessibility, which deals with all the various aspects of access to physical environment and activities and services generally available to non-disabled persons. There are Rules on how to make sectors like education, employment, social security, culture and recreation accessible. The main principle here is that such measures should be taken as a natural part of the sector concerned - mainstreaming. Regular schools, public and private employers generally, cultural and recreational institutions etc. should all be responsible for making their activities and environment accessible and available for persons with disabilities.

The Rule on family life and personal integrity is new and has no corresponding chapter in the World Programme. It reflects an area, which has attracted considerable attention during the decade.

The third section of the Rules, the implementation measures, presents a number of important measures, which are well-known in social engineering. I should here like to draw your attention to three of these Rules. In the Rule on legislation (Rule 15) the message is that states should create a legal base for measures to achieve full participation and equality for persons with disabilities. Legislative action may also be needed to remove conditions which may adversely affect the lives of persons with disabilities.

In Rule 18 it is said that states should recognize the right of the organizations of persons with disabilities to represent their groups at all levels. States should encourage and support the formation and strengthening of such organizations.

The third measure I should like to point to concerns coordination (Rule 17). Disability involves all spheres of society and therefore it is necessary to use a multisectorial approach. This also means that there is a constant need for coordination. It is therefore stated in the Rule that states are responsible for the establishment and strengthening of national coordinating committees or similar bodies.

The chapter on monitoring among other things contains the following:

"The purpose of the monitoring mechanism is to further the effective implementation of the Standard Rules. It will assist each state to assess its level of implementation of the Standard Rules and to measure its progress. The monitoring should identify obstacles and suggest suitable measures which would contribute to the successful implementation of the Rules.

...The Rules shall be monitored within the framework of the sessions of the Commission for Social Development. A Special Rapporteur...shall be appointed...for three years to monitor the implementation of the Rules. International organizations of persons with disabilities having consultative status with the Economic and Social Council...should be invited to create among themselves a panel of experts, on which organizations of persons with disabilities shall have a majority...to be consulted by the Special Rapporteur and, when appropriate, the secretariat."

Ladies and Gentlemen,

As is mentioned in the Standard Rules, there are still lots of obstacles, which prevent persons with disabilities from participating in the society they belong to. To remove these obstacles we must work in two main areas. We must do everything we can to empower persons who happen to be disabled to take their own decisions and to be as independent as possible. At the same time we must take the needs of disabled people into account when we design and build our society. These two areas are like communicating vessels. We have to work in both to obtain the goals we have set. From this perspective disability policy becomes an issue of social development. It is necessary, and also quite realistic, to identify such obstacles to participation. When we have found them, we must find or construct appropriate measures, through which we can remove or reduce the effects of these obstacles.

One obvious strength of the Standard Rules is that they suggest a number of principles and requirements, to which any nation can relate its own policies and programmes, or perhaps lack of policies and programmes. The Rules become an evaluative instrument, through which we may assess our situation and initiate new and appropriate measures, a classical approach in social development.

During the four years the Rules have existed, they have proved to be a useful tool in promoting the philosophy of full participation. In our global survey, 85% of

responding Governments indicate that the Rules have led to rethinking in the disability field. Generally the Rules have been used in the three following ways; to make new legislation, to elaborate national plans of action and to evaluate the situation. It is encouraging that a considerable number of countries already have adopted new "equal opportunities" legislation in the spirit of the Rules.

Another encouraging fact is that the position of organizations of persons with disabilities as representatives of their groups has become stronger in many countries. Governments are also cooperating more systematically with such organizations through national coordinating committees or councils.

However, the goal of full participation has more dimensions than social development. Again, according to the text of the Standard Rules there are "obstacles preventing persons with disabilities from exercising their rights and freedoms". As long as there are obstacles of such a nature, disability policy evidently is a human rights issue. If we study the Universal Declaration of Human Rights and the two Covenants, supporting the Declaration, it is obvious that each fundamental human right, enshrined in these documents, has a disability dimension.

Let me illustrate this by giving you some examples from our second survey.

The right to education is crucial in all human development. Still we find in many developing countries that the level of participation by disabled children in compulsory education is dramatically lower than for children in general. In some countries this is due to the fact that regular schools have not been made accessible and have not been provided with facilities to support disabled children. In other cases there are legal regulations, excluding groups of disabled children from education. One really challenging fact we found in a number of countries is that large development programmes in education, often supported by organizations like the UNDP, the World Bank Group and governmental funders, have not included any measures whatsoever for the integration of disabled children. Consequently I maintain that the right to education of disabled children is seriously violated in many different ways.

In our second survey, to which totally 83 governments responded, we put some questions directly dealing with the protection of the rights of persons with disabilities. The outcome is alarming. In a considerable number of countries we found infringements in several fundamental human rights. In about 20% of the

countries, providing information, there were limitations in the right to marriage and parenthood. In a number of countries there were limitations in the right to privacy, the right to property and access to law courts. In 14 countries there were infringements in the right to vote and stand for election. Our analysis showed that persons with mental disabilities were the most afflicted by this kind of discrimination.

Concerning economic and social rights our study indicates that 33 countries out of 82 make no exceptions concerning disabled people, while 49 countries make one or more exclusions in the rights to areas like health care, financial security, employment, training and rehabilitation. A comparison between different areas of legislation, indicates that the rights of disabled people seem to be somewhat better protected in the area of civil and political rights than concerning economic, social and cultural rights. Another general observation we can make is that both the judicial and administrative enforcement mechanisms in the area of disability rights seem to be weak or non-existent in many countries.

Ladies and Gentlemen,

The outcome of the first three years of monitoring the Standard Rules reveals that we have a tremendous task ahead of us. We must increase our efforts in all areas. We must improve the way in which we practice the principle of mainstreaming. The needs of persons with disabilities must be included in their natural context of development. In general development programmes in education, health, training and employment, physical planning etc., disability measures must be included as a matter of course. This is actually the only way to make real progress towards full participation. It is also the only way to ensure that the needs of disabled people are not being neglected and that disabled citizens are not being discriminated against.

As you may know, the special monitoring exercise in connection with the Standard Rules will continue for a second period - 1997-2000. I can assure you that the two areas of mainstreaming and human rights will really be in focus in our work. This second period of monitoring offers a real challenge to the Governments of the world and to the disability community to ensure progress in the promotion of the goal of full participation and equal opportunities. I hope you will join us in accepting this challenge.

Thank you for your attention!



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6th European Congress on Research in Rehabilitation

May 31-June 4 1998, Berlin, Germany

European Lecture

Dr Arthur O'Reilly

President

Rehabilitation International

It is a great honour for me to have been invited to deliver the European Lecture at the 6th European Congress on Research in Rehabilitation. It is a particular privilege to have been asked to speak in this year, the fiftieth anniversary of the proclamation of the Universal Declaration of Human Rights.

I was in Geneva a few weeks ago when the UN Commission on Human Rights was beginning its latest session. Speaking with one of the delegates concerning a draft Resolution on the Human Rights of Persons with Disabilities (which was subsequently adopted by the Commission), I was somewhat surprised when he remarked that, in his opinion, it was unlikely that the Universal Declaration would be adopted by the UN General Assembly if it was proposed today.

A second surprise came a week or so later, when I was asked to comment on a draft paper which an expert on international disability legislation was preparing for an important conference. Outlining the historical development of the rights-based perspective on disability in international law, the lawyer referred to the World Programme of Action Concerning Disabled Persons proclaimed by the UN General Assembly in 1992 and commented: 'The first two parts of the World Programme of Action looked *backwards* and reflected the *traditional* policy themes of prevention and rehabilitation....'

Perhaps I should not have been surprised at the implication that rehabilitation and prevention were dated policies. Rehabilitation International (RI) which was founded in 1922 as the first international effort to stimulate services for what were then known as crippled children has as its mission

✓ 'to improve the quality of life of people with disabilities throughout the world through rehabilitation, the prevention of disability and the equalisation of opportunities within society'.

RI does not see either rehabilitation or prevention as policies which are 'backwards' or out-of-date. On the contrary, advances in prevention and rehabilitation have significantly increased our potential as a society to safeguard and enhance the dignity and rights of people throughout the developed and developing world.

Prevention

The most common enemies of the world's children include five diseases that today kill over 8m children a year and malnutrition which holds back the mental and physical development of one child in three in the developing world¹. These five diseases - pneumonia, diarrhoea, measles, tetanus, whooping cough - are progressively being defeated. Deaths from measles, for example, dropped from

¹ UNICEF: The State of the World's Children

2.5m in 1980 to 1m in 1994. And the number of non-fatal cases of measles, a major cause of disability and malnutrition in children, fell over the same period from 75m to 25m. It is estimated that the increase in immunisation has so far prevented disability from polio in more than 3m children.

Oral rehydration therapy (ORT) is now saving 1m young lives a year. (ORT means increased fluid intake and continued feeding when a child has diarrhoea.) Yet more than 2m under-fives still die needlessly every year of diarrhoeal dehydration. And it remains a primary cause of malnutrition, which stunts the mental and physical growth of one in three children in the developing world.

Nearly 45m people in the world are blind, four out of five of them living in developing countries. About 80% of this blindness is treatable or preventable, but those affected remain blind for want of access to affordable eye care.

It is now estimated that nearly 1.6 billion people in over 110 countries are at risk from iodine deficiency and that some 300m have an intellectual disability as a result. Because their mothers lack iodine, at least 30,000 babies are stillborn every year, and over 120,000 are born with an intellectual and physical disability. The solution - iodising all salt supplies - is relatively simple and costs about 5 U.S. cents per person per year.

In the last decade alone, over 1.5m children have been killed in armed conflicts. A further 4m have been disabled, and uncounted millions are suffering from post-traumatic stress disorders.

These are but a very small sample of the reasons why prevention policy, practice and research should remain high on the agenda.

Group 1 diseases², which cause one-third of all deaths and a quarter of all disabilities, are largely avoidable and can be prevented. Poverty, which creates the conditions which give rise to many of the causes of death and disability, can be eradicated. Winning this struggle is no longer an aspiration: it is a practical possibility. Of course there are, and will continue to be, obstacles of vested interests, and opposition. But, as the UNDP says, scepticism and disbelief are just as disabling. Why, when all of these prevention goals are practical, and affordable, are we allowing many children and adults to die or acquire a disability? UNICEF, in its 1994 report 'The State of the World's Children', did not mince its words: I quote:

'When so much could be done for so many and at so little cost, then one central, shameful fact becomes unavoidable: the reason that these problems are not being rapidly overcome is not because the task is too

² Communicable diseases, maternal conditions arising during the perinatal period, and nutritional deficiencies.

large, or too difficult, or too expensive. It is because the job is not being given sufficient priority because those most severely affected are almost exclusively the poorest and least politically influential people on earth'.

At the World Summit for Social Development in Copenhagen - the largest summit ever, with 117 heads of State present and 185 governments represented - countries made, for the first time, clear commitments to eradicate poverty, not simply alleviate it:

'We commit ourselves to the goal of eradicating poverty in the world, through decisive national actions and international cooperation, as an ethical, social, political and economic imperative of humankind.'

Specific commitments were made, with quantified and time-bound goals.

Goals set at UN conferences are often greeted with scepticism. But the goals set at the World Summit for Children in 1990 are well on their way to being achieved³. So there is good reason to hope, and every reason to keep the pressure on, to ensure there is no weakening of commitment. Where progress has been slow - for

³ See UNICEF, World Summit for Children Follow-up: Mid Decade Review 1996. Secretary General's Report, New York

example, in improving access to clean water and in reducing the prevalence of malnutrition - the problem has been lack of political commitment and a failure to develop a strategy to get the job done. In the year 2000, governments will meet again to evaluate the action taken since the Copenhagen Summit and to agree on new initiatives. The UN General Assembly recently decided that this evaluation will be a special process through the Social Development Commission.

Failure to prevent preventable diseases, failure to treat treatable conditions should no longer be acceptable. As individuals, as organisations, we need to re-examine our values and speak out - to the media, to governments. The ultimate responsibility rests with governments: we must work to ensure that they do not shirk that responsibility and we must work to strengthen the political commitment that is so vital for success.

Rehabilitation

Increasingly I hear speakers at disability conferences decry the 'rehabilitation model' - which many equate with the so-called 'medical model' - of disability in favour of the social or rights model. The Universal Declaration states that all human beings are born free and equal in dignity and rights: it is the responsibility of all to promote respect for those rights and to secure their universal and effective recognition and observance. But is it not simplistic, or at least

counter-productive, to assume that there is one model, one right way, to achieve this? 'Rehabilitation bad, rights good' smacks of the maxim adopted by Orwell's ill-fated four-legged revolutionaries.

In the context of research, I am reminded of a paper written by Gerben De Jong⁴ some years ago in which the independent living paradigm is contrasted with the rehabilitation paradigm which has, in the author's words, 'dominated disability research'. De Jong borrows the concept of paradigm from Kuhn⁵, who observed that scientific facts do not emerge by simple accumulation or evolution, but are the products of new ways of thinking - new scientific paradigms. Paradigms provide the framework by which problems are identified and solved. De Jong also reminds us of two other concepts which are important in Kuhn's analytic frame of reference. The first is the concept of an anomaly - an event or observation which cannot be adequately explained by the dominant paradigm of the times. The second is the concept of paradigm shift - when one paradigm is replaced by another. A paradigm shift does not occur unless there is a new paradigm to replace the old.

At the time of writing, De Jong argued that the dominant paradigm in disability policy is the rehabilitation paradigm in which

⁴The Movement for Independent Living: Origins, Ideology and Implications for Disability Research. Michigan State University: University Centres for International Rehabilitation, 1979

⁵The Structure of Scientific Revolutions, 1970

'problems are generally defined in terms of inadequate performance in activities of daily living or in terms of inadequate preparation for gainful employment. In both instances, the problem is assumed to reside in the individual'.

According to the independent living paradigm, on the other hand, the problem does not reside in the individual but often in the solution offered by the rehabilitation paradigm, which De Jong describes as 'the dependency inducing features of the physician - patient or professional - client relationship.' Rehabilitation is perceived, in other words, to be part of the problem, not the solution.

Paradigms, in defining problems and the range of appropriate interventions, largely determine what is relevant for the purposes of research. If, as Kuhn suggests, there is no such thing as research in the absence of any paradigm, it is important that we critically and objectively appraise the political, ideological, social and professional frameworks in which we and our organisations fund, manage, publish or carry out disability research.

There are still many questions to be asked about the usefulness or utilisation of some of the research being conducted, questions which suggest that those whom the research is presumably intending to benefit have little or no involvement in identifying the issues to be

addressed or in the way in which the project is carried out. All of the parties to a research contract, including funders, researchers and subjects, have obligations and rights. There is an old saying: 'Whoever pays the piper calls the tune'. Perhaps those who fund research are in the best position to re-assess the basis on which research proposals should be made and to require, inter alia, that those submitting proposals at least consult with people with disabilities and/or their organisations on what issues are most important and how research might be of benefit.

Rehabilitation research has made, and has the continuing capacity to make in the future, a significant contribution to the effectiveness and improvement of rehabilitation. But there are good reasons why people with disabilities may be sceptical of the value of research, because of their lack of control over or involvement in research undertaken 'on their behalf' and the remoteness of much research from their immediate concerns.

The Politics of Evaluation

There are, I imagine, few people here today who believe that rehabilitation research programmes are adequately funded. While it would be a mistake to assume that research funding decisions are always made on some rational or scientific basis, one might nevertheless expect - at least insofar as research funding from

government or government agencies is concerned - that, all other things being equal, programmes which can be shown to produce savings in public expenditure should be accorded a higher priority for funding than programmes which fail to do so. Yet few rehabilitation programmes appear to have produced evaluations or cost-benefit analyses which could be used to support a case for better funding.

There is no argument about the need for evaluation. Any form of decision-making entails choice between alternatives. And choice implies evaluation, in two stages

- weighing the advantages (or benefits) of taking any course of action against the disadvantages (or costs) of that action
- comparing the relative outcomes of that process to choose the course of action which produces the result most favourable to the decision-maker.

The general need for better evaluative data has been reinforced by growing and competing demands on public expenditure. Competition for resources exists not only within the overall context of national and international economic and social policies, but also between disability policies (prevention versus rehabilitation versus equal opportunity, for example) and within the rehabilitation policy area itself. For instance, should available resources be allocated to

train all those who are disabled, concentrated on skill training for those most likely to get jobs, or devoted to those most in need?

Disability programmes operate in a political context. In their design and implementation they are open to pressures from numerous interest groups. They are often caught up in inter-agency and intra-agency manoeuvring for influence and advantage. Let me give some examples of the kind of political issues which can arise in evaluation work.

- Evaluations should start with programme goals. These should be clear, unambiguous and measurable. They tend, on the contrary, to be global, diffuse and diverse: this may be because the goals represent a coalition of different values and interests. It may also be because administrators prefer goal statements that inhibit evaluation.
- A further difficulty with goals is that, where programmes have multiple objectives, they may appear to be in conflict or inconsistent with each other. For example, a common practice in trying to cope with the difficulty of conflicting objectives in vocational rehabilitation is 'creaming'. Selecting or 'creaming' the more able to enhance placement outcomes is a recognised - if not always admitted - phenomenon in many countries.

- 'Defensive evaluation' by an agency of its own programmes may be carried out to pre-empt a less controlled evaluation by unfriendly outsiders.
- Funding agencies may impose an external evaluation in order to confirm their preconceptions. Such evaluations may even be carried out using methodologies (and/or evaluators) which fall short of generally accepted professional standards, but to question the process or results runs the risk of lessening future funding prospects.
- Evaluations, even where well carried out, may produce politically unpopular results. Such an exercise might, for example, establish as scientifically proven the proposition that children learn as well in large classes, as in small; yet few if any school principals would be willing to act on such a conclusive finding in assessing teaching staff requirements, or in advising parents on the educational needs of their children.
- Evaluations can be effectively used as a political tool to kill or delay innovative programmes, or programmes whose outcomes raise questions about funding policy.

In reality, evaluation studies appear to have little impact on agency policy making. If the results are positive, they reinforce the status

quo; if negative, the findings may be selectively ignored, refuted or rationalised.

Difficult though evaluation is, however, the easy solution of 'do not evaluate' implies an almost total disregard for the effective and efficient use of public funds. The current situation of growing public resource scarcity is producing a climate in which it is easier to make unpopular political decisions. This, allied to improvements in evaluation techniques, could improve the usefulness of evaluation studies. But we also need a greater understanding by policy makers and programme managers of the role of evaluation and how it might be used to improve their decision-making: one reason that negative evaluation results have such little impact is because those involved never seriously entertain the possibility that the results could come out negatively.

The imprecision inherent in any evaluation of rehabilitation programmes does not mean that evaluations should not be carried out or used as a guide to policy. There is no alternative, if policy affecting the future is to be based on a reasonable assessment of the problems with which that policy must deal.

The Challenge for Research, and Researchers

There are, some say, three certainties in this world - death, taxes and change. There is little one can do about the inevitability of the first and, apparently, the second. But does research not have a role in influencing the shape, direction and pace of change? Why, when economic difficulties arise, does research tend to be one of the sectors to suffer reduced funding, at the very time when more rather than less creativity and innovation is needed?

Let me mention three areas in which I believe problems lie.

The first is the public perception of science and scientists. I remember in my college days (the sexist language will tell you that was not yesterday) the maxim:

‘He who can, does.

He who can’t do, teaches.

And he who can’t teach does educational research.’

The boffin in the ivory tower, the remoteness of the academic from real life, are perceptions which are still more widely held than we might like to believe. Public confidence in the scientific establishment has not been helped by disagreements over ‘mad cow

disease' (BSE) and genetic engineering in agriculture, to take but two examples.

The population of Europe is ageing. The emerging age-structure represents a major threat to the future financial sustainability of European public pension systems. The rapid growth of the dependent population (by 2020 25% of the European population will be over 60 years old) is creating new healthcare and rehabilitation needs. Although most older people are not disabled, the majority of disabled people are elderly. Policy makers are under pressure not only to reform and adapt social protection systems but to improve the efficiency and cost-effectiveness of health systems. Here is a challenge, and an opportunity, for research. Notwithstanding the difficulties facing policy makers, this is not, I suggest, the time to reduce spending on medical and public health research.

The second problem area is the apparent lack of relevance of some rehabilitation research. I have already commented on the fact that research problems and designs are often developed with little input from consumers. Rehabilitation practitioners too should have a voice in determining research priorities, to enhance the relevance and eventual usefulness of the research⁶. President John F. Kennedy, in an address to the U.S. National Academy of Sciences twenty five years ago, said

⁶ See, for example, Rubin S.E. and Rice J.M. Quality and Relevance of Rehabilitation Research: A Critique and Recommendations. Rehabilitation Counselling Bulletin, September 1986, 33-42

'Scientists alone can establish the objectives of their research, but society, in extending support to science, must take account of its own needs'.

The European Commission is of the same view: as Commissioner Cresson⁷ says:

'Research must be considered as fundamentally serving people, matching their expectations and needs. It is in this spirit that the Commission has conceived the next - the fifth - European Union framework programme for research, technological development and demonstration activities'.

The third problem area is that of communication between scientists and policy makers/bureaucrats. This could, of itself, provide a sufficient subject for a conference, but I will mention just two points.

First, each party tends to speak and write to the other in a language which the other does not fully understand, and to be annoyed and frustrated when misunderstanding takes place. Secondly, each party seems to fail to appreciate the particular culture and structure within which the other is operating. In the absence of such an

⁷ responsible for science, research and development, education, training and youth. Quoted in EU Biomedical and Health Research Newsletter December 1997, Vol 8, No 1.

understanding, failure to communicate is almost inevitable. At the risk of alienating the majority of my audience, let me give you a quick example of what I mean by quoting from very different sources.

In looking at explanations which have been offered for bureaucratic problems, one could focus on three parts of the government system: the personal traits of the bureaucrats or *fonctionnaires*, the structural arrangements of public bureaucracy, and the political system which has ultimate authority over the bureaucracy⁸.

Merton, writing of bureaucratic structure and personality, says:

'Public bureaucrats are often described as being lazier, less competent, more power hungry than people in comparable jobs in profit making or non profit organisations. Sometimes it is suggested that public offices attract such people; it is often suggested that the structure and traditions of public bureaucracies turn otherwise decent people into 'bureaucratic personalities' characterised by negativism, complacency, rigidity and arrogance'⁹.

⁸ Barton, A.H. A Diagnosis of Bureaucratic Maladies, *Amer. Behav. Scientist*, 22,5, 1979.

⁹ Merton, R.K. Bureaucratic Structure and Personality, in *Social Theory and Social Structure*. New York: Free Press, 1968.

It has been argued that the structure of public bureaucracy is said to make it impossible even for well-motivated people to do a good job:

'Red tape - rigid rules and lack of managerial discretion - prevents efficient and innovative action by public officials, in contrast to the flexibility of action in the private sector. Civil service rules designed to prevent political purges and patronage make it impossible to fire the incompetent, or to hire and reward the competent and productive. The reward system is heavily biased against the risks of innovation compared with that of profit-making enterprises - the bureaucratic innovator who fails is crucified, while successful innovation has little payoff. Public agencies can only act within legally authorised jurisdictions and these are fragmented both in terms of subject matter and geographical area, so that effective problem-solving is impossible. Still worse, the incentive system for bureaucrats is perverse: they are rewarded with power and privileges for expanding their budgets and staff, regardless of costs and benefits to the public'¹⁰.

¹⁰ Barton, op cit

What of our friend, the scientist? A character in one of Arthur Koestler's books, which is about people like us attending conferences like this, says with tongue in cheek, that

'scientists pose as dispassionate servants of Truth, free from all emotional bias each of them possesses a small fragment of the Truth which he believes to be the whole Truth, which he carries around in his pocket like a tarnished bubble-gum ... There is no such thing (as interdisciplinary dialogue) except on the printed programme. When the dialogue is supposed to start, each gets his own bubble-gum out and blows it into the others' faces. Then they repair, satisfied, to the cocktail room'.

Exactly one hundred years ago, Otto von Bismarck said: 'Die Politik ist keine exakte Wissenschaft'. It is precisely because politics is not an exact science that scientists sometimes have difficulty accepting political decisions with regard to funding of research.

With such differences in cultures, traditions, structures and language, it is hardly surprising that communication is not as good as it should be.

Research awareness training, including the skills required to critically read research literature, should be an essential part of the education of policymakers and bureaucrats. And those intending to work in research should likewise learn the principles underlying the development and implementation of policy. Nothing, as Goethe remarked, is more terrible than to see ignorance in action.

Conclusion

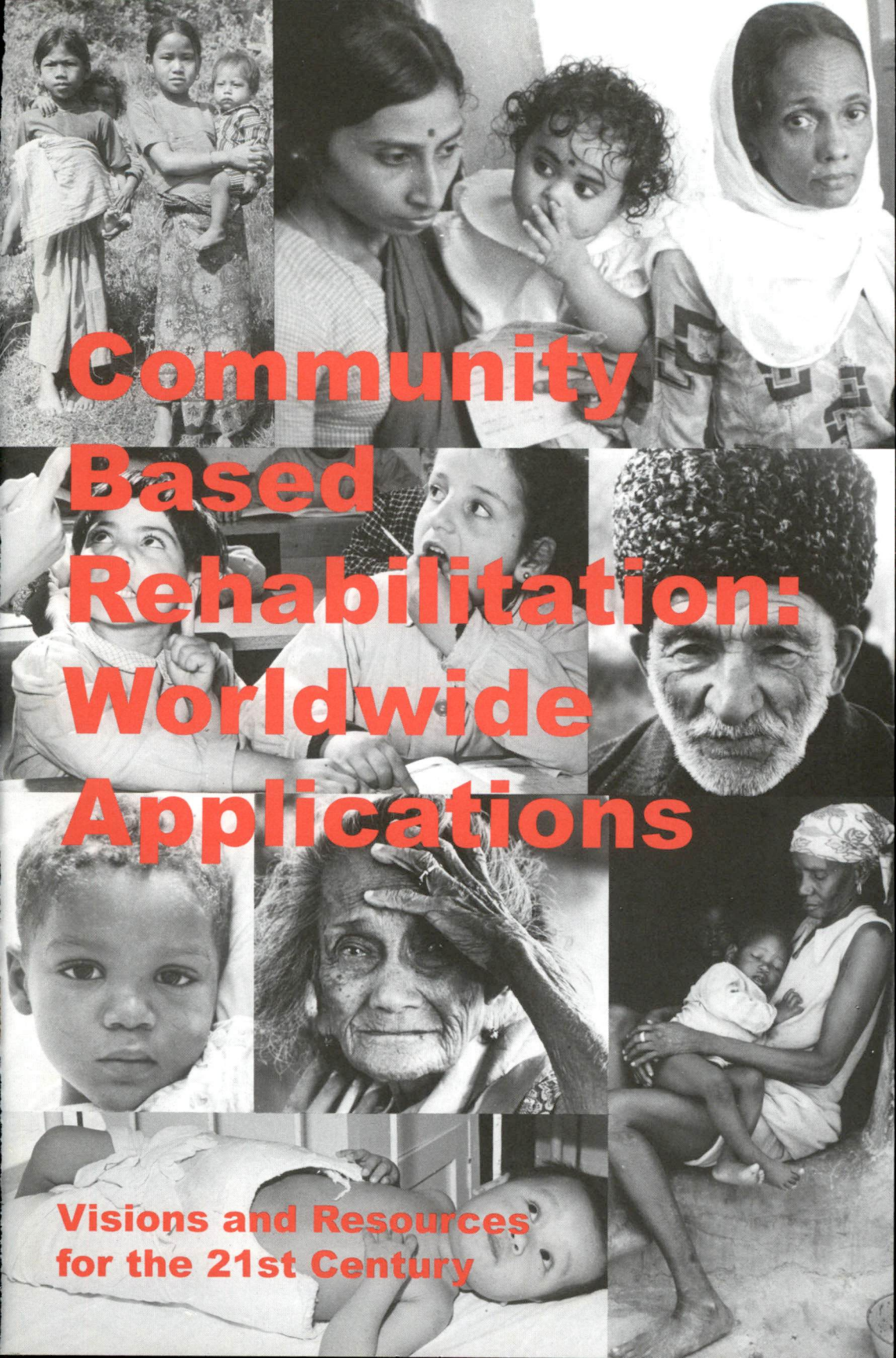
There are three points I would like to make in concluding.

Those who have a disability because the world failed in its duty to prevent the disease which caused it, did not have a choice. In committing ourselves to ending this affront to humanity, neither do we.

We should continue to pursue the goals of equal opportunity, full participation and social inclusion but we must also continue our efforts to develop and implement cost-effective policies of prevention and rehabilitation.

If politics is the art of the possible, and science the art of the soluble, then science and society working together can make things happen. This historic city has given an example to the world of how barriers can be dismantled: in the disability field, it is surely time to stop erecting barriers which divide, and to start building bridges which unite.

- End -



Community Based Rehabilitation: Worldwide Applications

**Visions and Resources
for the 21st Century**

This project, Community Based Rehabilitation: Worldwide Applications, has been carried out by Rehabilitation International with the support of the United Nations. This Resource kit consists of:

1) a video compilation of clips from selected CBR films & videos concentrating on early intervention, integration and attitude change; and

2) this booklet, containing: a viewer's guide on how to use the video compilation; a series of vision statements by CBR specialists and practitioners; and a selected annotated bibliography of 80 books, periodicals, studies, videos and training packages on CBR implementation.

A description of contributors to this Resource Kit appears on the inside back cover of this booklet.

Community Based Rehabilitation: *Worldwide Applications*

**Visions and Resources
for the 21st Century**

Produced by Rehabilitation International
with the generous support of
the Arab Gulf Programme for
United Nations Development Organizations (AGFUND)
through the United Nations Voluntary Fund on Disability
1998

Table of Contents

Part 1—A Viewer's Guide	1
Part 2—Introduction to Vision Statements	7
Building Partnerships through CBR	9
CBR: Target for the 21st Century	13
CBR: Dynamic Concept Requiring Strategy, Research and Vision	18
Empowerment of People with Disabilities: Primary Goal of CBR	22
Part 3—A Selection of CBR Resources	25
A. Newsletters/Journals	25
B. Selected Recent CBR Publications	30
Books	30
Manuals/Guides	35
Papers	37
United Nations Publications	39
C. Video Training Packages	42
D. Additional Resources	44

Part 1

Glimpses of Global Efforts in CBR for People with Disabilities: A Video Viewer's Guide

The accompanying video is a compilation of selections from numerous CBR videos from around the world. Rehabilitation International and its media consultant, Barbara Kolucki, screened over 100 videos in the preparation of this work. The selections represent most areas of the world and a variety of disabilities. Some of the videos produced were of high professional standard and others used non-professional and lesser quality equipment. However, it is the **content** that is most important. Portrayed are examples of **simple, practical and effective techniques** to improve the lives of children and adults with disabilities.

The video is divided into three segments. The first includes selections from CBR videos stressing the important of **early intervention** with disabled infants and young children. The second concentrates on **integration** of older children and adults into all aspects of community life, emphasizing school and employment. The third segment includes a selection of more innovative media designed to **change attitudes** about persons who are disabled, presenting sensitive topics like prevention in a positive way or integrating disability into mainstream media. The video ends with sound bites from women leaders who are disabled and who sum up the potential that can be realized by CBR or any rehabilitation intervention.

Video Use

Please feel free to use the video to suit your needs. It has been designed to be flexible and can be viewed in its entirety or in segments. There are several potential audiences for the video. These include:

- policy makers and local leaders with whom you are advocating CBR
- community development workers who are not currently involved with

disability but who you would like to interest in including children and adults who are disabled in their regular community development work

- participants in any type of CBR course
- trainer of trainers for grassroots CBR
- disability groups or other NGOs which are exploring how to develop their own media
- national or local media who you would like to have produce a video that is practical and innovative for your own purposes.



We would like to make one note at this point with regard to this last potential audience—media producers. Most organizations of and for persons with disability, as well as international and national NGOs have produced **documentaries and/or training films** on their projects. These are undoubtedly very useful and important. However, it is most likely that documentaries do not reach the wider audience of the general public who need the same practical information about options available if there is a disabled child or adult in their family, or if they are disabled themselves. The common phrase used for documentaries is that they “preach to the converted”.

Proposal

We would like to propose that you explore additional ways that media can be used to support or sell the messages of CBR to improve the quality of life of persons with disability. Some methods are portrayed in the last segment of this video. But we strongly encourage you to explore ways that disability information can be integrated into **mainstream media**—soap operas, children’s programming, advertisements, regular news programmes—and the wide selection of live media indigenous in many countries.

Examples of use in mainstream media

For example, if there is a programme on child development and indigenous practices such as infant massage, be sure to include children who are disabled and reinforce the message that it is **of the same or greater importance** to massage children who are disabled as it is for the non-disabled child. If there is a soap opera that features characters who are developing their own business, include someone who is disabled as the employer—as well as employee. What is important is that **people with disabilities are seen in as varied situations as non-disabled persons**. Parents of a newborn with disability must see that there are other children like theirs who go to school and participate in play activities. Research shows that if parents don't see role models for what their child can accomplish, they may not pursue education or training opportunities for them. Adults who are disabled must see that they too, are part of community life, work life, family life, etc. Our media must present positive **role models** that demonstrate that disability is just one more way of being different, not a tragedy.

Exercise

What follows are a few key questions and comments that you can use to **facilitate** a discussion and a better understanding of the video. It is suggested that after each segment, you ask the viewers to discuss:



- what they did/did not like
- why they did/did not like a particular selection
- what they learned
- if they could they use this information and activities in their own work
- how they would change or adapt what they saw

After viewing each segment, it might be important to have the group list the **key messages**. Suggestions can be general or specific. For ex-



ample, the first segment is about the importance of Early Intervention with children. Some of the **key messages** that are presented are: *play equals learning, simple activities are best, it is important that fathers nurture and stimulate chil-*

dren as well as mothers, rehab activities can be part of the activities of daily living of a family, etc.

1. Divide the viewers into smaller groups and have them discuss how what they saw could be adapted to your local situation. What is needed to begin? (Always include persons who are disabled and parents in all aspects of planning and implementation). For example, in the second segment there is a selection where agricultural workers are being trained to work with persons who are blind. Perhaps your community concentrates on arts & crafts products. How can you adapt what is shown in this video to train local artisans to work with blind persons?

2. Ask the small groups to write a simple Handout for parents or community workers based on what they saw in each segment. If you have an illustrator in the group, have her or him draw pictures of the practical activities and suggestions depicted in each selection of the video. For example, write a one page Handout for parents on how they can stimulate their child who is disabled through massage, games, music, local material of various colors to stimulate a child's vision, etc. Use as few words as possible and have your pictures tell the story.

3. Have each small group write a radio script, simple storybook/flipchart, short puppet show that presents the messages depicted in the video but uses people and customs from your own community. For

example, write a short six page children's book that shows how **all girls should be proud of who they are**, disabled and not, rich or poor, from majority or minority groups, etc.

4. Have each group list all the local customs and traditions that have been used in their community and that are appropriate and useful to persons who are disabled. Have them create a story about all that has been happening that they can be proud of with regard to the care of children and adults with disability. Make a list of case studies of families who worked hard to integrate their children into schools, of women and men who are disabled who can be role models for others, etc. Share this list with your local media and suggest that these be developed into story lines for production of electronic or print media.

Feedback on use

Rehabilitation International encourages feedback from you on how you have used this video. We also would like to hear from you with regard to what types of videos and other media can be of assistance in your CBR work. If your group has produced innovative videos, we would be grateful to receive a copy.

RI would like to thank all of the producers and organizations who shared their videos with us throughout the development of this product. We were limited in the numbers of selections we could include and hope that there will be sequels to this compilation. RI would like to acknowledge the following persons or organizations whose work is depicted in this compilation video. The original and full length cassette of each can be obtained by writing to the producers/distributors.

- Pakistan Public Service Announcements: UNICEF-Pakistan, c/o 3 UN Plaza, New York, NY 10017 USA
- 3D Projects, 14 Monk Street, Spanish Town, St. Catherine, JAMAICA
- Therapy Skill Builders, (Infant Massage for Children with Special Needs), 555 Academic Court, San Antonio, TX 78204, USA
- Learning to Move/Step by Step, c/o Cheshire Homes, Far Eastern Region, No. 1, Jalan Berjaya, Pulau Tikus, Penang, MALAYSIA
- "It's A Challenge", Save the Children, P.O. Box 472, Mbabane, SWAZILAND



- Ghana CBR, The Norwegian Association of the Disabled, P.O. Box 9217 Gronland 0134 Oslo, NORWAY
- "Training Agricultural Workers", ILO Publications, International Labor Office, CH-1211 Geneva 22, SWITZERLAND
- "Business As Usual", Fanlight Productions, 47 Halifax St., Boston, MA 02130, USA
- "Puppets with a Purpose", UNICEF, Division of Communications, 3 UN Plaza, New York, NY, 10017 USA
- Nepal Public Service Announcements on Polio Prevention and the Right to Education, UNICEF-Nepal, c/o UNICEF, 3 UN Plaza, New York, NY, 10017 USA
- "The Silent Shout", UNICEF, 3 UN Plaza, New York, NY, 10017 USA
- "Women with Disabilities Get the Work Done", ILO Publications, International Labor Office, CH-1211 Geneva 22, SWITZERLAND
- "Issues and Insights: A World Forum on Women with Disabilities" and "As We Are: From a Woman's Perspective", Third Millennium Events, 711 Brent Road. Rockville, MD 20850, USA; Fax: 301-838-3029, e-mail: Rbbieler@aol.com

Introduction to Vision Statements

Nearly 30 years ago, Rehabilitation International organized a World Congress and some associated small meetings of experts in Ireland. One of these "invited only" conclaves set out to deliberate a harmless sounding topic, "Development of Rehabilitation Services in Relation to Available Resources." In essence, this was the first international meeting to recognize and attempt to resolve the dilemma that decades of expensive efforts to replicate the rehabilitation services of industrialized nations in developing countries had little or no measurable effect, for a complex of reasons. The consensus of this meeting of mostly health-related professionals (rehabilitation medicine, occupational & physical therapy, prosthetics & orthotics, etc.) was that a modified or distilled version of their arts & sciences would be required to reach a significant proportion of the disabled population of developing countries. The meeting reached what sounded like a halfhearted conclusion that some sort of a paraprofessional with a crosshatch of skills might be needed.

Those who recall this seminal meeting agree that it constituted the birth of what became known as Community Based Rehabilitation, later given its first conceptual outline by the World Health Organization in planning papers published in 1975/6. (We can only guess that the apparent silence or gap between the 1969 meeting in Killarney and the 1975 WHO papers might best be explained by the reluctance of the various professions to promote diminished or "dumbed down" versions of themselves for work in Africa, Asia & Latin America.) In any case, RI has remained integrally involved in the development, testing, experimentation and research into CBR services from 1969 to the present through its regional meetings, publications, world congresses, projects and advocacy.

Historical understanding provides context for today's realities concerning the world's disabled persons. In 30 years demography mapping has evolved to show that 80% of disabled people live in the world's rural areas. It is known that the rural areas are often at the outer reaches of the supply lines distributing goods and services, including program technology. Effectively applying the lessons learned to date about CBR presumes that program design must adapt to the local environment, not the other way around.

More to the point, if local programs are to attain the state of grace called "sustainability", living on after initial creation, local people who have the greatest investment in the program must be involved from the beginning. Francine Arsenault (Canada) and Carmen Reyes Zubiaga (The Philippines) write their "Vision Statements" from personal experience—"empowerment" is not a gauzy concept. CBR as a crucible for systems change begins with consciously setting up situations in which disabled people are given the opportunity to make choices.

Linking resources to local CBR programming is today's challenge. Close enough attention has not been paid to the social and resultant economic gains possible to communities who host a dynamic CBR approach. Mike Miles and Penny Price write their "Vision Statements" from the perspective of seasoned workers at the field level.

Together, the four "Vision Statements" take us forward into what CBR can become in the 21st Century. Each is unique in its insights into the possible demands and responses, pitfalls and opportunities. They do agree on a few basics, however: we should not be unduly disturbed by the lack of universal definitions of what a CBR project or service is—it is dynamic and prone to the protective coloration of each community. The writers also agree that for CBR projects to bring about real and lasting changes in attitudes & behaviors, they must embrace: partnerships of mutual respect between rehabilitation and disability leadership, egalitarian information sharing, research into best practices, and a deep commitment to leadership development of people with disabilities. In fact, one of the authors states that the elusive sustainability of CBR actually lies in engaging leaders with disabilities in its implementation.

We look forward to your comments, reactions and additions.

Susan B. Parker
Secretary General

Building Partnerships through CBR

by Francine Arsenault

Following are some examples of partnership building projects I have observed or participated in as the Chair of the International Center for the Advancement of Community Based Rehabilitation (ICACBR) or on behalf of the Council of Canadians with Disabilities.

Latin America

In Mexico, Nicaragua, Costa Rica, El Salvador, Guatemala, or Panama, as in many other countries, persons with disabilities are the poorest of the poor. Take for an example, my friend Hector, who has in the past, gone on his hands and knees over one mile to get to the location of an extremely low paying job so he could hold his head up and say, "I work to support my family." To be employed and be a paraplegic in his homeland is a miracle. The meager wage he earns barely keeps his wife and two sons fed and clothed so there are no dollars left to cover the extra costs of disability, such as medicine, equipment or accessible housing.



When an exchange program with other persons with disabilities provided an opportunity for Hector to get training to learn how to repair damaged wheelchairs and prepare them to be given or sold to his people, he jumped at the chance and was one of the first recipients in the program. Now, Hector not only supports his family with pride and dignity, but helps provide an essential, previously lacking service to his community. This is a working partnership.

Many countries engage in civil wars that add significantly to disability. Hector was working in his garden before sunset when he got caught in the crossfire between guerillas and the government forces. Many quad-

riplegics and paraplegics in developing and war torn countries do not survive, because even if they get sufficient medical care at the onset of the disability, there seldom is follow-up care, proper hygiene or nutrition for continued good health. Nor is there rehabilitation, or necessary equipment such as leg bags or catheters and of course, very few wheel-chairs. Unless rigorous routines are developed by the individual and his or her self-worth emphasized, many become weakened by infections and pressure sores, give up and die.

We need to help establish effective partnerships in these countries which will use CBR methods in spreading information about proven "survive and thrive" approaches.

Caribbean

Almost worldwide, people with disabilities are so busy finding the essentials to survive that they don't have much time or energy left for other pursuits. Let's look at the Caribbean. I've been working with self-help groups of persons with disabilities in twelve countries there: Bahamas, Barbados, Belize, Cuba, Dominica, Grenada, Guyana, Jamaica, St. Kitts/Nevis, St. Lucia, St. Vincent and the Grenadines, Trinidad and Tobago and recently the USA. Every country had its unique characteristics and own special splendor.

Again, those with disabilities are usually the poorest of the poor, but during the United Nations Decade of the Disabled each country began to develop self-help groups. In every place I visited as a consultant with a disability, the self-help groups were beginning to get the necessary skills to participate in existing services or to propose services of their own that would supplement those in the community.

The self-help groups are learning to work with their governments, educators, health specialists and linking partners in other parts of the world to start community based rehabilitation programs to train persons with disabilities so that they become capable of giving actual rehabilitation and training to more disabled persons in their local communities.

Asia

Here is another example of true CBR in action: In Indonesia, "Pikat" and "Nunning" are two rare disabled women with university degrees. Their families broke with tradition and did not hide them or apologize for their shortened legs caused by polio. Their adaptation to using crutches took a

giant leap when they both learned to ride three wheeled motor-cycles to go to 18 villages. In the mountains in Java they carried the concept of CBR from the Solo CBR Training Center and after living with the community for a month convinced the villages to give



their support to the other disabled people in those communities. Their parents can now rest assured that they can support themselves, and they have become effective role models for the many disabled children and adults of those villages.

Bosnia

In Bosnia in November, I met many people struggling to adjust to their disability after they became injured from the war. Aida lost her husband after M.S. slurred her speech and made it so difficult to walk. Her ability to be a caregiver to her son (who now cares for her), went next. Her job is continued only through her sheer willpower and determination. Lack of vital medicines, which she could not afford even if they were available, will soon make it impossible for her to maintain her very life.

Cehic was lucky. His wife stayed with him after he became a paraplegic when he was shot near Bihac. He already had an education so continued to work to support his children. He directs the wheelchair basketball team and has regained some of the assertiveness and self-esteem he had lost.

But what of the others around the world? If we do not provide adequate rehabilitation services and support, both moral and financial, for self-help organizations of persons with disabilities how will the next generation of persons with disabilities not only survive but thrive?

It is imperative globally that we put the major issue of disability on the table to be dealt with realistically, sensitively and immediately.

Creating Partnerships for CBR

After the Year of the Disabled in 1981, I was asked to join a newly formed advocacy organization for persons with disabilities. In the next ten years I had chaired local, regional, provincial, national and international boards of directors. The rules of partnership I had learned in the past served me well here. We learned to empathize with all disabilities and our organizations did not do things for disabled people but taught them to do those things for themselves.

Partnership Principles

I believe it is important for us to connect on a personal level but also to try and demonstrate the tremendous impact positive partnerships can have on our understanding of ourselves and on our ability to grow and prosper in the communities in which we live. However, for partnerships to be positive they must be governed by the following principles:

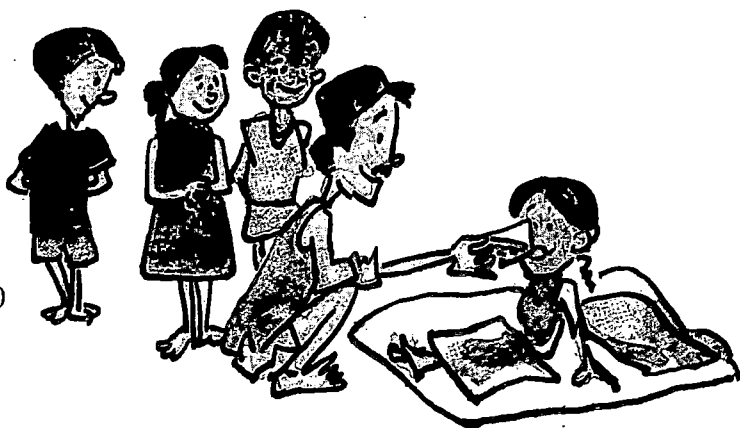
- Partnerships must be open, willing to make adjustments and be based on trust. They must truly be a coming together to make things work and remove the barriers that prohibit participation and growth.
- Positive partnership must focus on abilities. Yes, recognize the disability but focus on the ability.
- For partnerships to grow we must be willing to take chances, not fear taking risks.
- Partnerships must be truly equal, expectations must be shared as well as the responsibility for making things happen.
- Listening is the key to a healthy partnership.
- Respect for each other's ability is critical.
- Partnerships change, to remain static means to remain in the same place. Be prepared for partnership separation or cancellation. Be open to the formation of new partnerships.
- Partnerships take many forms and may include multidisciplinary approaches including people with disabilities, non-governmental organizations, health professionals, governments, families and the community.
- Partners must be included in planning, research, implementation and evaluation of projects.
- Good role models help partners to achieve their goals.

Our world is far from perfect for persons with disabilities. There is much work yet to be done. The most productive technique for creating positive change is not new. Critical to our success is the development of creative, inspiring partnerships.

CBR: Target for the 21st Century

by M. Miles

The western 'discovery of CBR' since the 1960s is still in its infancy, when one considers the past 300 to 3000 years of formal disability service development in Asia



and Africa. Knowledge of specialised treatment and education, and of disability prevention, has grown rapidly in western urban centres; and has been exported, usually with inadequate cultural and conceptual adaptation, to urban counterparts worldwide. Awareness has been raised about the negative economic, social and psychological pressures experienced by the majority of disabled people in every society. Yet public knowledge about how disabled adults actually live their daily lives, how families raise disabled children, how ordinary schoolteachers manage when they notice disabled children in their classrooms, how disabled people make a formal or informal contribution to their neighbourhood communities - in other words, the nitty-gritty of what ordinary people do, day by day, as they live with disability - such knowledge remains seriously inadequate, especially in countries with weak economies and poor information structures.

From private knowledge to public awareness

Of course, the ordinary people living their daily lives with disability know how they themselves do it: what obstacles they face, what successes they achieve, what would be the first steps that would help them forward, and what they can offer to other people. But that private knowledge has seldom been formulated and expressed, seldom aggregated across large numbers of people, and hardly ever communicated publicly so as to affect government policies or social consciences. In a few countries, ordinary people's knowledge and feedback have begun to be noticed by formal service providers such as special teachers, physio-

therapists, orthopaedic surgeons, equipment designers. These professionals have become more aware that their services are flawed if the results do not give satisfaction to users in everyday life. Yet such impact and awareness are exceptional and usually confined to countries with stable economies and high education levels, where substantial parts of the population feel some confidence in their ability to shape their own future. In most countries, where socio-economic changes are experienced as rapid, threatening and beyond personal control, it is harder to awaken the magnanimity that can result if powerful groups make resources available to develop the vast poorer groups, and to rescue those who have lost or never had the capacity to raise themselves.

Developing new roles

'CBR', a blanket term now covering a range of uneasy bedfellows, has described or facilitated some interesting new movement, communication and roles. Some rehabilitation professionals have moved towards people in their own homes, acting as enablers rather than instructors. Some disabled people have moved onto professional ground and won a place as trainers of young professionals, to whom they communicate their 'daily living' message. Some planners have begun to design environments that are easier for everyone to live in. Many associations have formed to promote their members' interests, whether of people in various 'disability categories', or their relatives, or professionals. Next, faced with the vast challenges of educating the general public and changing negative attitudes and practices of society, some parents, professionals and disabled people have dropped their mutual battles and begun to develop partnerships of mutual respect and support. There is an increasing recognition that no single group - whether parents, disabled adults, voluntary agencies, senior professionals, children's rights advocates, government planners, or grandmothers meeting under a tree - has 'the solution'. If several billion individuals in their local and national communities are to change patterns of thought and behaviour that have accumulated and solidified over centuries, it will require the united and sustained efforts of all the parties aiming for change.

Dreams vs. nightmares

On the positive side, studies of social history indicate that the 20th century is the first period during which humankind has seriously formulated the global target of developing a more positive life and status for all disabled people. This is a notable advance. During three millennia a recurrent

dream has been recorded, of a 'better world' from which disabilities have been eliminated - or disabled people excluded. Efforts to realise this dream - or nightmare - have continued to the present. In the nobler version, knowledge has been developed and applied to eliminate or control disabling diseases such as smallpox, polio, trachoma. In the nightmare version, people with disabilities have been judged 'worthless' and killed en masse by official order. Somewhere between these versions, and with

impassioned ethical debates, fetuses expected to have disabling conditions continue to be aborted, or allowed to die soon after birth. Nevertheless, as debates continue, the globally-agreed target has become firmer: that people with disabilities should enjoy the same rights and benefits as anyone else, and should be enabled to live as full and satisfying a life as possible within the usual range of choices and customs available in their community and society. This

'target' is hard to put

into words without enraging one group or another and without it being so idealistic as to remain a distant dream. Yet even though it is understood differently in various regions and languages, there is a growing consensus that humankind can, and must, move towards the broad goal. Governments must provide planning and finance to do so, local communities must use all possible resources, disabled people must make input to plans and must take up the opportunities. Positive change must take place.

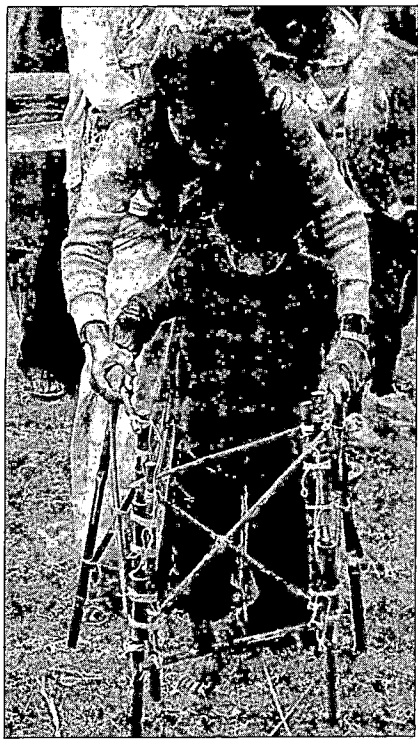


Problems with definitions

And CBR? The term can be understood as the sum of all these efforts. As such, it is of course vague. Concerned people will continue to pull it

in this or that direction. It is a feature of modern global communication, that the meanings of general terms very quickly diversify as people with different languages receive them and make sense of them in their own conceptual world. It is important to understand this- but we do not have to view it as a problem.

Community Based Rehabilitation can usefully be looked at as an 'information system', using various aspects of information as they are under-



stood in whatever community and language group. It is obvious that "knowledge, skills and design" are needed in CBR, whether we think of a mother at home with a disabled baby, a politician drafting a law about access to public transport, or some elderly deaf people learning new income-generating skills along with other elderly people in the local mosque. Underlying the necessary knowledge and skills, there are many deep, local "concepts" of how life is lived, how family members relate to one another, the behaviour expected of children, what sort of things are seen as disabilities, how disabilities affect living, what differences there are in the roles of men and of women. These concepts are much less obvious on the surface, but are of the utmost importance. Because the underlying concepts vary from region to region, and from one religion or

philosophy to another, 'CBR' and the target of CBR cannot be defined globally once and for all. To some extent, CBR has to be discovered and practised by the people themselves, in each country, each town, each village.

Scaffolding and construction

Self-discovery does not mean that the knowledge, skills and design developed in one place cannot be used in another. What it means is that 'imported' knowledge and skills should be seen as a sort of scaffolding, and to some extent building material, that enables people to construct a building based on their own conceptual foundations, with roots in their own country, their own history, their own

way of living and being. Such a construction cannot be imported from northern countries to southern. It cannot be imported from big city institutions to rural villages, or even to urban slums. Yet it can very seldom be constructed by villagers or slum-dwellers entirely by their own efforts. Partnership is needed. There is an absolute requirement of mutual listening and learning. Some of those with one sort of knowledge and skills (e.g. modern, urban, maybe educational or biomedical) must listen and learn from people with another sort (e.g. rural, survival-based, maybe religious). People within a traditional conceptual world must delve into their own folklore, art and drama, to uncover the positive and the ambivalent views of disability, and decide which are the authentic and valuable parts on which they will build. They are likely to do this only if they understand that the offer of help from the city or foreign CBR advocate includes a genuine respect for their culture and concepts.

Learning from the past and present

People with disabilities must offer their knowledge and experience - with a real awareness that traditional views cannot be changed overnight. Disability activists inspired by high ideals may lecture civil servants - but should also be prepared to listen to the constraints under which they work. The Director of Social Affairs, for example, seeks improvements that can be introduced and practised at least with moderate effectiveness by the average and below average staff constituting 90% of her workforce; costing no more than the present system; producing results measurable by ordinary means; that will not inflame religious teachers or other influential constituencies; that will not reinforce corruption and nepotism in staff postings; and that might deliver, within two or three years, benefits substantially outweighing the disruption involved in implementing the scheme. If no proposal meets these criteria, the Director prefers to continue the present system, whatever its flaws. Activists wishing to change the Director's mind should first learn how she sees the situation; and what happened to earlier attempts to change the system... This is more difficult than shouting slogans in the street; but in the long run, probably more effective.

None of the listening and learning will be easy. The development fields of agriculture, health and education have travelled this road for several decades, during which mutual understanding has grown with painful slowness. However, the disability and CBR field is not obliged to make exactly the same mistakes, or to take quite so long. We can learn from history.

CBR: Dynamic Concept Requiring Strategy, Research and Vision

by Penny Price

If the past decades can be interpreted as an initial establishment phase, then the second consolidation phase may require a more systematic approach in order to harness what has already been learned, and to translate it into action. This process will lead towards a third phase where universal acknowledgment of the rights of people with disabilities becomes inevitably linked to development of communities committed to meeting fully the needs of all community members. The seeds for the achievement of the third phase are visible in many of the activities of the first. Key aspects include acknowledgment of the complexity of the CBR concept, systematic information sharing, the generation of research based knowledge, continued advocacy and resource development, and applications of CBR to an increasingly diverse range of settings.



CBR--a dynamic concept

Experience from past decades has taught us that CBR will never be a 'tidy' concept, neatly defined, but dynamic and constantly growing and changing in response to both evolving philosophical and ethical frameworks, and the diverse social, political, economic, demographic and physical conditions to which it is applied. Currently conceived dichotomies will be reinterpreted as continua, at different points on which varied adaptations of the CBR concept will be seen to be specifically appropriate for different reasons at any particular point in time. Some of these dimensions might include the top-down/grass roots issue, the whole country/local community approach, the predominantly health focus and the disability within community development framework, leadership roles of profes-

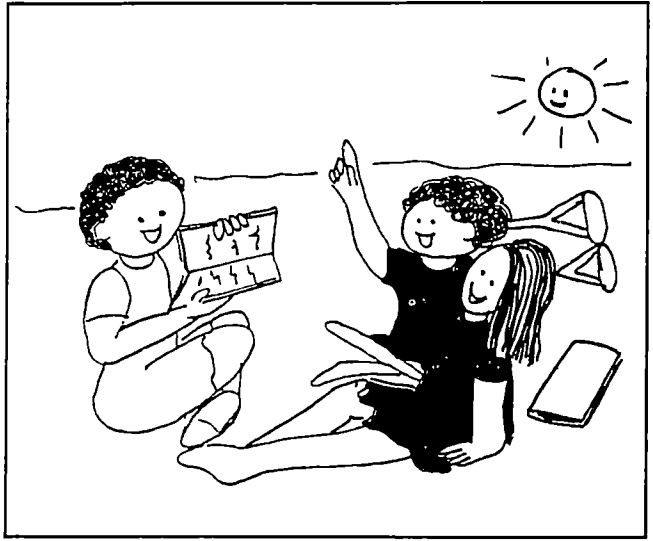
sionals and people with disabilities, and the applicability of CBR to developed as well as developing countries.

They will encourage the sharing of expertise and problem solving experiences, and will provide a source of continual encouragement in a shared endeavor for people often working in physically isolated situations.

Asia-Pacific strategies

Current examples within the Asia and

Pacific region include groups such as ActionAid in India, the Solo Forum on Human Resource Development in CBR, based in Indonesia, and the recently formed Pacific Network of Disability Workers. The sharing of detailed information and ideas informs and inspires others to try new strategies and approaches. Internet communication facilitates network linking but alternative strategies must be kept in place to ensure effective and mutually supportive linking for people in less technologically advanced settings.



Strategies to involve Government and provide links at inter-Governmental level must be further encouraged. Considerable success has been achieved by the implementation of regional strategies such as the UN Economic and Social Commission for Asia and the Pacific Decade of Disabled Persons, 1993-2002, established to mandate Government activity and to guide policy and action by means of specific targets set for achievement within a specific time-frame, and monitored annually. The strength of this initiative lies in its clearly stated mandates which provide the information base needed for action. Progress in small countries such as Fiji, currently investigating the viability of a nationwide CBR strategy, indicate clearly that previous failure to undertake effective action was due to lack of appropriate knowledge rather than lack of will. The imperative, is to develop the means and strategies to link non-participating countries into existing networks.

CBR and action research

A practical action-based CBR research agenda will help to build a systematic body of knowledge that can inform future practice and assist in

developing a series of 'best practice' guidelines, capable of preventing repetition of previous mistakes and lessons already learned. This may include descriptive, comparative and evaluative methodologies. At its simplest this will involve the documentation of any CBR initiative, a step-by-step description detailing the rationale, context, scale, resources, format, content and length of training, outcomes, and problems encountered, exemplified in the recent work of McConkey and O'Toole in Guyana. Comparative research may facilitate the identification of specific factors that act as catalysts for change, and enable them to be applied in other settings. This research would be relevant to the identification of factors which give rise to leadership of people with disabilities in community activities, so that other communities may learn how to promote this outcome. Evaluative research is the measure of maturity of the CBR approach, and enables both positive and negative outcomes to be turned into constructive guidance for the future CBR activities. More complex, and to some extent revolutionary, is the social policy change-agency research undertaken by the Partnerships in Community Living Project (Roeher Institute, 1997). The purpose of this research is to develop an achievable vision of community development based on a human rights perspective, by means of providing research based information on both the barriers to human rights and the necessary steps to achieve social change.

Advocacy and resource development

Although it is an ideal that CBR activities will be generated entirely at local levels, many are still reliant to a greater or lesser degree on funding and expertise from aid donor, government or other national or international agencies. The role of these agencies then becomes critical in maintaining the momentum for increased support and extension of current activity. Within the Asian and Pacific region there is a need for ESCAP to maintain an active role in education, awareness raising and training, and to promote leadership skills in people with disabilities so that their voice is heard in finding solutions to the problems which they face in their communities and countries, as well as persuading Governments to proclaim their commitment to the Asia and Pacific Decade Agenda for Action.

CBR in an increasingly diverse range of settings

Developed initially as a response to need in communities where conventional rehabilitation services were not available, CBR has developed into a model with applicability to an increasingly diverse range of settings, in

both more developed and less developed countries. A continuation of this trend may lead to a situation where CBR is an integral part of community and service development throughout the world. It has the capacity to meet the needs of people at all stages of the life span, and



intersects with early intervention, inclusive education, vocational training and income generation, full community participation, and the care of the aging and elderly.

CBR and Human Rights

Changes in the conceptualization of CBR are consonant with changes in the wider conceptualization of disability. The shift from a medical to a social model, within a human right framework, has been accompanied by the development and dissemination of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities. People with disabilities are increasingly partners in all endeavors affecting their lives. Where this is not the case then it is an area for focused attention to achieve the changes which will ensure that the voices of persons with disabilities are heard in all research and implementation processes--truly participatory--if more than lip service is to be paid to the adoption of a human rights framework for all CBR activity. The achievement of societies and communities whose every decision is based on, and framed in terms of, human rights, is perhaps a state that will be achieved in the third phase of CBR development.

Reference

Roehrer Institute (1997). "Policy, Practice and Partnerships: Children are Us", Roehrer Institute: York University, Toronto.

Empowerment of People with Disabilities: Primary Goal of CBR

by Carmen Reyes-Zubiaga

It is not true that CBR is cost effective... Volunteers will never stay forever in your program... You have to think doubly hard on how the community will adopt your program... To have a holistic approach, you should be a jane or jack-of -all trades in rehabilitation....

My Story:

When I had my first CBR sensitization activity in one community, folks focused all eyes on me. Disabled people who were present looked at me seeming somewhat embarrassed. Mothers were pointing me out to their children while I was talking to the town



mayor, who seemed to be very impressed with me. Among the audience were village captains, municipal officials and volunteer health workers, mostly older women. I later learned that it was the first time that a person with disability had talked in front of such a group about the possible contribution of people with disabilities to community development. I was happy with the audience response and they seemed ready to take some actions and accept my challenge.

Then the town mayor gave his response. Very supportive and encouraging, but I felt so disgusted at how he addressed people with disabilities. All I could do was give him a sour face every time he called people with disabilities with "names" such as cripple or damaged - which does not sound good in the Filipino language. In closing his speech, he wanted to show proof that he was supportive to disabled people so he told a story of one man whom he is helping by providing him a job at the municipality. Then he called the man to come upstage, saying "Where is Cripple? Cripple! Come up here." Then a man with a slight disability caused by

polio hesitantly approached the stage while people were laughing as the mayor pulled him forward.

I just shook my head and told myself: This is the community. What can CBR do to change this? If anyone of you encounter this situation, go over this resource kit and find solutions. If you cannot find any, feel free to write to me.

About this Resource Kit...

It is globally relevant! As community based rehabilitation is fast becoming a by word in every developing country and now recognized as an effective strategy to reach the maximum number of people with disabilities, this resource kit is indeed very useful for planners, implementors and evaluators. But, do not rely on everything they say. There are a lot of myths about CBR and an implementor should always look into the realities of life in the community before trying to build a world of dreams through CBR.

Patience & principles

To achieve success in CBR is like reaching for a perfect world for people with disabilities. It is a long term endeavor that requires patience and commitment to its principles. Results will not be visible overnight but there are some indicators as to its impact the community. Success in some communities may not be seen as such in another because of differences in cultures and beliefs. But there is one universal factor that rehabilitation workers all over the world should work for: integration of people with disabilities within the community system and encouraging their participation in building a better society. This universal factor always makes a CBR implementor try to be a jack-of-all-trades in rehabilitation. Sometimes he is a physical therapist who tries to teach small business management to a disabled person who just learned how to walk with an artificial leg, or a special education teacher sourcing funds to buy a wheelchair for a disabled child. But the best CBR Implementor is the one who has the ability to pull resources together to develop a holistic approach for program and does not try to be everything in one.

Sustainability = empowerment

The idea of a community adopting the programs, using their own resources and achieving sustainability will only be possible if the target group, people with disabilities themselves are sensitized, involved and participating in the decision making process. Empowerment of the people with disabilities should be the primary component of any CBR

program. CBR implementors should see to it that people with disabilities are being involved and should avoid making them feel like beneficiaries but rather, develop them as a partners. To empower people with disabilities may involve a lot money, time and resources and it will show that CBR is not really a low-cost program in the beginning , but empowerment is an effective way to achieve sustainability for CBR.

Government as partner

Do not forget the government. It might be an irony but a good CBR program should have a strong collaboration with the local government. Having government support is one factor for sustainability. An NGO may not always be there but the government is always present. The need for CBR to be integrated in local development plans should be given strong emphasis. This will only be achieved if the government staff concerned with disability issues are sensitized and have internalized the commitment to improve the lives of people with disabilities in their communities. Make them feel that they are important but show them that you can go ahead without them and they are "missing the boat" if they ignore your CBR Program.

Community volunteers

Follow-up is important as a successful CBR program does not develop overnight, but takes time to mature and instill commitment to its foundation. The foundation of a strong CBR program is the disabled people and their families who will carry on the program. And do not forget the volunteers. They work for the program because they want to help. Most of them are poor people who have nothing but goodwill and willingness to help, so do not abuse them by ignoring their need for resources to move around the community. When you develop a proposal for a CBR Program, allocate sufficient amount for travel expenses and training of community volunteers. They may never stay forever but they will always remember and advertise the experiences they gained.

Role models

The success of any CBR Program relies heavily on the commitment of the leaders towards achieving its goals. I will always say that the best leaders are people with disabilities who can always act as a role models. Therefore, it is always important to develop leadership among the target groups as they will portray what CBR wants to achieve for people with disabilities. And that is living their lives to the fullest as contributing members of their community.

The truth is....It can be done!

A Selection of CBR Resources

A. Newsletters/Journals



ActionAid Disability News is the newsletter of the Disability Division of ActionAid-INDIA. Topics range from the integration of CBR information into the curriculum for medical doctors, information on new training courses and materials to the relationship between prevention of disability and early detection as part of child survival and maternal care interventions. The newsletter is bi-annual and free upon request. Address: ActionAid-India, P.B. No. 5406,

No. 3, Rest House Road, Bangalore, 560 001 INDIA. Fax: 91 80 558 6284, e-mail: co.clr@actionaid.sprintrpg.ems.vsnl.net.in

African Journal of Special Needs Education is published bi-annually at the Uganda National Institute of Special Education. It covers topics related to CBR, inclusion, culture and disability, health/poverty/disability as well as related research. Consulting Editors come from the entire African region. Address: Uganda National Institute of Special Education, P.O. Box. 6478. Kampala, UGANDA. Fax: 256 41 222961

Asia Pacific Disability Rehabilitation Journal. This bi-annual journal, which was started in 1990 in a simpler format, was readership in 72 countries. The focus of the Journal is to promote the field of disability rehabilitation within the Asian region, but the quality of the research articles is such that it is of value to academics, administrators, policy makers and implementers and is internationally indexed. The Journal covers theoretical and practical aspects of CBR in a wide range of contexts, extending beyond its Asian origins.

Address: Asia Pacific Disability Rehabilitation Journal, c/o Dr Maya Thomas, Editor, J-124, Ushas Apartments, 16th Main, IV Block, Jayanagar, Bangalore - 560 011, Karnataka, India. Fax: 91-80-6638045.

Asia & Pacific Journal on Disability is a bi-annual publication sponsored by the Asia and Pacific Regional Committee of Rehabilitation International (RI) and the Regional NGO Network (RNN) for the promotion of the Asia and Pacific Decade of Disabled Persons, 1993-2002. The emphasis is on publishing articles or research papers that have significant impact on policy and practice concerning people with disabilities and their families. The Journal covers many aspects of rural and urban CBR. Address: Asia and Pacific Journal on Disability, c/o Karen Ngai, Executive Editor, City University of Hong Kong, Division of Social Studies, Tat Chee Avenue, Kowloon, Hong Kong. Fax: 852 2788 7709, e-mail: scngai@cityu.edu.hk

AHRTAG

CBR NEWS is an international newsletter on community-based rehabilitation and the concerns of disabled people. It is published by the Appropriate Health Resources &

Technology Action Group Ltd. (AHRTAG), published three times a year in English, including braille and cassette versions. This newsletter is also available in Hindi, "Indian English", Indian braille, and French. It is free to readers in developing countries. AHRTAG also has a wide range of media materials on CBR and primary health care. Address: AHRTAG, Farringdon Point, 29-35 Farringdon Road, London, EC1M 3JB, UK. Fax: 44 171 242 0041; e-mail: ahrtag@gn.apc.org; web site: <http://www.poptel.org.uk/ahrtag/>

CBR Update is the newsletter of the International Centre for the Advancement of Community-Based Rehabilitation (ICACBR) based at Queen's University in Canada. The newsletter publishes information about its collaborative CBR projects in developing countries, announcements of the most recent CBR research, networking opportunities and related conferences. Address: ICACBR, Queen's University, Kingston, Ontario, Canada K7L 3N6. Fax: 1 613 545 6882; e-mail: icacbr@post.queensu.ca



Child Health Dialogue is an international newsletter on child health and disease prevention published by AHRTAG. It often covers topics related to CBR as well as other issues concerning disability such as prevention, malnutrition and disability, resource lists, etc. Available in Chinese, French, Gujarati, Hindi, Portuguese, Spanish, Tamil, Urdu and Vietnamese. Address: AHRTAG, Farringdon Point, 29-35 Farringdon Road, London EC1M 3JB, UK. Fax: 44 171 242 0041, e-mail: *ahrtag@gn.apc.org

Deepshikha is the journal of the Spastics Society of Eastern India. It often covers topics of special interest to women with disabilities as well as information about early intervention for very young disabled children. Address: Spastics Society of Eastern India, P-35/1, Taratolla Road, Calcutta 700 088 INDIA.

Disability Awareness in Action is an international information network on disability and human rights for disabled people, their organisations and their allies. DAA publishes a monthly newsletter and occasional resource kits and is building a worldwide information resource on disability policy and human rights issues. One copy of each kit and each newsletter is free. Address: DAA, 11, Belgrave Road, London SW1V 1RB, U.K. Tel.: +44 171 834 0477; Fax: +44 171 821 9539; e-mail: 100726.136@compuserve.com; website: http://ourworld.compuserve.com/homepages/DAA_ORG

Disability International is the official publication of Disabled Peoples' International (DPI) and was formerly called "Vox Nostra". It is available quarterly in English, French and Spanish and includes articles on a variety of issues of concern to people with disability, including CBR. Address: Disability International, 309 -175 Hargrave, Winnipeg, Manitoba, Canada R3C 3R8.



Disability Frontline is the quarterly newsletter of the Southern Africa Federation of the Disabled, and covers projects in numerous southern Africa countries in both English and Portuguese. Address: P.O. Box 2247, 130 Herbert Chitepo St., Bulawayo, Zimbabwe. Tel.: 263 9 69356; Fax: 263 9 74398.

Families and Disability Newsletter is published three times a year by the Beach Center on Families and Disability at the University of Kansas in the USA. The newsletter focuses on family-cen-

tered services, policies and practices. The information is meant for both parents and professionals but with the aim of professionals facilitating the empowerment of families. It includes practical information on how to build on a family's strengths, quality indicators of family-centered work as well as unique resources. Addresses: Beach Center on Families and Disability, 3111 Haworth, The University of Kansas, Lawrence, KS 66045 USA. Fax: 1 785 864 7605; e-mail: BEACH@DOLE.LSI.UKANS.EDU; Website: <http://www.lsi.ukans.edu/beach/beachhp.htm>

FORWARD is the newsletter of COMBRA CBR Centre in Kampala, Uganda. It includes information on legislation with regard to disability, CBR courses in the region and case studies about individuals who are part of the CBR projects. Address: FORWARD, c/o COMBRA CBR, P.O. Box 708, Kampala, UGANDA.

the Hesperian Foundation



the world by providing resource for informed self-care. The newsletter provides an update on these resources as well as practical inserts on specific health issues, most recently on issues relating to women. Community-based projects are the focus of much of their work. Address: Hesperian Foundation, 1919 Addison St., Suite 304, Berkeley, CA 94704-1144, USA. Tel.: 1 510 845 1447; Fax: 1 510 845 9141; e-mail: hesperianfdn@igc.apc.org

Hesperian Foundation

News is the newsletter of the Foundation dedicated to improving the health of people in poor communities throughout

Hopeful Steps CBR Newsletter is published by the Guyana CBR Programme. It includes CBR information from the Guyana Region, particularly on training, employment projects and resources. Address: CBR News, 120 Parade Street, Kingston, Georgetown, GUYANA.

Inclusion - News from Inclusion International.

This journal is the annual publication of Inclusion International, the organization formerly known as the International League of Societies for Persons with Mental Handicap (ILSMH). The Journal addresses the main concerns of the organization--human rights, advocacy and self-advocacy for its grass roots membership of 50 million

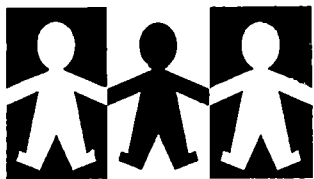


people with mental handicap and their families worldwide. The findings of specialized Project Groups are reported in a bi-annual publication called *Getting There*, and inclusive education, inclusive communities and CBR issues, approaches and projects are reported. Address: Inclusion International, Galleries de la Towson d'Or, 29 Chaussee d'Ixelles, # 393/32, B-1050 Brussels, Belgium. Fax: 32-2 502 2846; e-mail: incluit@skynet.be

International Rehabilitation Review (IRR) is the official publication of Rehabilitation International (RI) and includes in-depth coverage of key issues relating to CBR and other aspects of disability, media developments, news from around the world and highlights of RI activities. There are two issues of IRR each year which cost \$45.00. Complimentary subscriptions are available to editors of other disability periodicals (on an exchange basis) and to selected individuals and organizations in developing countries. Address: Rehabilitation International, 25 East 21 Street, New York, N.Y. 10010 USA, Fax: 1 212 505 0871; e-mail: rehabintl@aol.com



Newsletter of the Sierra Madre is put out by HealthWrights, a workgroup for people's health and rights. This newsletter highlights disability projects in developing countries with regular updates on Project PROJIMO, a program run by and for disabled young people in western Mexico. Available from HealthWrights, P.O. Box 1344, Palo Alto, CA 94302 USA. Fax: 1 650 325 1080; e-mail: healthwrights@igc.org; Website: www.healthwrights.org



One in Ten is a joint newsletter of Rehabilitation International and UNICEF on the topic of childhood disability. It often covers topics relating to CBR as well as prevention, the girl child, protection of children in especially difficult circumstances, etc. Available in English, French, and Spanish. Address: UNICEF House, 3 U.N. Plaza, New York, N.Y. 10017 USA. Fax: 1 212 824 6483 or from Rehabilitation International, 25 East 21 Street, N.Y., N.Y. 10010 USA. Fax: 1 212 505 0871; e-mail: rehabintl@aol.com

Pacific Network of Disability Workers is a new publication designed to keep disability workers who have undertaken the distance learning Certificate in Disability Studies from the University

of the South Pacific in contact with developments in the Pacific and on the global scene. The participating countries include Cook Islands, Fiji, Nauru, Niue, Solomon Islands, Tonga, Tuvalu, Vanuatu and Western Samoa. The publication contains current local developments and very practical information for practitioners in disability services. Address: Secretariat, Pacific Network of Disability Workers, University Extension, USP, P.O.Box 1168, Suva, Fiji Islands. e-mail: RADIO_L@uso.ac.fj

REHAB Today is the newsletter of the CBR Programme in Bacolod City in the Philippines. As one of the earliest CBR projects, many international visitors have been welcomed and this newsletter brings information about such visits as well as on-going CBR training and new efforts such as the 1996 "Village based Appropriate AIDS Store". It is published quarterly. Address: Negros Occidental Rehabilitation Center, Cor. Lacson Street-Cottage Road, Bacolod City 6100 Philippines. Fax: 63 34 81322.

Together is the CBR Newsletter of an ILO/UNDP project based in Iraq. Although the newsletter is printed only in Arabic, there is an English translation of the contents on the inside cover. In addition, if English translation of any of the articles is needed it will be sent on request. Address: Vocational Rehabilitation for Disabled People Project IRQ/95/002/ILO - UNDP Baghdad, P.O. Box 3606, P. Code 12902, Iraq. Tel.: 964 1 542 1674; Fax: 964 1 886 2523.

B. Selected Recent CBR Publications

Books

Beyond Basic Care: Special Education and Community Rehabilitation in Low Income Countries, edited by Roy Brown, David Baine and Aldred Neufeldt. The focus is on describing a variety of ideas and techniques used to solve rehabilitation and special education problems in various countries around the world, with the intent that this sharing may lead to the adoption and trialing of appropriate strategies previously untried. The issue of change-agency is addressed, with the strengths and problems of providing consultancy and technical assistance across cultural boundaries. Address: Captus Press, York University Campus, 4700 Keele Street, North York, Ontario, Canada, M3J 1P3. Fax: 1 416 736 5793; e-mail: Info@Captus.com

Community Based Rehabilitation is written by Malcolm Peat, Executive Director of ICACBR and professor at the Queen's University School of Rehabilitation Therapy. Published in 1998, this book reflects the view that there is no single approach that represents CBR, that it must be viewed as continuum. The book examines the development of CBR and the factors influencing its design and implementation, and is applicable to CBR planning and practice in developed and developing countries. Canadian \$65. Address: W.B. Saunders Co. Ltd., c/o ICACBR, Queen's University, Kingston, Ontario K7L 3N6, Canada. Fax: 613-545-6882; e-mail: icacbr@post.queensu.ca

Community-Based Rehabilitation: Existing Approach and Chakoria CBR: A Case Study of Rural CBR of Bangladesh is a review of CBR in Bangladesh by Shahidul Haque and Shahnas Begum. It focuses on CBR in remote villages that are often ignored by aid and relief organizations. Address: Sarpy-Bangladesh, GPO Box 4208, Dhaka 1000 Bangladesh. Cost is US \$ 10.00. Fax: 880 2 81 9774.



Critical Resources for Realizing a Human Rights Agenda for People with Disabilities. These publications were developed as part of a project called *Partnerships in Community Living: Toward Making the Human Rights Agenda for People with Disabilities a Reality*. The project focused on promoting the inclusion of children

and youths with disabilities in their communities, by means of achieving a consensual human rights declaration to guide all activity and service development within the 36 participating countries from the Americas. The Managua Declaration focuses on community-based research as a means towards participatory goal and vision setting and problem solving. It is a revolutionary document that may pave the way for new solutions to many of the problems currently addressed by CBR. Address: The Roeher Institute Publications, Kinsmen Building, York University, 4700 Keele Street, North York, Ontario, Canada M3J 1P3. Fax: 1-416 661 5701; e-mail : mticoll@roeher.ca

Daily Management of CBR Fieldworkers and Supervisors. Including Proposals for Internal Regulations and Monitoring Documents for CBR Programmes (Draft Version) This is the first CBR related publication that evaluates the success and failures of the CBR movement since the early 1980s. In it, the author Geert Vanneste challenges CBR managers to both question the ideas put forth in the book, as well as their own management practices in light of the fact that

often, time, energy and resources have been wasted to the detriment of many people with disabilities and their families. Chapters explore some of the myths of CBR, management styles or lack thereof, what a comprehensive CBR programme might look like, training and variety of monitoring and evaluation tools. This is a much needed resource in the field. Purchases can be made directly from the author. CCBRT Library, P.O. Box 23.310 Dar es Salaam, Tanzania. Fax: 255 811 321 1135.

Disability and Rehabilitation in Rural Jamaica: an ethnographic study by Ronnie Linda Leavitt, 249 pages, published 1992 by Associated University Press, 440 Forsgate Drive, Cranbury, NJ 08512 USA; 25 Sicilian Ave., London WC1A 2QH England; and P.O. Box 39, Clarkson Pstl. Stn., Mississauga, Ontario L5J 3X9, Canada. This book by a U.S. medical anthropologist is an in-depth analysis of a CBR project in Jamaica, known as the 3D Project, based on research undertaken by the author. The eight chapters cover: introduction to concepts; description of the 3D project; Jamaica—the nation and its people; health in Jamaica—the delivery system and present status of the people; methods of research; disabled children and their families—a quantitative and qualitative perspective; disabled children and their families—case histories; and a discussion, followed by recommendations and conclusions. Unusually comprehensive appendices cover: disability & rehabilitation in the third world; and theoretical constructs—a review of the literature.

Disabled Children and Developing Countries is edited by Pam Zinkin and Helen McConachie. It is a 1995 book covering most of the topics that are important to those concerned with children, ranging from the political arena to community based solutions. An international list of authors contributes their experiences working in developing countries and shares both successes and constraints. Emphasis is on early detection and intervention as well as the work of several landmark CBR programmes. The book is highly referenced and is particularly useful in academic and training situations. Address: Cambridge University Press, The Edinburgh Building, Shaftesbury Road, Cambridge CB22RU, UK or in North America, 40 West 20th Street, N.Y., N.Y. 10011 USA. Fax: 1 914 937 4712.

Gender and Disability: Women's Experiences in the Middle East by Lina Abu-Habib, provides an overview of the neglect of disabled women by both the feminist and disability movements. A review by Disability Awareness in Action stated that the publication documents both examples of the desperate situation of disabled women in the

region and examples of positive actions by and for disabled women. Available for £7.95 from Oxfam, c/o BEBC, PO Box 1496 Parkstone, Dorset BH12 3YD, UK or from \$9.95 from Oxfam, c/o Humanities Press, 165 First Ave., Atlantic Highlands, NJ 07716-1289, USA. Fax: 1 732 872 0717.

Inclusive Education, written by Ture Jonsson and published by the UNDP Inter-regional Programme for Disabled People, this book was prepared for all those involved in implementing the UNESCO Education for All Policy, in developing countries, at national, regional, district and community levels. The book makes explicit the connection between the concept of Inclusive Education and CBR. Concrete examples in the form of case studies form the basis for theoretical understanding. It is an invaluable resource book for educational managers, teacher trainers and teachers. Address: UNDP, Interregional Programme for Disabled People, Palais des Nations, CH-1211 Geneva, Switzerland. Fax: 41 22 979 9001.



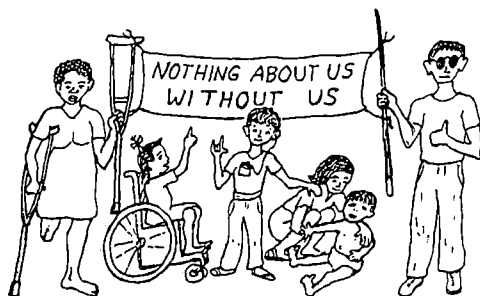
Innovations in Developing Countries for People with Disabilities is edited by Dr. Brian O'Toole and Dr. Roy McConkey, both of whom have spent over a decade working in developing countries on CBR and other aspects of disability awareness and rehabilitation. This book starts with a practical vision for the new millennium, never underestimating the difficulties but carefully documenting the issues and experiences of leading people who have been working in diverse locations in all parts of the world to develop the talents of, and create opportunities for, people with disabilities. The book emphasizes the key role played by disabled people themselves in developing enabling communities, and the importance of integrating services for people with disabilities into generic community development. The book is divided into three sections encompassing foundations, ways of meeting needs and of developing services. It covers empowerment, attitude change, mobilizing communities, parents and indigenous peoples, national planning and paths to economic independence in low income countries, diverse patterns of human resource selection, development and deployment, funding, evaluation and its vital link to program modification and improvement. Country program examples include Mexico, India, Guyana, Tanzania, the Philippines, Jamaica, Norway, Lesotho, Canada, Vietnam, Sri Lanka, Malaysia and Indonesia. The diversity is a testament to the

strength of the CBR concept, and the book contains more distilled wisdom, hard won through trial and error in field experience, than any other document published to date - an invaluable resource for anyone working or contemplating working in a 'disability within community' framework, anywhere in the world. Contact: Lisieux Hall Publishers, Lisieux Hall, Whittle-le Woods, Chorley, Lancashire PR6 7DX, U.K. Fax: 44 12572 65671

Listening for Health - Better Health Communication through Better Listening is a publication of the International Catholic Child Bureau and the Child-to-Child Trust, UK. It is designed for adults who want to help children to become good listeners as well as better agents of change in their community. CBR is one of the many Child-to-Child activities in countries around the world. Address: ICCB, 62 rue de Lausanne, CH-1202, Geneva, Switzerland. Fax: 41 22 731 9377.

New Life in the Neighborhood is one of several books by author Robert Perske and beautifully illustrated by Martha Perske. The book is about "how persons with retardation and other disabilities can help make a good community better". Although the book provides examples from North America, its philosophy, process and practical solutions are adaptable to anywhere in the world. It is an easily readable book which presents through illustration and text information ranging from the common prejudices of non-disabled people to the economic and ethical benefits of *all community members* participating in life in the neighborhood. The author and illustrator have published several other books on disability that could easily be adapted in other countries. Address: Abingdon Press, 201 8th Avenue South, Nashville, TN 37202 USA. Fax: 1 615 749 6172.

Nothing About Us Without Us: Developing Innovative Technologies For, By and With Disabled Persons is a book by David Werner, author of **Disabled Village Children** and **Where There is No Doctor**. It is published by *HealthWrights*, a workgroup for people's health and rights committed to advancing the health, rights, social equality and self determination of



disadvantaged persons and groups. The 350 page heavily illustrated book is "an idea book about problem solving" and includes numerous case studies which document the process of creative solutions which empower children and adults with disabilities--many of these solutions coming from the grassroots. It provides literally hundreds of practical suggestions which the author and publisher hope will serve as a spring-board for similar approaches to problem solving for individuals and projects around the world. A Spanish edition is planned for 1998. HealthWrights also distributes other publications as well as their *Newsletter from the Sierra Madre*. They also publish **Disabled Village Children**, one of the best and most practical texts for working with children with disabilities in developing countries. Address: HealthWrights, P.O. Box 1344, Palo Alto, CA 94302 USA. Fax: 1 650 325 1080; e-mail: healthwrights@igc.org; website: www.healthwrights.org



Rehabilitation Technology in Community Based Rehabilitation: A Compendium is a document providing information on rehabilitation technology as well as a literature review. CBR was the governing principle in defining the scope of the Compendium. Only English language references have been included. Address: The Compendium, School of Rehabilitation Therapy, Queen's

University, Kingston, Ontario, CANADA K7L 3N6, Fax: 1 613 545 6776, E-mail: olneys@qucdn.queensu.ca

Volver a Viver/Return to Life is based on the experiences of members of Project PROJIMO, a rehabilitation programme run by people with disabilities in Mexico. The book outlines several case studies of individuals who go through the process of adjusting to a disability to living a full life again. It is a highly illustrated and easy to read book for anyone working in a CBR or other rehabilitation project. The publisher, Hesperian Foundation, has several other books available both in Spanish and English, their newest being **Where Women Have No Doctor**. Address: Hesperian Foundation, 1919 Addison street, Suite 304, Berkeley, CA 94704 USA. Fax: 1 510 845 0539; e-mail: heperianfdn@igc.apc.org

Manuals/Guides

"Community-Based Rehabilitation" and "CBR of Children with Disabilities in Morocco" are two slide shows to assist CBR implementors from *Teaching Aids at Low Cost* (TALC). Each includes 24 slides, a script,

some questions and answers for discussion. An Arabic script is available on request. TALC has many additional multi-media materials on CBR and other aspects on disability. Address: TALC, P.O. Box 49, St. Albans, Herts, AL15TX, UK, Fax: 44 1727 846852.

HELEN KELLER

INTERNATIONAL

Community-Based Rehabilitation of the Rural Blind

is a publication of Helen Keller International, Inc. It is a

training guide for field workers and grew out of HKI's work in Indonesia and other developing countries. It includes practical information about blindness, orientation and mobility, activities of daily living, basic education and vocational skills. It is very practical, simply illustrated and can be adapted into work with children and adults with a variety of disabilities. Address: Helen Keller International, 90 Washington St., N.Y., N.Y. 10006, USA. Tel.: 1 212 943 0890; Fax: 1 212 943 1220.

Finding Out if Your Program Works: Evaluation and Monitoring.

Developed at the Solo CBR Development and Training Centre in Indonesia, with extensive input from Dr. Laura Krefting, this Manual has wide applicability. In simple language it spells out the different purposes and processes of evaluation, and the importance of participatory evaluation of CBR programs. Simple steps, forms and instructions are provided. Of use in both training and CBR program implementation. Address: Prof. Dr. Soeharso, CBR DTC, Jalan Adisucipto, KM 7, Colomadu, Solo 57176 Indonesia. Fax: 62-271-780976. E-mail: cbr@slo.mega.net

Manual: Community Based Rehabilitation for the Visually Impaired.

Written by S. Punani, D. Bhushan and Rawal Nandini on behalf of the National Association for the Blind, this manual was published in 1996 with the support of DANIDA and the Royal Danish Embassy in India. It documents 14 years of implementation of CBR projects in 111 locations across India. Also included in the 267 page manual are: descriptions of an itinerant system of integrated education, a detailed course curricula for training of trainers and field staff, and an annotated bibliography of CBR publications. Available free from Rural Activities Committee, National Association for the Blind, Vastrapur, Ahmedabad 380 015 India.

Special Education for Mentally Handicapped Pupils is a teaching manual by Christine Miles who worked for 12 years in Peshawar, Pakistan with the Mental Health Centre. The manual is based on the culture and educational conditions of people living in the Middle Eastern and Asian countries and is appropriate for anyone who is working with

children with mental handicaps. It is clear, simply illustrated, practical and covers numerous activities for a wide range of ability levels. The manual would be useful for persons working with children who are not disabled as well as those with other disabilities. Address: Mental Health Centre, Peshawar, Pakistan.

Training Materials for Community-Based Rehabilitation

Workers is a very practical and user-friendly series of manuals developed by the CBR Development and Training Centre in Solo, Indonesia. The series includes manuals on topics like: Helping Prevent Disability, Detection of Childhood Disability, Helping Children who have Difficulty Talking and Communicating, Finding Out About a Person and Her Problems, Finding Out if Your Programme Works, Evaluation and Monitoring. It also includes posters for training and community education. A variety of articles by Dr. Tjandrakusuma Handojo and colleagues are also available, including recent ones on Participatory Rural Appraisal in CBR by Drs. Heny Soelistyowati and Emmillianus Elip. Address: Prof. Dr. Soeharso Community Based Rehabilitation Development and Training Centre, Jalan Adisucipto, KM.7, Colomadu, Solo 57176 INDONESIA, Fax: 62 271 780976; e-mail: cbr@slo.mega.net

Papers

A Training Strategy for Personnel Working in Developing Countries is a paper by Brian O'Toole and Roy McConkey of the Guyana Community Based Rehabilitation Programme. Both doctors have been involved in CBR programmes since the earliest days and have consulted, produced videos and training materials on a variety of aspects of CBR. This paper describes the training strategy used at the CBR Programme in Guyana, South America. As of mid 1997, over 7,000 CBR volunteers, health workers and teachers in mainstream schools, families and villagers have gained access to information and skills on CBR. Additional CBR articles are available as well. Address: School of Health Sciences, University of Ulster, Newtownabbey, BT37 0QB, N. Ireland, UK. Fax: 44 1232 368202.

Community Based Rehabilitation: A Peace Building Opportunity

is a research paper produced by the International Centre for the Advancement of Community Based Rehabilitation (ICACBR) at Queen's University in Canada. The authors are Malcolm Peat, Lorna Jean

Edmonds, Will Boyce, Sandra Ballantyne, Jennifer Smith and Michael Koros. The publication addresses the benefits of CBR as an element of the peace building process and covers experience in and case studies from Bosnia, Afghanistan, Cambodia, Croatia, Lebanon, Mozambique, Palestine (West Bank and Gaza) and Sri Lanka. A Symposium entitled "Post-Conflict Integration of Persons with Disabilities", roundtable discussions and a vast literature search is the basis for much of this paper. This publication may be downloaded from the ICACBR webside: meds.queensu.ca/icacbr/ It can be ordered from ICACBR, Queen's University, School of Rehabilitation Therapy, Kingston, Ontario K7L 3N6 Canada. Fax: 1 613 545 6776.

Community-Based Rehabilitation: Information Accumulation & Exchange by Mike Miles is one of numerous papers about a variety of aspects of CBR written by the author who for 12 years directed the Mental Health Centre in Peshawar, Pakistan and now consults with numerous organizations working in CBR around the world. This particular monograph reviews the cultural background of disability information in South Asia as well as attempts to introduce CBR in this region. He reviews indigenous practices and compares them with the more western community responses to disability often proposed by aid organizations. There are also 247 references cited including a most comprehensive list from individuals and organizations in developing countries. Available from: M. Miles, 4 Princethorpe Rd., Birmingham B29 5PX, UK.

"Disabled Learners in South Asia: lessons from the past for educational exporters" and **"Community, Individual or Information Development: Dilemmas of concept and culture in South Asia disability planning"** are two articles by Mike Miles. The first includes a thorough look at the wealth of ideas and practices for educating children with special needs that were indigenous to South Asia for centuries and most of these contain the same educational principles that the west uses in its disability education work. In the second article, published in *Disability & Society*, the author argues that the wealth of disability information is still not reaching persons in most need. Yet often the 'info poor' are equal or superior in terms of commitment and practical skill base. All people, especially those labeled as recipients, need to be part of the information and skills exchange which are the basis for community development. Address: Mike Miles, 4 Princethorpe Rd., Birmingham B29 5PX, U.K.

"Strengthening Community-Based Rehabilitation in China" is a paper by Sheila Purves, the director of the WHO Collaborative Project

based in Wuhan, China and in Hong Kong. The paper offers unique insights into rehabilitation in the Chinese context and the successes and constraints inherent in the project. Although China now reports more than 300 CBR projects (or activities) in action throughout the country, these still adhere to a top-down approach which has not succeeded in sustainability or ownership by persons with disability. The paper identifies some possible solutions to this dilemma which would ultimately benefit more persons in need and become part of the Primary Health Care System reaching everyone in China. CBR videos from the Sun Yat Sen University in Guangzhou, China are also available. Address: WHO Collaborating Centre/ CBR Project, Hong Kong Society for Rehabilitation, 7 Sha Wan Drive, Pokfulam, Hong Kong. Fax: 852 2855 1947

Towards Inclusion: SCF UK's Experience in Integrated Education is a discussion paper based on Save the Children

Save the Children 

Fund's Global Seminar on Disability where people working both in CBR and more traditional education of children shared experiences and learned from each other. Emphasis was on SCF's educational programmes in Asia and Southern Africa. Case studies from several countries are included along with a discussion about Integrated Education's relationship with CBR. Address: Save the Children, Publication Sales, 17 Grove Lane, London SE5 8RD, UK. Tel.: 44 171 703 5400; Fax: 44 171 708 2508; e-mail: publications@scflondon.ccmil.compuserv.com

United Nations Publications

Mandates for Action is a key document of the United Nations ESCAP initiative, Asian and Pacific Decade of Disabled Persons, 1993-2002. Rehabilitation services are included as one of twelve major target areas for action during the decade, with specific targets set for achievement on a year by year basis. Requirements are explicit and are detailed in another ESCAP document *Implementation of the Agenda for Action for the Asian and Pacific Decade of Disabled Persons: Targets by Area*. Address: Project Expert on Disability, UN ESCAP, Social Development Division, UN Building, Rajdamern Avenue, Bangkok 10200, Thailand. Fax: 662-288 1030 e-mail: takamine.unescap@un.org

OMAR in Rehabilitation: A Guide on Operations Monitoring and Analysis of Results. Written by Ture Jonsson and published by the UNDP Inter-regional Programme for Disabled People, this Guide is a serious attempt to address the need for a comprehensive, simple, user-

friendly monitoring and evaluation instrument, universally applicable, assessing program progress and change in relation to relevance, effectiveness, efficiency, sustainability and impact. In Part 1 the Guide provides a case study to illustrate the application of the procedures. In Part 2 model forms are provided which constitute the substance of any CBR program data collection and record keeping system. These include modified forms adapted from *Training in the Community for People with Disabilities* (WHO 1989), covering individual assessment and progress, as well as additional information on the overall aspects of a program which are of essential interest to policy and decision makers, persons in charge at the national, regional and local level, to rehabilitation committees, NGOs and donor agencies. A software diskette which contains the entire second set of forms is included. The Guide will serve as a resource book in staff training, as well as a handbook for use in programme implementation. Address: United Nations Development Program, 304 East 45th Street, Room FF92, New York, NY 10017, USA. Fax: 1 212 906 6350/6336.

Prejudice and Dignity, An Introduction to Community-Based Rehabilitation is a 1992 book by E. Helander, then consultant for the International Programme for Disabled People, United Nations Development Programme. The author introduces the concepts and practices of CBR and advocates for fundamental changes in rehabilitation systems to make them sustainable from national resources. He maintains that governments should take responsibility for providing CBR systems. Available from United Nations Development Programme, 304 E. 45th St., Rm. FF982, New York, NY 10017, USA. Fax: 1 212 906 6336; website: <http://www.undp.org/hiv>

Sharing Opportunities, A Guide to Disabled People's Participation in Sustainable Human Development is a publication by E. Helander, focusing on the need for participation and leadership of people with disabilities in community initiatives in order to achieve sustainable human development. Address: UNDP, Interregional Programme for Disabled People, Palais des Nations, CH-1211 Geneva, Switzerland. Fax: 41 22 979 9001.

Training the Disabled in the Community, Version 2, is a series of manuals for use by grass-roots organizations wishing to implement CBR in their communities by E. Helander, P. Mendis, G. Nelson.. Address: WHO, Rehabilitation Unit, Avenue Appia, CH 1211 Geneva 27, Switzerland. Fax: 41 22 791 0746.

Understanding Community-Based Rehabilitation is the formal document of the United Nations Economic and Social Commission for Asia and the Pacific - Document Number—ST/ESCAP/1761. The statement does not attempt further definition of the term CBR, but rather clarification and component description. It emphasizes the multi-sectoral nature of CBR as a community development program with seven components, requiring the collaboration and cooperation of seven relevant sectors. Address: UN ESCAP, Social Development Division, UN Building, Rajdamnern Avenue, Bangkok 10200, Thailand. Fax: 662 288 1030 e-mail: takamine.unescap@un.org



The following publications are available from either the ILO, WHO or UNESCO. The addresses are: **ILO** (see below) / **WHO**, Rehab Unit, Avenue Appia, CH 1211 Geneva 27, Switzerland. Fax: 41 22 791 0746 / **UNESCO**, Place de Fontenoy, Paris 75700 France. Fax: 33 1 45 67 16 90

"Community-Based Rehabilitation for and with People with Disabilities: a joint position paper" published in 1994 jointly by the ILO/UNESCO/WHO. Available from either of the three organizations in English, French, Spanish and Arabic. No cost.

Multisectoral Collaboration for the Equalization of Opportunities for People with Disabilities, published 1996. No cost.

The following are publications related to CBR available from the **International Labour Organization (ILO)**. The address is: ILO Publications, Vocational Rehabilitation Branch, ILO, CH 1211, Geneva 22 Switzerland. Fax: 41 22 798 8685

Challenging Disability: a guide for frontline social workers in Africa by Helen Jackson, 1993, Set of 11 modules. Price 50 SFR, 25 SFR for organizations in developing countries.

Guide for Community-Based Vocational Rehabilitation of Disabled People: the case of the Philippines, 1994. No cost.

How to Start a Small Business: a manual for community workers assisting persons with disability by Lena Karlsson, 1992 (also available in Portuguese). Price: 50 SFR, 25 SFR in developing countries.

Training for Integration and Participation: a manual for conducting a sensitization course on integration and disability, 1992, set of 17 booklets (also available in French) Price: 50 SFR, 25 SFR for organizations in developing countries.

Listen to the People: a guide for planners of disability programmes, 1994. No cost

Working Together with the Media: a practical guide for people with disabilities by Barbara Kolucki and Barbara Duncan, 1994. No cost. Also available from: Rehabilitation International, 25 E. 21 Street, New York, N.Y. 10010 USA. Fax: 1 212 505 0871.

C. Video Training Packages

3 D Projects in Jamaica, under the direction of Dr. Molly Thornburn, has produced a series of training manuals and videos. The topics include: Parent Training, The Work Experience Project, Income Generating Projects, Stroke Rehabilitation for Community Workers, Teacher Orientation to early Childhood Disability, Conducting Disability Surveys, Early Detection and Intervention in Childhood Disability, Assessment of Children with Disabilities, Orientation on Disability, Child Rearing Skills, Parent-to-Parent Counseling and Drama in Community Education. Address: 3D Projects, 14 Monk Street, Spanish Town, St. Catherine, JAMAICA. Fax: 1 809 984 7808.

Video courses: A New Concept in Training Courses for Disability Services in Africa is an eight part package that was videotaped in eight African locations and is designed to provide training opportunities to people with disabilities, their families, community workers and rehabilitation personnel. They were developed by Roy McConkey, Sarah Holloway and Liz Lee with partners in each of the African countries. It illustrates the development of children with physical and mental disabilities and how parents and communities members can support their growth and development. A Tutor's Guide accompanies the videos, together with developmental check-

lists and activity suggestions. A video programme is also available on **Moving On: Preparing African Teenagers with a Disability for Living in the Community**. Address: Penny Mharapara, Training Programme Co-ordinator, P.O. Box 1198, Avondale, Harare, Zimbabwe.

Preparing Teachers for Inclusive Education is a video-based training package for use in teacher training courses. It is based on the SCF-UK's projects in Lesotho where they have attempted to integrate children with disabilities into local schools. It includes 13 video programmes along with guides. Part 1 deals with inclusive education, attitudes toward disability, and screening for disability. Part 2 is about good classroom practices for children with specific disabilities and Part 3 is about adapting the curriculum. Part 4 includes classroom practice, changing behavior and teaching strategies. The series was developed by Lineo Phacaka, Lillian Mariga and Roy McConkey. Address: Lineo Phacaka, Special Education Unit, Ministry of Education, P.O. Box 47, Constitution Road, Maseru, Lesotho.

Hopeful Steps: Guyana Community-Based Rehabilitation Programme is a vide training series which includes: 1. *Hopeful Steps* - - six programmes examining learning to move, talk, think and be independent. 2. *Community Action on Disability* -- eight programmes including parent/community involvement, working with teachers, community networks and motivating volunteers. 3. *Identification of Disabilities* -- one video for Primary Health and CBR workers. 4. *Facts for Life* -- one video analyzing the major challenges in developing healthy lives. 5. *A New Tomorrow* -- a series of eight programmes that examine the development of native Amerindian peoples of Guyana. 6. *Educating Communities about Disability* presents a series of short puppet shows on attitudes toward disability. 7. *When There is No Nursery School* -- seven programmes offering ideas to parents and teachers for stimulating the growth and development of the preschool child. 8. *Introducing Children with Disabilities into Mainstream Schools* -- eight programmes on enrolling children with disabilities into ordinary schools. 9. *Steps to Reading* -- six programmes providing an introduction to reading. 10. *CBR in the Rupununi, Guyana* -- one video analyzing CBR with native Amerindian people of Guyana. 11. *Baha'i Community Health Partnership* is one video tracing the development of Primary Health Care in Guyana run by the Baha'i community. Many in the series are accompanied by a manual. Address: for NTSC copies, Dr. Brian

O'Toole, CBR Programme, EEC, PO Box 10847, Georgetown, Guyana, South America, Fax: 592 2 62615; for PAL copies, Dr. Roy McConkey, St. Aidans, Gattonside, Melrose, Roxburgshire, Scotland, TD6 9NN, UK, Fax: 44 89 682 2159.

A Better Life: for People with Mental Handicap, Living and Learning, Teaching Skills: for use when teaching People who have a Mental Handicap, Community-Based Services, Community-based Education, Disability and Community and Training for Work: Increasing employment opportunities for people with disabilities are all Video courses developed by Dr. Roy McConkey, Alice Bradley and Sarah Holloway with support from the Far Eastern Region Cheshire Homes. They are all appropriate for use in CBR projects and many are available in English, Mandarin, Bahasa Malaysia. Practical manuals accompany many of the series and represent the work in Malaysia, Philippines, Guyana, Sri Lanka and Morocco. Address: Diana E. Khoo, Cheshire Homes Far Eastern Region, 515 Q, Jalan Hashim, 11200 Tanjung Bungah, Penang, Malaysia.

D. Additional Resources

The Institute of Child Health publishes numerous publications updates, fact sheets and material on the topics related to CBR and other aspects of disability. The Institute was the pioneers of the first courses in CBR and have continued to expand their programmes to include a Masters Course in Community Disability Studies, Research Degrees and Attachments as well as provide consultation in both industrialized and low income countries. Most of the coursework now takes place in developing countries. Address: Institute of Child Health and Great Ormond Street Hospital for Children NHS Trust, University College London Medical School, 30 Guilford Street, London WC1N 1EH, U.K. Fax: 44 171 404 2062; e-mail: cich@ich.ucl.ac.uk

The Enabling Education Network (EENET) is an information-sharing network aimed at supporting the inclusion of marginalized groups in education around the world. It was initiated by Save the Children UK and is in partnership with UK and international NGOs and research institutions. It disseminates information to teachers, disabled people, parents, children, policy-makers and practitioners as well as promoting action research training. It also supports

South-South and South-North initiatives. They are currently producing videotapes on Integrated Education. Address: EENET, Centre for Educational Needs, School of Education, The University of Manchester, Oxford Road, Manchester M13 9PL, UK. Fax: 44 161 275 3548; e-mail: eenet@man.ac.uk

ICACBR Research: One of the biggest changes in the last five plus years in CBR is that there is now a body of research on various aspects of CBR. Much of this is emanating from the International Centre for the Advancement of CBR based at Queen's University in Canada. The ICACBR research programme covers a variety of disability issues from psycho-social attitudes to policy issues. The primary area of research include the role of women in CBR, community organizations, policy studies, skill and knowledge transfer, and psycho-social issues. Collaboration is made with partner organizations in developing countries, particularly those in India, Bangladesh and Indonesia. Address: ICACBR, c/o Dr. Will Boyce, Queens University, Kingston, Ontario, K7L 3N6 CANADA. Fax: 1 613 545 6776

Training in Planning and Management of CBR is a course based in Dar es Salaam, Tanzania. It is unique in that it concentrates on a comprehensive, cross disability CBR management with full time local staff and a formal management structure. The course runs for 6 weeks and covers much of what is usually introduced in CBR training. However, it concentrates on planning and management issues for the 21st Century. This approach hopes to offer an alternative to the often donor-driven isolated CBR projects that are not sustainable in the long run. Thus far over 100 CBR managers from 28 countries have attended these courses. They are sponsored by Chirstoffel Blind Mission. Address: Dr. Geert Vanneste, CBR Programmes (CBM/UNDP), PO Box 23.310, Dar es Salaam, Tanzania. Fax: 255 811 321135; e-mail: vanneste@twiga.com

Training Programmes for CBR in Developing Countries is organized by Seva-in-Action of India. It includes a Diploma for teachers, planners and coordinators of CBR, a Diploma in integrated education and CBR and a Certificate Course in CBR. Address: SEVA-in-ACTION, 2487 17th Main, 25th Cross, Banashankari II Stag, Bangalore 560 070, Karnataka, INDIA

CBR Web Page is an effort by Gene Rodgers of the USA to compile and share CBR research and other material. His address is 1941 Gaston

Place, Apt. 122, Austin, TX 78723 USA. The Website is : <http://www.onr.com/user/geno>

Planning and Management of CBR Programs in Developing Countries is a course run by the International Institute for Rehabilitation Management, in cooperation with the UN Development Program. This course was run twice in 1997, and has been used by managers of CBR projects in a variety of Asian countries, including Indonesia, Bhutan, the Phillippines. The course focuses on sustainable planning and management practices, with a strong emphasis on monitoring and evaluation. Address: Course Director, International Institute for Rehabilitation Management, F-45230 Chatillon-Coligny, France. Ph: 33 38925571.

Skills for Working within the Community is Module 3 of a Certificate in Disability Studies offered as a Continuing Education course at the University of the South Pacific, Suva, Fiji. The course covers community education and public awareness, rehabilitation in the community, developing a CBR program, vocational training and advocacy skills, towards equalization of opportunities and community service planning. Address: Laisani Radio, Course Coordinator, Certificate in Disability Studies, Continuing Education, University of the South Pacific, Suva, Fiji. e-mail: RADIO_L@uso.ac.fj

Community Based Rehabilitation Development and Training Centre, Solo, Indonesia runs courses for training trainers who will be involved in implementing CBR programs in their own countries, and has plans in 1998 to run leadership training courses for people with disabilities. Address: Prof. Dr. Soeharso, CBR DTC, Jalan Adisucipto, KM 7, Colomadu, Solo 57176 Indonesia. Fax: 62-271-780976; e-mail: cbr@slo.mega.net

About the Contributors

Author/Project Coordinator:

Barbara Kolucki is an international media consultant, not only to Rehabilitation International but also to several United Nations agencies, such as UNICEF, the ILO, and UNDP. Kolucki began her work on media and disability when she became the Program Director, Special Education, at Children's Television Workshop, the producers of *Sesame Street*. In recent years she has trained people in several developing countries to become producers of media for, about and with children.

"Vision Statement" Authors:

Francine Arsenault, well-known Canadian activist, works with the Council of Canadians with Disabilities and is the Chair of the International Center for the Advancement of Community Based Rehabilitation (ICACBR). Most recently she has consulted in Bosnia and the Caribbean to support expansion of disability services in these countries.

M. Miles of the U.K. worked in Pakistan for more than a decade to establish community-based and other services for children with disabilities. He has carried out consultancies on disability service development in Asia and Africa and collaborates with Inclusion International to increase its effectiveness in developing countries. Miles is best known for his voluminous writings and research.

Penny Price (Australia) lectures on Disability Studies at MacQuarrie University, Sydney. Price spent several years implementing CBR in Fiji and the Cook Islands. She is a member of the newly-established RI CBR Group which met in Korea in September 1997 to elaborate strategies to promote CBR development in the Asia/Pacific region.

Carmen Reyes Zubiaga of the Philippines is now serving as the Executive Director of the National Center of Disabled Persons, Phnom Penh, Cambodia. In both countries she has worked to establish CBR services and to expand the participation of disabled people in program design and implementation.

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Rehabilitation International is a federation of national and international organizations and agencies working for the prevention of disability, the rehabilitation of persons with disabilities and the equalization of opportunities within society on behalf of persons with disabilities and their families throughout the world. RI is currently composed of some 200 organizations involved in disability prevention and rehabilitation service development in nearly 100 nations in all of the world's regions.

Rehabilitation International maintains official relations with the United Nations Economic and Social Council, the World Health Organization, the International Labor Office, UNESCO, UNICEF, the Organization of American States, the Commission of European Communities and the Council of Europe.

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