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Follow-up to the World Summit for Social Development and the twenty-fourth special session of the General Assembly: review of relevant United Nations plans and programmes of action pertaining to the situation of social groups

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

Note by the Secretary-General

1. At its forty-eighth session, the General Assembly adopted the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, contained in the annex to its resolution 48/96 of 20 December 1993.¹ These 22 Rules provide a framework to further implement the goals of “equality” and “full participation” of disabled persons in social life and development set forth in the World Programme of Action concerning Disabled Persons, adopted by the General Assembly in its resolution 37/52 of 3 December 1982.²

2. In section IV, paragraph 2, of the Standard Rules, it is stipulated that the Rules shall be monitored within the framework of the sessions of the Commission for Social Development. The appointment of a Special Rapporteur to monitor their implementation within the framework of the Commission for Social Development was also envisaged in that paragraph.

3. In March 1994, the Secretary-General appointed Bengt Lindqvist (Sweden) as Special Rapporteur on

Disability of the Commission for Social Development. The Special Rapporteur prepared a report for the consideration of the Commission for Social Development at its thirty-fourth session in 1995.³ On the basis of that report and the findings of a working group established during the Commission, the Commission adopted resolution 34/2 entitled “Monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities”.⁴ In that resolution, the Commission took note with appreciation of the report of the Special Rapporteur and of his recommendations and welcomed his general approach to monitoring, including the emphasis to be placed on advice and support to States in the implementation of the Rules.

4. At its thirty-fifth session in 1997, the Commission for Social Development considered the report of the Special Rapporteur on monitoring the implementation of the Standard Rules for the period from 1994 to 1996.⁵ The Commission took note with appreciation of the valuable work done by the Special Rapporteur, decided to renew his mandate for a further

* E/CN.5/2002/1.



three years and requested the Special Rapporteur to prepare a report for submission to the Commission at its thirty-eighth session in 2000.⁶

5. At its thirty-eighth session in 2000, the Commission for Social Development considered the report of the Special Rapporteur on monitoring the implementation of the Standard Rules for the period from 1997 to 2000.⁷ The Commission took note with appreciation of the valuable work done by the Special Rapporteur, decided to renew his mandate for a further period through the year 2002 and requested the Special Rapporteur to prepare a report for submission to the Commission at its fortieth session in 2002 in which he should, inter alia, present his views on further developing the proposals contained in his report on his second mission⁸ and on forms for complementing and developing the Standard Rules.⁹

6. In section IV, paragraph 12 of the Rules, it is further stipulated that at its session following the end of the Special Rapporteur's mandate, the Commission should examine the possibility of either renewing that mandate, appointing a new Special Rapporteur or considering another monitoring mechanism, and should make appropriate recommendations to the Economic and Social Council. The present mandate of the Special Rapporteur will come to an end in 2002. The Commission is requested to make its recommendations in that regard to the Economic and Social Council and the General Assembly.

7. The Secretary-General has the honour to transmit to the Commission the report of the Special Rapporteur on monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities during the period 2000-2002.

Notes

¹ Available from <http://www.un.org/esa/socdev/enable/dissre00.htm>.

² A/37/351/Add.1 and Add.1/Corr.1, sect VIII. Available from <http://www.un.org/esa/socdev/enable/diswpa00.htm>.

³ A/50/374, annex.

⁴ *Official Records of the Economic and Social Council, 1995, Supplement No. 4 (E/1995/24)*, chap. I, sect. E.

⁵ A/52/56, annex. Available from <http://www.un.org/esa/socdev/enable/dismsre0.htm>.

⁶ *Official Records of the Economic and Social Council, 1997, Supplement No. 6 (E/1997/26)*, chap. I, sect. A, subsequently adopted as Economic and Social Council resolution 1997/19 of 21 July 1997.

⁷ E/CN.5/2000/3, annex. Available from <http://www.un.org/esa/socdev/enable/disecn003e0.htm>.

⁸ Ibid.

⁹ *Official Records of the Economic and Social Council, 2000, Supplement No. 6 (E/2000/26)*, chap. I, sect. A, subsequently adopted as Economic and Social Council resolution 2000/10 of 27 July 2000.

**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 on his third mandate, 2000-2002**

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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. (General Assembly resolution 48/96 of 20 December 1993, annex, paragraph 15)

I. Introduction

1. 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 on the third period of monitoring (2000-2002) to the Commission for Social Development. 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 Economic and Social Council for showing confidence in me by renewing my mandate for a third period. I also would like to thank all those Governments that have contributed financially to this project, including the Government of Sweden, which has provided me with office resources throughout the entire exercise.

2. From the beginning and during the whole period of monitoring, I have enjoyed full support from the Under-Secretary-General of the Department of Economic and Social Affairs, Nitin Desai, and excellent professional advice from the Division for Social Policy and Development. I have benefited from the cooperation of a number of United Nations agencies, especially the World Health Organization (WHO), which in close collaboration with me has conducted a global survey on the implementation of a number of the Standard Rules. I would also like to express my appreciation for the excellent work performed by Eva Sagström in my Swedish office and by Anneli Joneken, who worked as a consultant concerning the supplement to the Standard Rules.

3. One key element in this monitoring exercise has been the panel of experts, established in 1994 by six major international non-governmental organizations in the disability field. The panel members, five men and five women representing all regions and 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.

4. Finally, I want to thank all those Governments and non-governmental organizations that have

cooperated with me during my missions and who have provided information for my work.

II. The mandate

5. My report to the Commission for Social Development (E/CN.5/2000/3, annex) at its thirty-eighth session contained a number of recommendations for future action. Suggestions were made about a future monitoring system, areas to be developed in the present text version of the Standard Rules document, improved information exchange and the future development of the issue of human rights and disability.

6. These topics were discussed within the open-ended working group during the Commission meeting. The outcome of the Commission deliberations are reflected in Economic and Social Council resolution 2000/10 of 27 July 2000. According to paragraph 7 of that resolution regarding the tasks to be carried out by the Special Rapporteur in the renewed, third mandate, the Council *decided* to renew the mandate of the Special Rapporteur for a further period through the year 2002 so that the results of his continued promotion and monitoring of the implementation of the Standard Rules, in accordance with section IV of the Standard Rules, would be available to the fourth quinquennial review and appraisal of the World Programme of Action concerning Disabled Persons,¹ in accordance with General Assembly resolution 52/82, and to request the Special Rapporteur, assisted by the United Nations Secretariat and in consultation with his panel of experts, to prepare a report for submission to the Commission for Social Development at its fortieth session, in which he should, inter alia, present his views on further developing the proposals contained in his report on his second mission (E/CN.5/2000/3, annex) and on forms for complementing and developing the Standard Rules, and on how to enhance the involvement of the relevant bodies and organizations of the United Nations system and relevant intergovernmental regional organizations regarding the implementation of the Standard Rules.

7. The resolution contains a number of specific tasks for the Special Rapporteur to carry out during the term of his third mandate:

(a) Promote and monitor the implementation of the Standard Rules, in accordance with section IV of the Rules. The work during this third period should mainly continue along the lines indicated in the Standard Rules document, which meant continuing to go on advisory and monitoring missions to countries, participate in conferences and seminars promoting the implementation of the Rules, and collect information on the further policy development in countries and regions;

(b) Present his views on forms for complementing and developing the Standard Rules. In the report on my second mandate (E/CN.5/2000/3, annex) I pointed out a number of dimensions that should be developed and strengthened in the light of experiences gained since the adoption of the Standard Rules in 1993 (annex to General Assembly resolution 48/96 of 20 December 1993). My interpretation of this instruction was that I should develop new texts on the basis of my observations in the report and suggest forms for their treatment and possible adoption by the Commission;

(c) Present his views on how to involve the relevant bodies and organizations of the United Nations system and relevant intergovernmental regional organizations regarding the implementation of the Standard Rules. In my previous reports to the Commission I pointed out the need for improved and more systematic information exchange and joint planning in the disability field among United Nations organizations and agencies. The obvious vehicle for this would be the re-establishment of an inter-agency mechanism. However, with regard to financial constraints, in the present report I have presented a simple mechanism for information exchange through the use of modern information and communication technologies, particularly Internet-based technologies;

(d) Present his views on further developing the proposals contained in his report on his second mandate. In addition to the three areas mentioned above, my report to the Commission at its thirty-eighth session considered a number of options for a future monitoring mechanism. The present report reviews this subject. In that report, I also made an analysis and

some observations concerning the issue of human rights and disability. I continue that analysis below.

III. Activities during the period of the third mandate

A. Missions

8. Beginning early in 2000, I continued to promote the implementation of the Standard Rules by visiting countries on the invitation of Governments. In accordance with my mandate I concentrated my missions in countries in transition and those in developing regions. Visits to discuss and promote disability policy were made to Belarus, Bulgaria, China, Malawi, Mauritania and Uganda.

9. During these visits, meetings were organized with ministers, representatives of ministries, organizations and often international organizations, such as the United Nations Development Programme (UNDP), the World Health Organization (WHO), the United Nations Children's Fund (UNICEF) and the United Nations Educational, Scientific and Cultural Organization (UNESCO). National policies, programmes and legislation were presented and discussed from a Standard Rules perspective. One common issue was how to integrate disability measures into general plans and programmes. Other frequently discussed subjects included the collection of data on living conditions and disability statistics and how to develop cooperation between the Government and organizations in the disability field.

10. I was invited to deliver speeches and lectures at a number of conferences. I visited Brazil for the XIX Rehabilitation International World Congress (Rio de Janeiro, 25-29 August 2000). In Canada, I participated in the Sixth International Congress on Including Children with Disabilities in the Community (Edmonton, Alberta, 22-24 October 2000), which attracted three hundred participants from over 50 nations and a number of non-governmental organizations. In Hungary, I took part in a seminar on the implementation of the Standard Rules with participants from 14 countries from Eastern and Central Europe (Budapest, 11-13 October 2000). In the Russian Federation, a national conference on equal opportunities for the disabled (Moscow, 2-3 October 2000) was organized jointly by the *Duma* (parliament), concerned government offices and disability

organizations, with participants from 60 of the 89 regions in the Russian Federation. The conference considered, among other topics, the application of the Standard Rules principles in a regional setting. During my mission to Mauritania, from 13-15 February 2001, I had the opportunity to participate in a subregional seminar on the implementation of the Standard Rules in which 60 delegates participated, representing governmental and non-governmental organizations from several Maghreb countries.

11. In February and April 2001 I participated in and chaired two consultations on disability and human rights, organized by the United Nations Secretariat in New York (9 February 2001) and the Office of the United Nations High Commissioner for Human Rights in Geneva (17 April 2001).

B. Panel of experts

12. The panel of experts, established in 1994 by six major international non-governmental disability organizations as part of the monitoring mechanism, met in New York from 9 to 11 February 2000. The meeting coincided with the thirty-eighth session of the Commission for Social Development, which made it possible for panel members to follow the deliberations of the Commission. One important issue discussed by the panel was the future options for United Nations involvement in disability policy development. The panel emphasized the importance of developing the human rights dimension and of obtaining greater involvement in this issue by the United Nations human rights monitoring bodies. At the same time, disability should remain an important commitment in the field of social development. In both of these areas the Standard Rules should continue to be a main tool for policy development.

13. The panel met again in New York from 4 to 6 September 2001. The main purpose of that meeting was to consult with me as Special Rapporteur on the issues to be brought before the fortieth session of the Commission for Social Development in February 2002.

14. I had prepared an extensive text presenting a considerable number of additions and changes to the text of the Standard Rules. Based on our interpretation of the mandate in this respect, we agreed on the contents of what should be put forward to the Commission. However, it was left to me as Special

Rapporteur to find the most suitable ways to present the recommendations to the Commission for its consideration.

15. The panel also discussed at length options for future monitoring. Two main alternatives were identified: (a) appointment of a new Rapporteur and (b) integration of the monitoring mechanism into the United Nations Secretariat. The discussion took place under the assumption that it would be difficult to find funding for continuing the monitoring with a new Rapporteur. The main discussion therefore was about ways of integrating the different functions of the monitoring mechanism into the work of the United Nations Secretariat.

16. The panel of experts attached to the Standard Rules monitoring mechanism represents a unique form for cooperation between the non-governmental community and the United Nations. During the seven years it has served as a consultative body in this monitoring exercise, it has proved to be very useful for both the United Nations and the organizations concerned. The panel has also been involved in consultations with other international organizations and such agencies as the World Health Organization, the International Labour Organization (ILO), the World Bank and UNESCO. In connection with the global surveys, the more than 600 national affiliates of the six organizations represented on the panel were invited to reply to the same questionnaires as those submitted to their Governments. These national disability organizations also greatly contributed to the unusually high response rates from Governments.

C. Rights for disabled children

17. In January 2000 four international non-governmental disability organizations together with Save the Children International Alliance decided to establish a project entitled "Rights for disabled children". Funding was received for a three-year period from the Swedish International Development Agency (Sida). The Rights for Disabled Children project entered into an agreement with Disability Awareness in Action (a non-governmental organization) in the United Kingdom to coordinate and administer project activities.

18. The purpose of the project is to assist the Committee on the Rights of the Child, which monitors

the Convention on the Rights of the Child, in developing the disability dimension of its monitoring.

19. Among the activities run by the Rights for Disabled Children project the following can be specifically mentioned:

(a) Three times per year, nine Governments are requested by the Committee to report on their achievements. The project decided to analyse these reports by Governments from a disability perspective and to present the results at “pre-sessional” meetings before the Committee session. The three rounds of 2001 were completed, which means that 27 country reports were analysed from a disability perspective, and the findings presented to the Committee. The Rights for Disabled Children project reports were well received. The information collected in this way will later on constitute an interesting body of material for analysis concerning the ways in which States deal with disability within the framework of the Convention on the Rights of the Child;

(b) Another important Rights for Disabled Children project activity is to conduct in-depth studies in four selected countries. The purpose is to study the situation of children with disabilities, to collect information about violations of the rights of disabled children and to identify and describe good examples. In the second half of 2001 the first study was initiated in South Africa.

20. The project is trying to increase the visibility of children with disabilities, both in the documents related to the planned special session of the General Assembly on children and at the actual meeting. The Rights for Disabled Children project has issued a special report on the situation of disabled children, entitled “It is our world, too”, which includes cartoons, pictures and quotations by disabled children.

D. Third survey on selected Standard Rules in collaboration with the World Health Organization

21. The first four Rules in the Standard Rules document state the preconditions for the equal participation of persons with disabilities. Three of these Rules — Rules 2-4, comprising medical care, rehabilitation and support services respectively — are within the mandate of the World Health Organization.

22. In 1999, WHO conducted a global survey to collect information about these three areas as well as selected information on personnel training (Rule 19). In cooperation with me and the panel of experts, a questionnaire was constructed and circulated to all 189 WHO member States, two associate member States and more than 600 national non-governmental organizations in the field of disability.

23. In my report to the thirty-eighth session of the Commission for Social Development (E/CN.5/2000/3, annex), I included a summary of the main results of replies received from the 104 Governments responding to the questionnaire. The final report, *The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities: Government Responses to the Implementation of the Rules on Medical Care, Rehabilitation, Support Services and Personnel Training*, is now available from the World Health Organization.² Six regional reports (Africa — AFRO, Americas — AMRO, Eastern Mediterranean — EMRO, Europe — EURO, South East Asia — SEARO and Western Pacific — WPRO) based on the same set of data are also available from WHO.³

24. The geographical distribution of government replies to the questionnaire is as follows: 27 from AFRO, 17 from AMRO, 4 from SEARO, 25 from EURO, 11 from EMRO and 20 from WPRO.

25. Similar reports are under preparation based on the replies received from 115 non-governmental organizations. The total number of countries covered by the responses from Governments or non-governmental organizations is 130.

26. The distribution of responses from non-governmental organizations by region is as follows: 22 NGO responses from AFRO; 21 from AMRO; 6 from SEARO; 42 from EURO; 10 from EMRO; and 14 from WPRO.

27. WHO will also conduct a complementary study to compare and interpret the differences between the governmental and NGO responses in each country.

28. The result of the WHO survey on the selected Standard Rules can be used in several ways. It will first of all provide information concerning the degree of implementation of the various provisions in the four different Rules. The most useful comparative analysis is probably the one based on regions, since this would provide a more similar social, economic and cultural

context. Replies from the Government and NGOs in the same country can often provide valuable information on the situation of persons with disabilities.

IV. Issues for the future

A. Complementing the Standard Rules

29. In paragraphs 117 to 119 of my report to the Commission at its thirty-eighth session (E/CN.5/2000/3, annex) I made the following analysis of the Standard Rules as a major international policy document:

“It is obvious that more progress in policy development and legislation has taken place in the 1990s than in earlier decades. It is also evident that the progress during the last 10 years is clearly connected with the International Year of Disabled Persons (1981), the World Programme of Action (1982) and the political process initiated at that time. A considerable number of countries throughout the world have adopted new legislation and developed national policies in harmony with international guidelines. In this process, the Standard Rules have played a significant role. Above all the Standard Rules have clearly defined the role of the State in implementing measures towards full participation and equal opportunities, strengthened the human rights dimensions and provided an active monitoring mechanism within the United Nations system.

“The Standard Rules document has many merits. It is concise and provides a concentrated presentation of guidelines in a number of areas. These guidelines have been used in a great number of countries in many different ways. The fact that the recommendations are at the international level has created room for national application and adjustment to regional and local circumstances.

“There are, however, shortcomings in the Standard Rules document. Some dimensions of disability policy have not been treated sufficiently. This is true concerning children with disabilities, in the gender dimension and for certain groups, mainly persons with developmental and psychiatric disabilities. It has

been pointed out that the Rules do not include a strategy for improving living conditions of disabled people in regions with extreme poverty. Disabled persons in refugee or emergency situations are other areas that have not been dealt with. As I pointed out in my previous report to the Commission for Social Development (A/52/56) the whole area of housing has not been included. Among other things this means that there is no guidance concerning the handling of the institutions where a great number of persons with disabilities still spend their whole lives under miserable circumstances. The important events in the human rights area during the 1990s should perhaps also be more clearly reflected.”

30. The above list of areas in need of development forms the most important basis for elaborating the proposed supplement to the Standard Rules, which is included as the annex to the current report. Another important source of information comes from activities generated by the World Health Organization. As I have mentioned, WHO conducted a survey on the implementation of selected Standard Rules. In addition, in 2001 WHO, in collaboration with the Government of Norway, organized the global Conference on Rethinking Care (Oslo, 22-25 April 2001).⁴ One task for conference participants was to identify the strengths and weaknesses in the first four Standard Rules and formulate conclusions and recommendations for the future. In view of the great importance of this conference, its adopted recommendations were taken into account in the elaboration of the attached proposed supplement to the Standard Rules.

31. A special grant from the Government of Sweden made it possible to employ a consultant (Anneli Joneken) to compile material and draft the proposals for supplementing the Rules. At an early stage in this project I invited organizations and individual experts to present their views on text amendments on the basis of the areas in the Rules identified as being in need of development. A considerable number of valuable suggestions and comments were received, especially concerning the needs of children with disabilities and their families and persons with developmental and psychiatric disabilities.

32. With the assistance of Ms. Joneken, I have elaborated guidelines for an adequate standard of living.⁵ These guidelines provided the bases for housing as well as those related to poverty and persons

with disabilities, as presented in the attached proposals to supplement the Standard Rules.

33. In connection with housing, such issues as self-determination, privacy and personal integrity are immediately apparent. In the disability field these concerns lead to the important issue of the institutions where children and adults with disabilities spend their lives. Based on information about the current situation and recent development initiatives, I have drafted some policy guidelines. During the process of compiling material for the supplement, it became evident that some areas needed more extensive development than others. From the perspective of gender and with regard to children's rights, the issue of violence and abuse needs to be pursued further. Measures to support families with one member who is disabled need to be elaborated in greater detail.

34. When analysing the texts of the Standard Rules from the perspective of persons with developmental and psychiatric disabilities, the need to develop guidelines for issues concerning self-determination becomes evident. Particularly in areas such as medical care, rehabilitation and support services, additional guidelines are needed concerning informed consent, the right to refuse treatment and medication, and involuntary confinement.

35. The proposed supplement to the Standard Rules covers 15 subject areas. Each section contains a number of recommendations that should be considered as additions to the recommendations currently presented in the Rules. To provide background and context for the recommendations for new or expanded text, some sections include an initial commentary. There is no direct correspondence between the structure of the 15 sections of the supplement and that of the original Standard Rules document (annex to General Assembly resolution 48/96).

36. Nearly 10 years have passed since the adoption of the Standard Rules by the General Assembly. During this time, the Rules have developed into a major implementation tool used both by Governments and by international and national non-governmental organizations in the disability field. In the development of human rights for persons with disabilities, the Standard Rules have been recognized as a yardstick for measures to put an end to exclusion and discrimination of persons with disabilities.

37. To make the Standard Rules an even more effective tool for the future development of policy, legislation and programmes, the present text of the Rules should be further developed and complemented. I recommend that the attached proposed supplement to the Standard Rules be adopted by a United Nations body and published.

B. Human rights and disability

1. Background and update

38. International recognition of disability as a human rights issue is increasing. There also is growing recognition that disability and disability-related exclusion and marginalization are concerns for the human rights bodies of the United Nations.

39. The World Programme of Action concerning Disabled Persons, adopted by the United Nations General Assembly in 1982, recognized the responsibility of organizations and bodies within the United Nations system to address the human rights of persons with disabilities, in the following (and related) recommendation:

“Organizations and bodies involved in the United Nations system responsible for the preparation and administration of international agreements, covenants and other instruments that might have a direct or indirect impact on persons with disabilities should ensure that such instruments fully take into account the situation of persons who are disabled.”⁶

40. In August 1984, the Sub-Commission on Prevention of Discrimination and Protection of Minorities adopted resolution 1984/20, in which it decided to appoint a Special Rapporteur, Leandro Despouy, to conduct a comprehensive study on the relationship between human rights and disability. In his report, *Human Rights and Disabled Persons*,⁷ Mr. Despouy made it clear that disability is a human rights concern in which the United Nations monitoring bodies should be involved. In paragraph 274 of that report he made the following recommendation:

“After the [United Nations] Decade [of Disabled Persons, 1983-1992] has ended, the question of human rights and disability should be kept on the agendas of the General Assembly, the Economic and Social Council, the Commission

on Human Rights and the Sub-Commission [on Prevention of Discrimination and Protection of Minorities] as an item of constant concern and on-going attention.”

41. The Committee on Economic, Social and Cultural Rights in 1994 assumed the responsibility for disability rights by issuing general comment No. 5,⁸ in which the Committee analysed disability as a human rights issue. The general comment stated:

“The Covenant [on Economic, Social and Cultural Rights] 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, insofar 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 (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.”⁹

42. At its fifty-fourth session, in 1998, the Commission on Human Rights adopted resolution 1998/31 of 21 April 1998, in which it made a series of statements and recommendations for future development in this area.¹⁰ Commission on Human Rights resolution 1998/31 represented a major breakthrough and general recognition of the United Nations responsibility for human rights and persons with disabilities. Therefore, expectations for some progress in the area were high. However, in the two years following the adoption of that resolution, little follow-up occurred. This was a major concern when the Commission on Human Rights again discussed human rights and disability at its fifty-sixth session in April 2000. As a result of that discussion, the Commission adopted resolution 2000/51 of 25 April 2000,¹¹ which incorporated and expanded upon the recommendations contained in its resolution 1998/31.

43. In the first paragraph of resolution 2000/51, the Commission recognized the Standard Rules as an evaluative instrument to be used to assess the degree of compliance with human rights standards concerning persons with disabilities:

“[The Commission] ... recognizes that any violation of the fundamental principle of equality or any discrimination or other negative differential treatment of persons with disabilities inconsistent with the Standard Rules on the Equalization of Opportunities for Persons with Disabilities is an infringement of the human rights of persons with disabilities.”

44. Further, by its resolution 2000/51 the Commission encouraged all the treaty bodies to monitor the compliance of States with their commitments in order to ensure full enjoyment of rights by persons with disabilities. In paragraph 11, Governments were urged to cover fully the question of the human rights of persons with disabilities when reporting under the relevant United Nations human rights instruments:

“[The Commission] invites 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.”

45. In addition, paragraph 30, added during consideration of the draft resolution, reflected the recognition of an urgent need for action related to the rights of persons with disabilities:

“[The Commission] invites the United Nations High Commissioner for Human Rights, in cooperation with the Special Rapporteur on disability of the Commission for Social Development, to examine measures to strengthen the protection and monitoring of the human rights of persons with disabilities and solicit input and proposals from interested parties, including particularly the panel of experts.”

46. In my report to the thirty-eighth session of the Commission for Social Development (E/CN.5/2000/3, annex), I gave an account of the development of disability as a human rights issue and reviewed various ways to strengthen United Nations documents in the disability field. I recommended that the Standard Rules should be complemented and developed in specific areas. I also considered how the issue of disability should be developed within the United Nations human rights system. I indicated ways to strengthen the monitoring of the Rules through the regular system for monitoring international instruments. Relevant activities would include developing general comments, special protocols, thematic studies and similar activities on the subject of disability. Finally, I mentioned the possibility of elaborating a special convention on the rights of persons with disabilities. However, I emphasized the need for clarification concerning the role that such a convention should have in relation to other existing conventions as well as to the Standard Rules.

47. At the thirty-eighth session of the Commission for Social Development, one national non-governmental organization in the disability field presented a proposal for the elaboration of a special convention on the rights of persons with disabilities. During the meetings of the open-ended working group convened by that session of the Commission, extensive discussions took place on how to proceed with the issue of disability and human rights. The discussions resulted in a request by the Economic and Social Council, in paragraph 7 of its resolution 2000/10 of 27 July 2000, that the Special Rapporteur present his views on further developing the proposals contained in his report on his second mandate and on forms for complementing and developing the Standard Rules.

48. In early 2001, the Office of the United Nations High Commissioner for Human Rights commissioned a study on the current use and future potential of United Nations human rights instruments in the context of disability. The directors of the research, Theresia Degener (Germany) and Gerard Quinn (Ireland), are working with three research assistants on this project. Six United Nations human rights treaties are to be examined in the specific context of disability.

49. The study will examine closely the operation of United Nations human rights instruments in the context of disability. It will look at the nature of State obligations under the relevant treaties in the context of

disability and at the various enforcement mechanisms under the treaties. It will specify the various access points for the involvement of non-governmental organizations in the disability field.

50. It is envisaged that a key part of the research findings will focus on the users' perspective. A comprehensive questionnaire has been distributed to non-governmental organizations in the disability field worldwide. A companion questionnaire was distributed to national human rights institutions (e.g., human rights commissions) worldwide to assess their level of engagement on the rights of persons with disabilities.

51. At one level the report will function as a manual for non-governmental organizations so that they may become better acquainted with these instruments and begin to use them more actively. As such the report of study findings will help fill an important knowledge gap. The study also has an evaluative side, assessing current levels of usage of the treaties in the context of disability and making practical proposals for maximizing their potential in this regard.

52. For disability to develop into a human rights issue, it is necessary to build capacity and structures outside the United Nations system as well. In November 2000, I organized a seminar in Sweden ("Let the world know; a seminar on human rights and disability", Stockholm, 5-9 November 2000) whose purpose was to develop capacities to identify and report violations and abuses of human rights in the disability field. Twenty-seven experts, including representatives from the United Nations system (both the Office of the United Nations High Commissioner in Geneva and the United Nations Secretariat in New York) and from major international non-governmental disability organizations as well as experts in human rights and disability from all over the world, participated in the seminar.

53. The report of the Stockholm seminar, published in early 2001,¹² includes a number of recommendations for further development concerning the rights of persons with disabilities. Seminar participants recommend that action be taken in the following five areas: monitoring of individual cases, analysis of existing legislation and legal cases, media coverage of disability and monitoring of existing government policies, programmes and services. During 2001, plans were elaborated by interested parties for follow-up action to the seminar.

54. To provide an update on developments in the area of human rights and disability, two consultative meetings were organized in 2001 in connection with the thirty-ninth session of the Commission for Social Development and the fifty-seventh session of the Commission on Human Rights respectively. Governments, intergovernmental organizations, and United Nations bodies and organizations as well as non-governmental organizations were invited. In connection with the consultation organized by the United Nations High Commissioner for Human Rights, national human rights institutions also participated.

55. A matter of principal concern for both the Stockholm expert meeting and the informal consultative meeting at United Nations Headquarters was how to proceed in order to strengthen the disability dimension in human rights monitoring and protection. Participants at both meetings discussed what could be done to develop disability as a human rights issue within the existing human rights framework. The issue of a special convention was another important subject during the discussions.

56. The report of the informal consultative meeting on international norms and standards, held on 9 February 2001 at United Nations Headquarters, New York,¹³ stated:

“Several Governments expressed interest in addressing the rights of persons with disabilities by means of a ‘twin-track’ approach, which would involve elaboration of a convention, and studies on options to mainstream promotion and protection of the rights of persons with disabilities in current international instruments. A convention was viewed as a complement and not as a mutually exclusive alternative to current international instruments and the rights of persons with disabilities. One Government expressed the view that special attention should be directed to the situation of intellectually disabled persons, since this had not been adequately treated to date.

“In this connection, the representative of the Office of the High Commissioner for Human Rights recalled for meeting participants a 1985 resolution adopted by the Commission on Human Rights on new international human rights instruments, which states that new standards must be relevant to fundamental issues and that new

standards must not be less than existing standards.”

57. Some government representatives at the informal consultative meeting took note of efforts by non-governmental organizations to promote awareness and support for elaborating a convention on the rights of persons with disabilities. The view was expressed that attention and support as appropriate should be accorded to this strong aspiration by the non-governmental organizations.

58. Representatives of the non-governmental organizations observed that the meeting was timely and necessary. They expressed the view that elaboration of a convention on the rights of persons with disabilities was of great importance, particularly since disability was now looked upon primarily as an issue of human rights rather than a matter of concern for medical and social welfare services. The representatives added that a convention would now be considered to be a complement to the Standard Rules and not an alternative instrument. While non-binding, the Standard Rules represented an essential instrument and provided useful guidance for policy and practice.

59. The consultations held on 17 April 2001 at the World Health Organization headquarters in Geneva involved discussions of a similar nature. In addition, the consultations allowed non-governmental organizations in the disability field to affirm their intention to work closely with human rights mechanisms and national human rights institutions and to reaffirm their commitment to giving appropriate attention to the issue of the human rights of persons with disabilities in their work. The consultations permitted national institutions to share their national experiences on good practices to protect and promote the rights of persons with disabilities.

2. Strategy for the future

60. As a result of a number of important events, beginning in the 1990s, including the publication of the report by Leandro Despouy on *Human Rights and Disabled Persons*,¹⁴ the issuance of general comment No. 5 by the Committee on Economic, Social and Cultural Rights¹⁵ and the adoption of relevant resolutions by the Commission on Human Rights,¹⁶ disability has been recognized as a human rights issue. The question now is how the recognition of this principle can be turned into practical action. Disability

must be developed as an integral dimension of human rights procedures within the United Nations, and effective reporting and monitoring routines must be put into effect.

61. While these efforts are taking place within the United Nations system, development work must also be carried out at national level by Governments, national human rights institutions and national disability organizations.

The mainstream alternative

62. General comment No. 5, issued by the Committee on Economic, Social and Cultural Rights in 1994, is a milestone in the process of developing disability as a human rights issue. The message of general comment 5 is that disability-related infringements of human rights are a responsibility for all human rights monitoring mechanisms. The message is the same in the resolutions adopted by the Commission on Human Rights.¹⁷ However, up to now, disability has been included in the way intended only to a very limited extent in reporting and monitoring procedures. Experience would suggest that improved reporting and monitoring of disability-related infringements of human rights will not develop automatically. Consequently, concrete measures must be taken by the Commission on Human Rights and the Office of the High Commissioner to build the necessary competence and to develop the needed structures within United Nations monitoring systems.

63. The present debate to a large extent concerns the approach to apply in order to achieve effective protection of the rights of persons with disabilities. Should a disability dimension be developed within the monitoring mechanisms in connection with already existing covenants and conventions, or is the best way to develop a special instrument? Is there a third way, where these two alternatives complement each other?

64. The principles of full participation and inclusion, which are the dominant ideas in modern disability policy, strongly favour building effective monitoring of the human rights of persons with disabilities as an integral part of existing monitoring mechanisms. One important difference between disability and other areas, such as gender and the rights of children, is that the Standard Rules already exist in the disability field and have proved to be a useful instrument for the development of national policies and legislation. The

Rules would support the monitoring of human rights within the regular United Nations monitoring systems and would serve as a reference document when various provisions of existing conventions were to be applied on the basis of disability needs.

65. Furthermore, the recommendations and criticism coming from the Committees monitoring the International Covenant on Economic, Social and Cultural Rights¹⁸ and the International Covenant on Civil and Political Rights¹⁹ would probably have a greater impact on policies in Member States than could be achieved through a special mechanism on disability. Another consideration in support of the development of a disability dimension within the regular human rights monitoring system is that elaboration of a convention would take a long time. Reaching an agreement on provisions to be included in a special convention that would be accepted by a majority of the member States and that would really make a difference in living conditions for persons with disabilities would probably take several years. In the meantime, the mainstream approach must be developed to the greatest extent possible.

The role of a convention

66. In the period since the meeting of the Commission on Human Rights in 2000, the issue of a special convention on the rights of persons with disabilities has been actively promoted by international disability organizations.²⁰ The issue has been discussed at many international events that I have attended.

67. During these discussions, it has been possible to distinguish four major motives for elaborating a special convention on the rights of persons with disabilities:

(a) Even if the Standard Rules have proved to be a useful implementation tool and have led to progressive policy development in a considerable number of countries, it has often been pointed out that their main weakness is that they are not legally binding. Many representatives of organizations of persons with disabilities see a convention, with its legally binding provisions, as a more effective tool in the struggle to achieve higher priority accorded to disability needs at the national level;

(b) A common view exists that the measures needed within the regular United Nations monitoring system for effective protection of the human rights of persons with disabilities will never really be put in

place. Many different reasons for this belief have been mentioned in discussions: a general notion among human rights experts that disability is a social and medical issue and not a human rights concern; a perceived preference to address other urgent rights issues; and, owing to heavy workloads, an unwillingness to develop a new human rights dimension;

(c) Even if some development may be achieved within the regular United Nations monitoring system, mainstreaming will not be sufficient to strengthen the rights of persons with disabilities;

(d) The fourth argument concerns authority and real recognition. The argument stems from experiences in connection with the Convention on the Political Rights of Women²¹ and the Convention on the Elimination of All Forms of Discrimination against Women.²² This argument suggests that disability will not really be recognized and accepted as a human rights issue until a special convention has been adopted.

The initiative of the Government of Mexico

68. During the second half of 2001, the Government of Mexico raised the issue of a future convention on the rights of persons with disabilities on two occasions. In connection with the World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance (Durban, South Africa, 31 August to 7 September 2001)²³ an initiative by Mexico²⁴ resulted in the following paragraph in the Programme of Action adopted by the Conference:

“Invites the United Nations General Assembly to consider elaborating an integral and comprehensive international convention to protect and promote the rights and dignity of disabled people, including, especially, provisions that address the discriminatory practices and treatment affecting them (para. 180).”²⁵

69. During the deliberations of the Third Committee at the fifty-sixth session of the General Assembly, the delegation of Mexico raised the question of elaborating a convention on the rights of persons with disabilities. President Vicente Fox of Mexico underscored the importance of this question during the general debate on 10 November 2001.²⁶

70. At the 52nd meeting of the Third Committee, on 29 November 2001, the representative of Mexico introduced a draft resolution on an international convention on the rights of persons with disabilities, which the Committee recommended for adoption by the General Assembly. General Assembly resolution 56/168, entitled “Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities”, was adopted on 19 December 2001. In paragraph 1 of that resolution, the General Assembly decided to establish an Ad Hoc Committee open to the participation of all Member States and observers of the United Nations to consider proposals for elaborating such a convention, based on the holistic approach in the work done in the field of social development, human rights and non-discrimination and taking into account the recommendations of the Commission on Human Rights and the Commission for Social Development.

71. Pursuant to the resolution, the Ad Hoc Committee should hold at least one meeting of ten working days before the fifty-seventh session of the General Assembly. United Nations entities, governmental bodies, and non-governmental organizations with an interest in disability and human rights were invited to contribute to the work of the Ad Hoc Committee. Regional seminars should be organized to contribute to its work by making recommendations regarding the content and practical measures that should be considered in the international convention.

72. The adoption of General Assembly resolution 56/168 means that the process of elaborating a convention has begun. In my opinion the first step in this process should be to make a preparatory analysis of a number of basic questions:

(a) What areas should a future convention cover?

(b) What relation should it have to existing general conventions?

(c) Should it be expressed as a set of principles, general in nature but possible to apply in a variety of national situations around the world?

(d) Should the main perspective be based on the needs in developing countries?

(e) Should this future convention replace the Standard Rules, or should the Standard Rules and the convention complement each other?

73. In my view, these are some of the questions that should be answered in order to take a final decision on the terms of reference for the elaboration of a convention and on the contents of such an international instrument.

Twin-track approach recommended

74. With the adoption of General Assembly resolution 56/168, the process of elaborating a convention on the rights of persons with disabilities has entered its first phase. At this stage, a number of fundamental questions concerning the role and contents of such a convention should be considered. In addition to the recommendations by the Commission for Social Development and the Commission on Human Rights, contributions received from entities of the United Nations system as well as from governmental bodies and non-governmental organizations should be taken into account before an agreement is made on the terms of reference for the actual elaboration of a convention.

75. The process of elaborating a convention may take several years. In the meantime, it is important to use the momentum created by the Commission on Human Rights to develop the disability dimension within the existing United Nations human rights monitoring system. In this sense, a twin-track approach is recommended.

C. Information exchange and cooperation between United Nations bodies and organizations

1. Background

76. A growing number of United Nations bodies and organizations have disability-related content and activities in their respective programmes, even if many of these activities are small and require additional resources in relation to their needs and potential activities. During recent years, the Office of the United Nations High Commissioner for Human Rights has started to incorporate the disability dimension in its various activities. The World Bank has recently initiated efforts to expand its involvement in disability matters, and informal contacts and ad hoc meetings have also taken place between United Nations organizations and specialized agencies, such as ILO, UNESCO, WHO and UNICEF. UNDP and the Office of the United Nations High Commissioner for Refugees

(UNHCR) should, in my opinion, increase their disability involvement in their programmes.

77. Two previous reports (A/52/56, annex, and E/CN.5/2000/3, annex) to the Commission for Social Development have highlighted the need for more systematic exchanges of experiences and ideas between the United Nations bodies and organizations with programmes in the disability field. In this effort, the Programme on Disability of the Department of Economic and Social Affairs should have a coordinating role. I have suggested that the inter-agency mechanism that existed during the United Nations Decade of Disabled Persons (1983-1992) should be re-established. Unfortunately, no initiative has been taken. Nevertheless, the number of United Nations organizations and agencies with an involvement in the disability field has increased; consequently there is an even stronger reason for such a mechanism today.

2. Virtual inter-agency meeting mechanism recommended

78. My contacts with United Nations bodies and organizations have made it clear that there is a need for a more systematic exchange of information, experiences and ideas. These entities, particularly the ones that have recently begun to involve themselves in disability issues, could benefit from the experiences of other members of the United Nations system. All would gain from mutual dialogue and information exchange. Budgetary constraints are the main reason for the absence of an initiative on improved cooperation.

79. Modern information and communication technologies offer new possibilities for the type of systematic exchanges that are urgently needed. The cost of using such a mechanism would be low. The United Nations Secretariat already has experience in conducting virtual meetings for exchanges of information. Every participating body and organization could present a short summary of its activities in order to inform others. Agreements for dealing with special topics could be made. An additional advantage of organizing such virtual meetings on an annual basis would be that the information could be used as input for the reports that the Secretary-General submits to the General Assembly on progress in the field of disability.

80. I suggest that the Programme on Disability of the Department of Economic and Social Affairs should organize annually a virtual inter-agency meeting, based on accessible Internet communication technologies.

D. Future monitoring system for the Standard Rules

1. Background

81. The present monitoring mechanism in connection with the Standard Rules will end in December 2002. Even if considerable emphasis will be put on the human rights development and the role of the Commission on Human Rights, it is necessary to maintain disability as a development issue within the United Nations system and as a responsibility for the Commission for Social Development.

82. The first paragraph of chapter IV of the Standard Rules expresses the purpose of the monitoring as follows:

“The purpose of a monitoring mechanism 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. ... An important element should also be the provision of advisory services and the exchange of experience and information between States.”²⁷

83. In the work done since 1994, all these elements of the monitoring mechanism have been present. With some simplification one could say that its two main elements are to promote the implementation of the Rules by Member States and to assess the degree of development in Member States and on a global basis.

84. There is no doubt that much happened during the 1990s in the area of international policy development in the disability field. Even if there are many reasons for this encouraging trend, it is obvious that the activities created through the special monitoring mechanism in connection with the Rules have contributed to the present state of affairs. The fact that resources were available for a considerable number of missions and for conducting international surveys on the situation of persons with disabilities was of great value. The creation of an advisory panel, established by

the major international non-governmental organizations in the disability field, provided expertise throughout the work and led to the mobilization of a large network of national disability organizations around the world.

2. Future monitoring mechanism

85. With regard to the experience gained since 1994, the point of departure for discussions on what should happen from 2003 onward is that an active monitoring mechanism for the implementation of the Standard Rules should remain in place for the future. The two main functions — assessment and promotion — should be kept. One question is if these two functions should be applied separately.

Measures to assess the situation

86. One important part of the monitoring mechanism is to assess the degree of progress made in Member States in implementing the Rules. Since 1994 this has been done three times by conducting global surveys. The results of the third survey, carried out by WHO in cooperation with the Special Rapporteur, are mentioned in chapter III of the present report. As a parallel exercise, the World Programme of Action concerning Disabled Persons has been monitored through quinquennial reviews and appraisals, also based mainly on information obtained from Member States. The Programme of Action and the Standard Rules are based on the same disability philosophy and contain very similar guidelines. Therefore, these two monitoring exercises, both intended to assess progress worldwide, should be merged and carried out as one activity in the future.

87. The system with quinquennial surveys should be kept and the surveys should be made in cooperation with the major international non-governmental organizations in the disability field. One part of the questionnaire could be standardized to ensure the future possibility of comparison over time. A second part of the questionnaire could be used for ad hoc studies of special aspects. The system of mobilizing national affiliates of international non-governmental organizations, both to prepare replies and to assist in obtaining replies from Governments, should be copied from the routine practised with success in the Standard Rules monitoring mechanisms of the current Special Rapporteur.

Measures for promotion and advice

88. In paragraph 12 of chapter IV of the Rules, the Commission for Social Development is given the following instructions:

“... The Commission should examine the possibility of either renewing the Special Rapporteur’s mandate, appointing a new Special Rapporteur or considering another monitoring mechanism, and should make appropriate recommendations to the Economic and Social Council.”

89. The first of these three alternatives — renewal of the mandate — can be ruled out, as the current Rapporteur is retiring after three terms of office. When considering the two remaining alternatives, some important aspects must be taken into account. Are the two alternatives equal when it comes to obtaining regular funding and attracting extrabudgetary resources from Governments or other sources? Are the two alternatives equal with regard to the recruitment and appointment of persons who are really suitable for the function?

90. Based on the experience gained, the most rational way to proceed would be to appoint a new Special Rapporteur. This would mean that the work could continue within the same framework and with the same guidelines as it has up to now. This alternative, however, is largely dependent on finding a suitable person for the function and on the provision of extrabudgetary funding from a number of Governments. In relation to other alternatives, the advantage is the great degree of independence for the Special Rapporteur, who may act freely within the framework indicated in chapter IV of the Standard Rules.

91. The other main alternative is to integrate the promotional function into the Programme on Disability of the Department of Economic and Social Affairs. If so, a senior position as technical advisor should be added to the disability staff. As in the case of a Special Rapporteur, such a person must have a good professional background, experience in government work concerning disability matters and the respect and trust of the international disability movement. A prerequisite for this alternative would be the availability of sufficient resources particularly for missions to countries and related activities.

92. In my previous report (E/CN.5/2000/3, annex) I introduced the idea of establishing a monitoring system with regional advisers. Recent discussions have clarified that such a system could be achieved in two different ways. One possibility would be to establish full-time positions as regional advisers in the developing regions and in countries with economies in transition in Central and Eastern Europe. A natural location for such positions would be in an office of a regional intergovernmental body. Apart from strengthening the advisory services considerably, the advantage is that regional advisers would be closer to the economic, political and cultural conditions in the countries concerned. It would be natural to look for funding of such advisers through UNDP or other major donors of development cooperation resources.

93. Another way of implementing regional advisory services would be to recruit a group of experts from the different regions who are all qualified for the function, but with different specialties. They should be willing to accept ad hoc missions of limited duration to countries in their region. Such missions could be supported and funded, resources permitting, either by the United Nations Secretariat or by regional sources.

94. These alternatives for regional advisory services would probably be needed to support the work of a technical adviser based in the United Nations Secretariat. The proposed regional advisers could also supplement and strengthen the work of a future Special Rapporteur.

The panel of experts

95. One of the most unique contributions to the social development work within the United Nations system is the advisory panel of experts, established by the major international non-governmental organizations in the disability field. The basis for this is contained in chapter IV, paragraph 3, of the Standard Rules:

“International organizations of persons with disabilities having consultative status with the Economic and Social Council and organizations representing persons with disabilities who have not yet formed their own organizations should be invited to create among themselves a panel of experts, on which organizations of persons with disabilities shall have a majority, taking into account the different kinds of disabilities and necessary equitable geographical distribution, to

be consulted by the Special Rapporteur and, when appropriate, by the Secretariat.”

96. In September 1994 the following six organizations agreed on the composition of the panel: Disabled People’s International, Inclusion International, Rehabilitation International, World Blind Union, World Federation of the Deaf, and World Network of Users and Survivors of Psychiatry. The panel consists of ten members, five women and five men, who have different disabilities and come from different parts of the world. As mentioned above, the panel has functioned well and has provided excellent support to my work. In addition, there are more than 600 national affiliates of the six international non-governmental disability organizations that have formed a powerful network for obtaining information and contacts in countries. This has been useful both during my missions to individual countries and in the conduct of global surveys. An additional advantage is that the panel has brought the international organizations together and facilitated communication between the organizations and the United Nations.

97. Whatever form the monitoring takes, it is important to maintain the system of a panel of experts attached to the monitoring mechanism. The panel would be able to play an important advisory role in connection with future periodic surveys to Member States by participating in the formulation of questions as well as by interpreting the results. Naturally, the panel could also provide support and advice to a future Special Rapporteur or technical adviser in their various activities.

Continued monitoring recommended

98. The Standard Rules should continue to play a role as an international tool for policy development in the disability field. A precondition for this is the existence of an active monitoring mechanism, promoting the further implementation of the Rules and assessing the degree of progress. If a solution can be found, the best way to proceed is to appoint a new Special Rapporteur, who will continue to work along the lines indicated in chapter IV of the Standard Rules. If this cannot be achieved within a foreseeable time, the monitoring mechanism should be integrated into the United Nations Secretariat and a senior post of technical adviser should be established. In either case, a system with a panel of experts, established in the same way as

it is now, should provide advice and support to the various activities within the monitoring effort.

99. In addition, a system with regional advisory services should be developed to supplement and support the work performed by the Special Rapporteur or technical adviser.

100. The two monitoring and evaluation processes, carried out in connection with the World Programme of Action concerning Disabled Persons and the Standard Rules to assess progress worldwide, should be merged into a single, periodic exercise, carried out by the Programme on Disability of the Department of Economic and Social Affairs.

101. A prerequisite for a well-functioning monitoring mechanism is that sufficient funding — regular and extrabudgetary — can be made available for the different monitoring functions.

V. Summary and recommendations

102. In its resolution 2000/10 of 27 July 2000, the Economic and Social Council decided to renew my mandate for a third period, from 2000 to 2002. In addition to the monitoring activities outlined in chapter IV of the Standard Rules, I was requested to provide further analyses in a number of areas.

103. This report contains a brief account of the missions and other activities carried out during the period. It describes the activities within the project “Rights for disabled children” and refers to the global survey on the implementation of certain Rules carried out by the World Health Organization.

104. Based on information received during missions to countries, participation in conferences and in international consultations, it is evident that the Standard Rules play a major role, assisting in policy development and serving as a tool for advocacy. The recognition by the Commission on Human Rights of the Standard Rules as a yardstick for measures to combat exclusion and discrimination has further strengthened the position of the present document.

105. Based on its commitments, the United Nations must strengthen its leading role in the struggle against social exclusion and human rights abuse in the disability field. On the basis of my current mandate, I identified four areas for further analysis, which would be carried out in order to:

- (a) Complement the Standard Rules;
- (b) Suggest measures for further development of disability as a human rights issue;
- (c) Improve cooperation within the United Nations system in the field of disability;
- (d) Examine forms for future monitoring of the Standard Rules.

106. With respect to complementing the Standard Rules, attached to the present report is a proposed supplement to the Rules that I have drafted for consideration by the Commission.

107. The recommendations for future action that I wish to submit are outlined below.

A. Supplement to the Standard Rules

108. Nearly ten years have passed since the adoption of the United Nations Standard Rules. During this time, the Rules have developed into a major tool for policy making and action, used by Governments and by international and national non-governmental organizations in the disability field. In human rights development, the Standard Rules have been recognized as a yardstick for ways to put an end to exclusion and discrimination.

109. To make the Standard Rules an even more effective tool for future development of policy, legislation and programmes, a complement to the Rules should be created. I recommend that the attached proposed supplement to the Standard Rules be adopted and published by the United Nations.

B. Twin-track approach in human rights

110. Adoption by the General Assembly of its resolution 56/168 on the "Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities", signals the beginning of the process of elaborating a convention on the rights of persons with disabilities. During the first phase of this work a number of fundamental questions concerning the role and contents of such a convention should be considered. The recommendations by the Commission for Social Development and the Commission on Human Rights should be taken into account, and contributions

received from entities of the United Nations system, governmental bodies and non-governmental organizations should be considered before an agreement is made on the terms of reference for the actual elaboration of a convention on the rights of persons with disabilities.

111. The process of elaborating a convention may take several years. In the meantime, it is important to use the momentum created by the Commission on Human Rights to develop the disability dimension within the existing United Nations human rights monitoring system. In this sense, a twin-track approach is recommended.

C. Improved cooperation between United Nations bodies and organizations in the field of disability

112. As a result of my contacts with United Nations bodies and organizations, I can clearly see the need for a more systematic exchange of information, experiences and ideas. United Nations bodies and organizations that have recently started to involve themselves in disability issues could benefit from the experiences of others. All would gain from mutual dialogue and information exchange. Budgetary constraints are the main reason for the absence of an initiative to date to improve inter-agency cooperation.

113. Modern information and communication technologies offer new and low-cost possibilities for the types of exchange needed. The Programme on Disability of the Department of Economic and Social Affairs should organize an annual "virtual inter-agency meeting" based on accessible Internet technologies.

D. Continued monitoring

114. The Standard Rules should continue to play a role as an international instrument for policy development in the disability field. A precondition for this is the existence of an active monitoring mechanism to promote the further implementation of the Rules and assess the degree of progress. If a solution can be found, the best way to proceed is to appoint a new Special Rapporteur, who will continue to work along the lines indicated in chapter IV of the Standard Rules. If this cannot be achieved within the foreseeable future, the monitoring mechanism should be integrated into the Secretariat and a senior post of technical adviser

should be established. In either case, a system with a panel of experts, established in the same way as it is now, should provide advice and support to the various activities within the monitoring effort. A prerequisite for a well-functioning monitoring mechanism is to ensure is the availability of sufficient funding, regular or extrabudgetary, for the different functions of monitoring.

115. The two monitoring and evaluation processes now carried out in connection with the Programme of Action and the Standard Rules to assess progress worldwide should be merged into one periodic exercise, carried out by the Programme on Disability of the Department of Economic and Social Affairs.

116. A system with regional advisory services should be developed to supplement and support the work performed by the Special Rapporteur or the technical adviser.

Notes

¹ A/37/351/Add.1 and Corr.1, annex, sect. VIII, recommendation I (iv).

² World Health Organization, *The UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities: Government Responses to the Implementation of the Rules on Medical Care, Rehabilitation, Support Services and Personnel Training: Summary*, vol. I (WHO/DAR/01.1) and *Main Report*, vol. II (WHO/DAR/01.2).

³ *Ibid.*, *Regional report AFRO* (WHO/DAR/01.3); *Regional report AMRO* (WHO/DAR/01.4); *Regional report EMRO* (WHO/DAR/01.5); *Regional report EURO* (WHO/DAR/01.6); *Regional report SEARO* (WHO/DAR/01.7); *Regional report WPRO* (WHO/DAR/01.8).

⁴ World Health Organization, *Report of the Conference on Rethinking Care* (WHO/DAR/01.11). Available from <http://www.rethinkingcare.org/>.

⁵ The right to an "adequate standard of living" is set forth in a number of international human rights instruments (see Office of the United Nations High Commissioner for Human Rights, *International Human Rights Instruments* [Geneva, n.d.], available from <http://www.unhchr.ch/html/intlinst.htm>). These include the Universal Declaration of Human Rights, article 25 (1) (General Assembly resolution 217 A (III) of 10 December 1948); the International Covenant on Economic, Social and Cultural Rights, article 11 (1) (General Assembly resolution 2200 A (XXI) of 16 December 1966); the Convention on the Rights of the

Child, article 27 (1) (General Assembly resolution 44/25 of 20 November 1989); the Convention on the Elimination of All Forms of Discrimination against Women, article 14, sect. 2 (h) (General Assembly resolution 34/180 of 18 December 1979); and the International Convention on the Elimination of All Forms of Racial Discrimination, article 5 (e) (General Assembly resolution 2106 (XX) of 21 December 1965). See also General Assembly resolution 48/96 of 20 December 1993, annex, chap. II.

⁶ A/37/351/Add.1 and Add.1/Corr.1, annex, sect. VIII, para. 164. Available from <http://www.un.org/esa/socdev/enable/diswpa00.htm>.

⁷ Leandro Despouy, *Human Rights and Disabled Persons*, Human Rights Study Series No. 6 (United Nations publication, Sales No. E.92.XIV.4).

⁸ *Official Records of the Economic and Social Council, 1995, Supplement No. 3* (E/1995/22), annex IV.

⁹ *Ibid.*, para. 5.

¹⁰ See *Official Records of the Economic and Social Council, 1998, Supplement No. 3* (E/1998/23).

¹¹ See *Official Records of the Economic and Social Council, 2000, Supplement No. 3* (E/2000/23).

¹² Office of the Special Rapporteur on Disability, Commission for Social Development, "Let the world know: report of a seminar on human rights and disability", Stockholm, 5-9 November 2000 (New York, Division for Social Policy and Development, 2001), last update 28 August 2001, available from <http://www.un.org/esa/socdev/enable/stockholmnov2000.htm>.

¹³ Report of the informal consultative meeting on international norms and standards for persons with disabilities, New York, 9 February 2001 (New York, Division for Social Policy and Development, 2001), para. 22, available from <http://www.un.org/esa/socdev/enable/consultnyfeb2001.htm>.

¹⁴ Despouy, *op. cit.*

¹⁵ *Official Records of the Economic and Social Council, 1995, Supplement No. 3* (E/1995/22), annex IV.

¹⁶ See, in particular, Commission on Human Rights resolutions 1998/31 of 21 April 1998 and 2000/51 of 25 April 2000.

¹⁷ *Ibid.*

¹⁸ General Assembly resolution 2200 A (XXI) of 16 December 1966.

¹⁹ *Ibid.*

²⁰ See, for example, the Beijing declaration on the rights of people with disabilities in the new century (A/54/861-E/2000/47, annex).

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- ²¹ General Assembly resolution 640 (VII) of 20 December 1952.
- ²² General Assembly resolution 34/180 of 18 December 1979.
- ²³ *World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, Durban, South Africa, 31 August-7 September 2001* (A/CONF.189/5).
- ²⁴ Statement of Gilberto Rincón Gallardo, representative of Mexico (2 September 2001), available from <http://www.un.org/WCAR/statements/mexicoE.htm>.
- ²⁵ See *World Conference against Racism, Racial Discrimination, Xenophobia and Related Intolerance, Durban, South Africa, 31 August-7 September 2001* (A/CONF.189/5), chap. I.
- ²⁶ Statement available (in Spanish) from <http://www.un.org/webcast/ga/56/statements/011110mexicoS.htm>.
- ²⁷ General Assembly resolution 48/96, annex, chap. IV, para. 1. Available from <http://www.un.org/esa/socdev/enable/dissre06.htm>.

Annex**Reaching the most vulnerable; proposed supplement to the Standard Rules on the Equalization of Opportunities for Persons with Disabilities****Contents**

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I. Introduction

1. The 1990s brought more progress in disability policy and legislation than earlier decades. This development was initiated through the activities in connection with the observance of the International Year of Disabled Persons (1981), the adoption of the World Programme of Action concerning Disabled Persons (A/37/351/Add.1 and Add.1/Corr.1, annex, sect. VIII) and the activities during the International Decade of Disabled Persons (1983-1992).

2. Since the adoption of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities by the General Assembly in its resolution 48/96 (annex) of 20 December 1993, and the establishment of its monitoring mechanism in 1994, the Rules have played a significant role worldwide in the elaboration of national policies and legislation in the disability field. This active and practical application of the Rules has provided new and valuable experience on how to use the Rules in the future. At the same time, it has revealed certain weaknesses and omissions in the present text.

3. Throughout the entire Standard Rules text, the term “persons with disabilities” is used to refer to persons of all ages with disabilities. In the text of the proposed supplement the term should always be understood as meaning “girls, boys, women and men with disabilities” when no other qualifying term is indicated.

4. The purpose of preparing the proposed supplement to the United Nations Standard Rules is to complement and develop the text in certain areas. The work is based on the analysis of gaps and shortcomings presented by the Special Rapporteur on Disability in his report to the thirty-sixth session of the Commission for Social Development (E/CN.5/2000/3, annex). In that analysis the following were pointed out: gender concerns; housing and communication issues; the needs of children and older persons; the needs of persons with developmental and psychiatric disabilities; and the needs of persons with disabilities in poverty situations.

5. In the process of elaborating this supplement, several international organizations and individual experts have contributed, particularly those representing the interests of persons with developmental and psychiatric disabilities and children. The panel of experts, attached to the Standard Rules

monitoring mechanism, has worked with the text and made many valuable suggestions. Finally, the outcome of the global Conference on Rethinking Care (Oslo, 22-25 April 2001), organized by the World Health Organization in cooperation with the Government of Norway, has been taken into account.

6. The text of this supplement does not follow the structure of the Standard Rules. The order of sections has been chosen to avoid unnecessary repetition. The mode of presentation combines a commentary and explanation of the text with a set of recommendations, presented in the same way as in the Rules.

7. The most obvious common feature of the comments and recommendations in this supplement is that they bring into focus the needs of the most vulnerable among children and adults with disabilities.

II. Proposed supplement to the Standard Rules

A. Fundamental concepts

8. The Standard Rules include a presentation of the International Classification of Impairment, Disabilities and Handicaps, which was adopted by the World Health Assembly of the World Health Organization (WHO) in 1980. This classification has now been revised. In 2001 the World Health Assembly endorsed the International Classification of Functioning, Disability and Health, in which functioning and disability are understood to occur in a context characterized by personal and environmental factors: physical, social and attitudinal. Functioning and disability are classified at the levels of the body, the person and the society. The Classification can be used to describe an individual’s capacity to execute simple and complex actions, which can be employed to determine appropriate health interventions and other changes to the person. In addition, the Classification can be used to describe actual performance in an individual’s current environment. It is then possible to identify the environmental factors that facilitate or hinder that performance so as to determine appropriate environmental modifications or health-related interventions to improve it. In this supplement, however, the terminology used in the Standard Rules has been retained in order to avoid confusion.

9. It should be noted that considerable confusion has arisen concerning the use of the word “handicap”. Even if the term is established in many languages, it has acquired a derogatory, negative and even insulting connotation in several languages, and should therefore be used with great care.

10. It should also be emphasized that the term “prevention”, as outlined in the Standard Rules, must never be used to justify the denial of the right to life or to equal participation in society for persons who have disabilities.

B. Adequate standard of living and poverty alleviation

11. It is obvious that in developing countries, as in more developed areas, persons with disabilities and their families are more likely than the rest of the population to live in poverty. It is a two-way relationship: disability adds to the risk of poverty, and conditions of poverty increase the risk of disability. Prejudice and social stigma affect the lives of both children and adults with disabilities and lead to isolation and exclusion from the life of their communities.

12. The attainment of an adequate standard of living by persons with disabilities is implied in the principle of equal rights for all and in the process of equalization of opportunities for persons with disabilities.

13. States should ensure that persons with disabilities receive the support they need within the ordinary systems of society, such as education, health, employment and social services.

14. When taking measures to combat poverty, States should include programmes to support empowerment of persons with disabilities and promote their active participation in society.

15. As part of their development programmes, States should also ensure access to adequate and safe housing, food and nutrition, water and clothing for persons with disabilities.

16. In the framework of community-based services, States should provide education, rehabilitation, assistive devices and employment services to persons with disabilities.

17. States should encourage the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all conditions affecting the lives of persons with disabilities.

18. In cooperation with local and regional authorities, the Office of the United Nations High Commissioner for Refugees (UNHCR) and other actors, States should provide the necessary assistance to homeless persons, displaced persons and refugees with disabilities, enabling them to attain self-sufficiency and promoting sustainable solutions to their problems.

19. Organizations of persons with disabilities should be consulted at all levels in programmes affecting the standard of living of persons with disabilities.

C. Housing, including the issue of residential institutions

20. A prerequisite for full participation and equality is that persons with disabilities can grow up, live and develop their potential in the community they belong to. In this context the provision of suitable housing is crucial.

21. States should ensure safe, habitable, accessible, affordable housing and shelter for all persons with disabilities, adequate for their health and well-being. Such housing conditions, including the social and physical infrastructure, should enable children with disabilities to grow up with their parents and should enable adults with disabilities to be part of the community.

22. Measures should also include awareness-raising campaigns to combat negative attitudes among neighbours as well as the local population.

23. In countries where the policy has been to house many groups of persons with disabilities in separate and large institutions States should reorient their policies towards community-based services and family support. In this way it should be possible to initiate programmes to stop admissions to such facilities as well as plan for their ultimate closure.

24. For orphans with disabilities and for other groups of disabled children without family or other personal support, substitute families should be found. For adults in the same situation, small family-like facilities (group

homes), situated in the community, should replace large institutions.

25. States should ensure that appropriate support is provided for residents with disabilities when they leave their residential institutions to rejoin the community, and that the support services continue for as long as required.

26. With regard to persons still living in institutions, States must ensure that their basic needs are met, and ensure respect for their right to a private space where they may receive visitors as well as keep their files, correspondence and other personal belongings. The treatment of every person should be directed to preserving and enhancing personal autonomy. States must also ensure that opportunities for meaningful participation and involvement in community life occur.

D. Health and medical care

27. Recognizing that health is a human right, States must ensure access to high quality and safe medical services and facilities for all people, regardless of the nature and/or severity of impairment, age, gender, race, ethnicity and sexual orientation. States should recognize that persons with disabilities have the same right to self-determination as other citizens, including the right to accept or refuse treatment. States must ensure that the right to life is paramount in the delivery of medical and health services.

28. States should ensure that persons with disabilities get the same level of medical care within the same system as other members of society, and do not face discrimination on the grounds of presumptions of their quality of life and potential.

29. States should ensure that all medical, paramedical and related personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology. To understand fully what it means to live with a disability, future professionals should meet and learn from persons with disabilities.

30. Medical and paramedical personnel should give full and balanced information and advice concerning diagnosis and treatment to persons with disabilities. This is particularly important in the situation of prenatal diagnosis. In the case of children, information

should be given to parents and, when appropriate, to other family members.

31. States should design and implement programmes with the full involvement of women and men with disabilities to give them appropriate and fully accessible education, information and services to address their reproductive and sexual health needs.

32. States should raise awareness of, prevent and treat sexually transmitted infections, including HIV/AIDS.

33. States should ensure that medical facilities and personnel inform people with disabilities of their right to self-determination, including the requirement of informed consent, the right to refuse treatment and the right not to comply with forced admission to institutional facilities. States should also prevent unwanted medical and related interventions and/or corrective surgeries from being imposed on persons with disabilities.

34. States should develop national rehabilitation programmes for all groups of persons with disabilities. Such programmes should be based on the actual individual needs of persons with disabilities. The training should be based on the principles of full participation and equality, and aim at the removal of barriers for their participation in the mainstream of community life.

E. Emergency situations

35. It has often been recognized that the needs of persons with disabilities are forgotten or neglected in general relief programmes.

36. In cooperation with concerned United Nations agencies such as UNHCR and the United Nations Development Programme (UNDP), States should develop policies and guidelines for the inclusion of support measures with regard to persons with disabilities in emergency situations. Their emergency services should be adequately equipped and prepared to provide medical treatment and support to persons with disabilities and their families.

37. Special attention should be paid to the fact that persons with disabilities are particularly vulnerable to abuse in emergency situations.

F. Access to the social environment

38. Two dimensions of accessibility are pointed out in Rule 5 of the Standard Rules: access to the physical environment and access to information and communication. Experience has shown that it is necessary to include a third dimension — access to the social environment — in national disability programmes.

39. States should encourage measures to remove all obstacles resulting from ignorance and negative attitudes towards persons with disabilities.

40. Measures to combat prejudice should be taken through public education and information campaigns, awareness-raising and encouragement of a positive portrayal of persons with disabilities in the media. Particular emphasis should be given to the gender dimension, to persons with developmental and psychiatric disabilities, to children with disabilities and to persons with multiple or invisible disabilities.

41. When planning measures to combat social prejudice, it is of particular importance for States to ensure the involvement of organizations of persons with disabilities.

G. Communication issues

1. Information and communication technology

42. Information and communication technologies and infrastructures are rapidly growing in importance in the provision of information and services to the population. These technologies must therefore be made accessible and their great potential to assist and support persons with disabilities must be utilized.

43. States should ensure that information and communication technologies and service systems offered to the general public are either made initially accessible or adapted to be made accessible to persons with disabilities. It is also important to create opportunities for special training courses as well as access to affordable equipment and software and to distance learning through these technologies for persons with disabilities.

44. States should consider presenting accessibility and usability standards and guidelines as a precondition for public funding and recognize public procurement as a tool to achieve accessibility.

45. States should initiate the development and use of special technical and legal arrangements to make information and communication technologies accessible to persons with disabilities.

2. Sign language

46. During the 1990s an increasing number of States recognized sign language as the main means of communication for deaf people. In view of the decisive importance of sign language in the personal development of deaf people, such recognition must be encouraged worldwide.

47. States should recognize sign language as a natural language and as the medium of communication among deaf people. It should be used in the education of deaf children, in their families and in the communities.

48. Sign language interpretation services should be provided to facilitate communication between deaf persons and others.

3. Other communication needs

49. Consideration should be given to the needs of people with other communication disabilities, such as the speech-impaired, the hard-of-hearing, the deaf-blind and persons with developmental and psychiatric disabilities, who require specific forms of assistance.

50. In addition to information and communication technologies, special assistive devices and interpreter services may be needed.

H. Personnel training

51. A key element in all programmes and services for persons with disabilities is to have well-trained and informed personnel. Furthermore, information on disability and the living conditions of persons with disabilities should be provided to professional groups serving the general population, such as medical doctors, teachers and social workers as part of their basic training. In addition to technical information, professionals should have knowledge of the prevailing attitudes towards persons with disabilities.

52. States should ensure that all authorities providing services in the disability field give adequate training to their personnel and that an understanding of the substance of the United Nations Standard Rules is an outcome of such training.

53. States should ensure that personnel are educated to recognize acts of discrimination based on gender, ethnicity, race, age and/or sexual orientation against children and adults with disabilities.

54. States should facilitate training for persons with various types of disabilities so they may work as professionals in the disability field and serve as role models.

55. Access to continuing education on a regular basis should be available and encouraged for all persons, groups and institutions concerned with disabilities.

I. Gender

56. Women with disabilities are often exposed to double, or even triple, discrimination. They suffer discrimination as women, as disabled persons and on the grounds of their economic status.

57. In many cultures, the status of women with disabilities is negatively affected by the fact that they less frequently get married and have children. They are often exposed to discrimination in medical care and rehabilitation, education, vocational rehabilitation and employment.

58. The initial sentence of every Rule in the Standard Rules document contains the term "persons with disabilities". This should always be understood as referring to "girls, boys, women and men with disabilities". It is important to emphasize both gender equality and the inclusion of children and youth, wherever appropriate.

59. In gender-sensitive development programmes, women and girls with disabilities should be identified as target beneficiaries.

60. Organizations of persons with disabilities should take action to get the concerns of women and girls with disabilities onto their agenda, and onto the agendas of women's organizations and organizations representing children.

J. Children with disabilities and the family

61. In some cultures, a disability is often seen as a punishment and is connected with feelings of fear and shame. Owing to this, children with disabilities may be

hidden away or neglected by the rest of the community. As a consequence it is not possible for them to live a decent life, and they are sometimes even denied the right to survival.

62. Children with disabilities are often neglected by the school system. Obstacles in the physical environment prevent the children from moving around freely, from playing and from sharing the company of other children.

63. States should initiate programmes for early detection and intervention and ensure that children with disabilities, including children with severe and/or multiple disabilities, have access to medical care and rehabilitation services. These services should be provided without any bias based on gender, age or other status.

64. Training and rehabilitation programmes should not disrupt the disabled child's right to family life and social interaction with their non-disabled peers.

65. All children with disabilities, including those with severe disabilities, should have access to education. Special attention should be given to very young children, girls and young women with disabilities.

66. States should encourage measures that enable children with disabilities to play and to be together with other children in the community.

67. States should ensure that children, adolescents and youth with disabilities are entitled freely to express their views on matters of concern to them and to have their views taken seriously in accordance with their age and maturity.

68. States should develop adequate support to families who have children with disabilities, including disability-specific assistance and information, access to mainstream parent support and possibilities for parent-to-parent exchanges.

69. States should encourage employers to make reasonable adjustments to accommodate family members responsible for the care of children and adults with disabilities.

70. States should support women and men with disabilities wanting to pursue a separation or a divorce owing to abuse or violence.

K. Violence and abuse

71. Studies during recent years have shown that experience of sexual abuse and of other forms of violence and abuse are frequent among persons with disabilities. Owing to the special circumstances, such problems are often difficult to discover, as they may occur in closed environments and are sometimes committed against children and adults who have difficulty explaining what has happened.

72. States should develop programmes to recognize and eradicate abuse and violations of girls, boys, women and men with disabilities. It may occur in the family, in the community, in institutions and/or in emergency situations.

73. Persons with disabilities need to be educated about how to avoid the occurrence of abuse, how to recognize when abuse has occurred and how to report it.

74. States should provide information to persons with disabilities and their families about ways to take precautions against sexual and other forms of abuse.

75. Professionals should be trained how to identify conditions leading to possible victimization, how to avoid such situations, how to recognize when abuse has occurred, how to support a victim with a disability and how to report on such acts.

76. Police and judicial authorities should be trained to work with persons with disabilities so that they can receive testimonies from such persons and treat instances of abuse seriously. Perpetrators of abuse should be identified and brought to justice.

77. Special legislative measures may be needed to protect the right to personal integrity and privacy for children and adults with disabilities, in order to avoid their exploitation and abuse.

L. Older persons

78. There are two main categories of older persons with disabilities. For those who experienced their disabilities earlier in life, the needs may change with advancing age. The other group consists of people who lose physical, sensory or mental functions due to ageing. With the increase in life expectancy, owing to the general improvement in the standard of living, this group is growing in number.

79. The Standard Rules do not make any age distinctions. The term "persons with disabilities" refers to persons of all ages. However, experience has shown that the needs of older persons with disabilities are often not included in national disability policies and programmes, and therefore some clarification may be appropriate.

80. States should ensure that the needs of older persons with disabilities are included in the policies, programmes and services designed to meet the needs of persons with disabilities.

81. Special attention should be paid to the needs of older persons with disabilities in the provision of health and medical care services, rehabilitation, assistive devices and other forms of support services.

82. The situation of older persons with disabilities should be included in research, in the collection of statistics and in the general monitoring of the living conditions of persons with disabilities.

83. Public information and awareness-raising campaigns should pay attention to the situation of older persons with disabilities.

M. Developmental and psychiatric disabilities

84. The two groups of persons, those with developmental and those with psychiatric disabilities, are different in regard to both the origin and the character of their problems. However, both groups belong to the most vulnerable among citizens of society. Their disabilities are surrounded with more negative attitudes and prejudice than most other groups of persons with disabilities. Particularly in developing regions and in countries with economies in transition, the voice of persons with developmental and psychiatric disabilities is seldom heard. Consequently, their needs are often forgotten or neglected when plans are made to improve the living conditions of persons with disabilities.

85. One of the more serious weaknesses of the Standard Rules is that the needs of persons with developmental and psychiatric disabilities are not dealt with in a satisfactory way. Areas such as health and medical care, rehabilitation, support services, housing conditions, family life and personal integrity are of vital importance for both these groups. Their needs

constituted an important perspective when these policy areas were elaborated for this supplement.

86. States should ensure that the special needs of persons with developmental and psychiatric disabilities are respected in health and medical care, and in rehabilitation and support services. Particular emphasis should be given to issues of self-determination.

87. States should develop forms of support for families who have children or adult family members with developmental or psychiatric disabilities. Such support may be necessary to make it possible for the disabled person to live with the family.

88. Many adults with developmental or psychiatric disabilities need special housing arrangements to be able to cope with their situation. Small family-like facilities (group homes) with sufficient support services, sometimes provided within the framework of independent living schemes, may be useful alternatives.

89. States should ensure that the situation of persons with developmental and psychiatric disabilities is included in research, data collection and general monitoring of the disability field.

90. States should encourage and support the development of organizations representing the interests of persons with developmental and psychiatric disabilities, including self-advocacy groups and parent action groups.

N. Invisible disabilities

91. An important group of persons with disabilities are those who have disabilities that are not easily discovered by others. This often leads to misunderstandings and wrong conclusions. Among such groups with invisible disabilities, the following may be mentioned: persons with psychiatric or developmental disabilities; those with disabilities from chronic diseases; and those who are hard of hearing or deaf.

92. In public awareness programmes, it is important to include information about persons with invisible disabilities and the special problems they may experience.

93. It is also important to include the unique characteristics of invisible disabilities when taking

measures towards full participation and equal opportunities for persons with disabilities.

O. Suggested further initiatives in national policy and legislation

94. As a result of the experience gained in the use of the Standard Rules for a number of years and as a consequence of the development in the human rights area, the following general recommendations concerning governmental policy can be made:

(a) States should introduce comprehensive mandatory anti-discrimination laws to secure the removal of obstacles to equal participation in mainstream community life by persons with disabilities. They should ensure the inclusion of persons with disabilities among indigenous peoples and other minorities in this process;

(b) States should consider the introduction of mandatory legislation to ensure the provision of assistive technologies, personal assistance and interpreter services, according to the needs of persons with disabilities, and those of their family caregivers, as important measures to achieve equal opportunities;

(c) States should consider the use of public procurement as a tool to obtain accessibility. Accessibility requirements should be included in the design and construction of the physical environment from the beginning of the designing process;

(d) Legislative measures should also be considered to encourage and support the development of accessibility in transportation systems, housing, and information and communication services;

(e) States should support and promote the international exchange of research findings and experiences and the dissemination of best practices in all sectors of society;

(f) States should take action to include reporting on the situation regarding persons with disabilities in their periodic reports to the committees of the various human rights conventions to which they are parties. Information should be gathered and submitted whether or not articles in each convention refer specifically to persons with disabilities. States should support the participation of organizations of persons with disabilities and encourage them to express their views during the review process;

(g) Before making decisions on policies, programmes and legislation that affect the lives of the population generally, consequence analyses concerning the effects on persons with disabilities should be made.
