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Background paper on the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities

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Ladies and Gentlemen,  
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. To create "decent conditions of life for all men" as an obligation for all - what a wonderful vision!

Today is 2001 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 cannot 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 for war and destruction.

Ladies and gentlemen,

In this presentation I will mainly concentrate on the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities. However, I will also give you an account of important events in the human rights area.

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. They were adopted in December 1993.

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, 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 labour 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,

Another target group of particular interest is the group of children and youth. As you know the UN Convention on the Rights of the Child protects the rights of all children up to the age of 18. There is a special article (article 23) on disabled children and naturally the convention as a whole is valid for this group of children too. One special issue to discuss is how these two UN documents relate to, and how they could support and complement each other.

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 pre-schools 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,

I should also like to draw your attention to the situation of people with disabilities from mental illness. All the recommendations and guidelines in the Standard Rules are there to be taken into account for all groups of disabled people. The concept of disability which is applied in the Rules makes this quite clear. Let me quote the following from the introductory chapter, para 17: "The term 'disability' summarizes a great number of different functional limitations occurring in any population in any country of the world. People may be disabled by physical, intellectual or sensory impairment, medical conditions or mental illness. Such impairments, conditions or illnesses may be permanent or transitory in nature."

As I have said before, the Rules concern all groups of people with disabilities. However, it is obvious that the recommendations and guidelines are more concrete when it comes to other groups than mentally disabled people. Actually, there are very few direct references to people with mental disabilities in the Standard Rules. In most cases we have to combine the general principles and recommendations of the Rules with our knowledge about the situation of mentally disabled people.

With regard to these circumstances it is a great asset in my work to have representatives of the World Network of Users and Survivors of Psychiatry as members of the Panel of Experts. The voice of persons with mental disabilities must be strengthened in all countries of the world and especially in developing regions.

Ladies and Gentlemen,

The monitoring exercise in connection with the UN Standard Rules started in 1994, when I was appointed Special Rapporteur and when the following six international disability organizations established a Panel of Experts, consisting of ten people from all over the world: Disabled Peoples' International (DPI), Inclusion International, Rehabilitation International (RI), World Blind Union (WBU), World Federation of the Deaf (WFD) and World Network of Users and Survivors of Psychiatry (WNUSP).

During the six years of monitoring I have visited a considerable number of countries; I have presented three reports (1995, 1997 and 2000) to the UN Commission for Social

Development; I have published one book and five reports as a result of a global questionnaire, circulated early 1996. In 1999 I participated in a WHO survey on the world situation in areas like medical care, rehabilitation and the provision of assistive devices. A report will be published in 2001. The Panel has performed its consultative role at five meetings and the organizations involved have offered cooperation through their extensive network of national organizations.

Both my mandate and the function of the Panel of experts were renewed by UN ECOSOC in July 2000. My new and final mandate will run until the end of 2002.

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 these areas to obtain the goals we have set. When we use this approach, 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.

During the seven 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.

The goal of full participation has many dimensions. Again, according to the text of the Standard Rules there are "obstacles preventing persons with disabilities from exercising their rights and freedoms". In the Standard Rules, disability 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 all fundamental human rights, enshrined in these documents, have 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 the right to education of disabled children is seriously violated.

In our second survey 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 49 countries out of 82 providing information, 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,

I am now going to devote my remaining time to point to some extremely important things, which have happened in the human rights area within the United Nations. First I should like to mention that the former Special Rapporteur on Disability, Mr. Leandro Despouy, in his final report in 1992 among other things, suggested that the Committee monitoring the Convention on Economic, Social and Cultural Rights, should take the general interest in monitoring the situation of persons with disabilities. The Committee has assumed this responsibility and the most obvious expression of this is the extremely interesting analyses included in General Comment No. 5. This document among other things states the following:

“The Covenant does not refer explicitly to persons with disabilities. Nevertheless, the Universal Declaration of Human Rights recognizes that all human beings are born free and equal in dignity and rights and, since the Covenant’s provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognized in

the Covenant. In addition, in so far as special treatment is necessary, States parties are required to take appropriate measures, to the maximum extent of their available resources, to enable such persons to seek to overcome any disadvantages, in terms of the enjoyment of the rights specified in the Covenant, flowing from their disability. Moreover, the requirement contained in article 2 of the Covenant that the rights 'enunciated .... will be exercised without discrimination of any kind' based on certain specified grounds 'or other status' clearly applies to discrimination on the grounds of disability."

In the following text of the General Comment, the Committee enters into an interesting analyses of the reasons for paying special attention to the situation of persons with disabilities. The Committee also urges States to improve considerably their reporting on the situation of persons with disabilities. As I am sure you understand that this is a great step forward in our struggle for the recognition of full enjoyment of human rights by girls, boys, women and men with disabilities.

As a consequence of these events, the UN Commission on Human Rights brought up disability on its agenda several times during the late 1990's. The most obvious result of this is the adoption of a series of resolutions, of which the latest is resolution 2000/51. I should here like to draw your attention to the main initiatives and recommendations included in the resolution:

There are totally 31 operative paragraphs. Before going through these, I would, however, like to stress once again that the most important result is that this resolution has been adopted by the Commission, which means that the disability issue from now on will be recognized as a dimension of human rights in the monitoring of these rights by all the UN entities. In other words the issue will be permanently present on the agenda of this Commission and of other similar bodies. In fact the Commission requests that all other UN treaty monitoring bodies and appointed Special Rapporteurs should include the disability dimension in their work. The first paragraph establishes an important link between the UN Standard Rules and human rights. The UN Standard Rules in this way becomes a recognized human rights instrument - a yardstick for assessing the national disability programmes from a human rights perspective. This can certainly be used in advocating better conditions for persons with disabilities.

There are two important requests addressed to the UN Secretary General to report biennially to the General Assembly on the issue of human rights and disability and to make my latest report available to the Commission.

One interesting message in the resolution is that the Committee monitoring the Covenant on Economic, Social and Cultural Rights, is clearly identified by the Commission as the main actor in monitoring the human rights of persons with disabilities. The Commission draws the attention to the work of this Committee in different ways. One task ahead will be to find out more about how this Committee operates and how we can approach it and communicate our information.

In another paragraph the Commission encourages organizations in the disability field to avail themselves of the technical assistance provided by the Office of the High Commissioner for

Human Rights. Such assistance should aim at helping the organizations to function effectively in the human rights sphere.

Another interesting thing concerns the role of the High Commissioner, who is recommended to take account of information concerning legislation affecting the human rights and persons with disabilities.

Finally, I should like to draw your attention to paragraph 30, in which the High Commissioner is invited to examine measures to strengthen the protection and monitoring of the human rights of persons with disabilities. This examination should be open to input from interested parties, among others the Panel of Experts within the Standard Rules monitoring mechanism.

Ladies and Gentlemen,

We have had a series of successes during the 1990's. The opportunities offered to us to influence and to cooperate with important agencies in the area of global development have been created. It is a real challenge for all of us, who fight for better conditions for all persons with disabilities, to respond constructively and convincingly to these new opportunities. I congratulate you on the achievements made so far and I appeal to you to utilize these new opportunities to the maximum, even if it takes hard work and new ways of working. If we work effectively together I am sure we can make a difference.

Thank you for your attention!

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