

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

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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.

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More information on:

<http://www.un.org/esa/socdev/enable/disecon520024e.doc>

To see the comments of the Special Rapporteur on Disability on the proposed supplement, see:

<http://www.un.org/esa/socdev/enable/en-srvIEWSOCT04.htm>