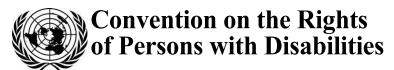
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Social inclusion and the right to the highest attainable standard of health

Note by the Secretariat

The present note was prepared by the Secretariat in consultation with United Nations entities, representatives of civil society and other relevant stakeholders to facilitate the round-table discussion on the theme "Social inclusion and the right to the highest attainable standard of health". The Secretariat hereby transmits the note, as approved by the Bureau of the Conference, to the Conference of States Parties to the Convention on the Rights of Persons with Disabilities at its twelfth session.

^{*} CRPD/CSP/2019/1.





I. Introduction

- 1. Health is essential to individual well-being and happiness, allowing individuals to reach their full potential. The enjoyment of the highest attainable standard of health is one of the fundamental human rights of every human being and is reaffirmed for persons with disabilities in the Convention on the Rights of Persons with Disabilities. Health and well-being are also a precondition for a full and productive life for persons with disabilities because they affect a person's ability to participate fully in all aspects of life, work and education and to live independently and be included in the community.
- 2. Health and social inclusion are intimately related. At the individual level, good health and well-being are crucial for participation and active engagement in society. Similarly, social inclusion supports physical and mental health and resilience. At the community level, inclusive and accessible health information, facilities and services can help all groups including persons with disabilities to access the care that they need, with due respect for their right to choice.
- 3. In a 2018 report (A/73/161), the Special Rapporteur on the rights of persons with disabilities underscored the various challenges faced by persons with disabilities to the enjoyment of their right to the highest attainable standard of health and provided options on how to promote health-care services that are inclusive and accessible.

II. Relevant international frameworks

- In article 25 of the Convention on the Rights of Persons with Disabilities, adopted in 2006, States parties recognize the right of persons with disabilities to enjoy the highest attainable standard of health without discrimination on the basis of disability. Under the article, States parties commit to providing persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons and to requiring health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent. States parties also commit to prohibiting discrimination against persons with disabilities in the provision of health insurance and to preventing discriminatory denial of health care or health services on the basis of disability. Under article 9 of the Convention, States parties commit to taking appropriate measures to ensure access for persons with disabilities, on an equal basis with others, to medical facilities, including the identification and elimination of obstacles and barriers to accessing such facilities. Article 26, in which States parties are called upon to organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, should be considered alongside article 25, since rehabilitation is part of universal health coverage and involves the provision of mainstream services together with health promotion, prevention, treatment and palliative services to anyone who needs them.
- 5. Under article 16 of the Convention, States parties commit to taking all appropriate measures to protect persons with disabilities from all forms of exploitation, violence and abuse, including their gender-based aspects, and to taking all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration is to take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.

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- 6. The Convention must be read as a whole in order to fully understand the impact of its rights-based and development-focused approach to persons with disabilities in the domain of health. In addition to articles 9, 25 and 26, the Convention contains other articles in which States parties commit to promoting employment opportunities and enhancing the participation of persons with disabilities in economic, community and political life in short, to ensuring their full participation and inclusion in all aspects of life all of which have an impact on a person's state of health. Articles 12, 14, 15, 16 and 17 also set out the conditions necessary for persons with disabilities to participate in an environment free from violence, to enjoy the right to make their own choices and to live in the community.
- 7. Other instruments focus on the health of children and women with disabilities. In article 23 of the Convention on the Rights of the Child, adopted in 1989, the rights of children and adolescents with disabilities are protected to ensure that such children and adolescents have effective access to health-care services. In the Convention on the Elimination of All Forms of Discrimination against Women, States are required to ensure that women, including women with disabilities, have access to reproductive health care (under article 12) and are protected from coercive pressures. Under Sustainable Development Goal 5 (Achieve gender equality and empower all women and girls), target 5.6 calls for ensuring universal access to sexual and reproductive health and reproductive rights as agreed in accordance with the Programme of Action of the International Conference on Population and Development and the Beijing Platform for Action and the outcome documents of their review conferences. The target is especially important for women and girls with disabilities, as, in many parts of the world, they are less likely to have access to sexual and reproductive health information and services.
- 8. The 2030 Agenda for Sustainable Development sets out an ambitious global vision: to reach and empower those who are left behind, including persons with disabilities. Sustainable Development Goal 3 of the 2030 Agenda calls for ensuring healthy lives and promoting well-being for all at all ages. The implementation of the Goal represents an opportunity to advance the right to health of persons with disabilities. As the Goals of the 2030 Agenda are interrelated, advances in health also contribute to ensuring progress towards the achievement of a wide range of other Goals, and vice versa. To support such a process and for the first time, disability in relation to the Sustainable Development Goals was examined at the global level in a United Nations 2018 flagship report on disability and development. ¹

III. Situation of persons with disabilities and current practices

A. Health status and access to health information and services

- 9. In order to achieve the highest attainable standard of health, it is essential to bring about transformative change in the underlying determinants of health, such as access to adequate sanitation, supply of safe food, nutrition and housing, as well as access to good-quality, effective and affordable health information and services. Persons with disabilities should also be involved in health-related decision-making at the community, national and international levels.
- 10. However, access to health services is still a challenge for persons with disabilities owing to numerous barriers to the availability, accessibility and affordability of the full range of good-quality health-care services, limitations on

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¹ United Nations, Department of Economic and Social Affairs, United Nations Flagship Report on Disability and Development 2018: Realization of the Sustainable Development Goals By, For and With Persons With Disabilities.

health insurance and legal, institutional and attitudinal barriers and stigmas concerning persons with disabilities within the health-care system. Moreover, persons with disabilities are more likely to be found in different kinds of formal and informal institutional settings in which there is poor access to general health care provided on the basis of free and informed choice.

- 11. Persons with disabilities can lead active, productive, long and healthy lives. Having an impairment is not synonymous with being unhealthy. However, owing to the fact that persons with disabilities are more likely to experience poverty, discrimination, violence and social exclusion, they are at a higher risk of developing ill health than the general population. Persons with disabilities have a shorter life expectancy and are at greater risk of developing secondary, iatrogenic, comorbid and age-related health conditions, such as depression, pain and osteoporosis. According to recent surveys across 43 countries, health was self-perceived as very good or good by an average of 21 per cent of persons with disabilities, compared with 80 per cent of persons without disabilities. Similarly, 42 per cent of persons with disabilities perceived their health as poor or very poor, compared with 6 per cent of persons without disabilities. Women with disabilities were more likely to report poorer health than men with disabilities, but data disaggregated by gender and disability remain scarce. Persons with disabilities tended to report poorer health in countries with lower gross domestic product per capita. 3
- 12. Persons with disabilities have more health-care needs, but their needs are less likely to be met. Such needs include both standard needs, such as immunization, screening for cancer and treatment of infections, and needs linked to underlying health conditions and impairments, such as adequate treatment of diabetes or malnutrition. Persons with disabilities are not only more susceptible to worsening health⁴ but also more frequently in need of health-care services. Therefore, they are more vulnerable than others to the impact of low-quality or inaccessible health-care services. At the same time, since they face greater barriers to accessing services, persons with disabilities consistently have a poorer uptake of both general and specialized health-care services when they need them.⁵ Persons with disabilities have specific health-care needs that may require access to rehabilitation and assistive technologies or devices. However, rehabilitation services, such as physiotherapy, occupational therapy and speech and hearing therapy, are not always available for persons with disabilities. In some countries, more than 50 per cent of persons with disabilities who need rehabilitation services do not receive them. ⁶ The situation is similar for some groups of persons with intellectual, developmental, psychosocial or multiple disabilities in low- and middle-income countries. For many, access to assistive technology is essential to enable independent living and full participation in society; however, available evidence shows that, in several developing countries, more than half of the persons with disabilities who need assistive devices are not able to receive them.

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World Health Organization (WHO) and World Bank, World Report on Disability (Geneva, 2011); Edward Chesney, Guy M. Goodwin and Seena Fazel, "Risks of all-cause and suicide mortality in mental disorders: a meta-review", World Psychiatry, vol. 13, No. 2 (June 2014); Sophie Mitra, Disability, Health and Human Development, Palgrave Studies in Disability and International Development (New York, Palgrave MacMillan, 2018).

³ Department of Economic and Social Affairs, United Nations Flagship Report.

⁴ WHO and World Bank, *World Report on Disability*; Tess Bright and Hannah Kuper, "A systematic review of access to general healthcare services for people with disabilities in low and middle income countries". *International Journal of Environmental Research and Public Health*, vol. 15, No. 9 (September 2018).

⁵ Bright and Kuper, "A systematic review".

⁶ Department of Economic and Social Affairs, United Nations Flagship Report.

- 13. Persons with disabilities are also regularly excluded from the provision of sexual, reproductive, maternal and adolescent health information and services. Even in some countries in which the percentage of births assisted by skilled health personnel is similar for mothers with disabilities and mothers without disabilities, gaps in access to family planning between persons with disabilities and persons without disabilities are more often found. 7 For women and girls, stigma and discrimination surrounding both disability and gender, for example, the misconception that women with disabilities are not sexually active or will not marry, are barriers to access to sexual and reproductive health information and services. Persons with disabilities also indicate fear as a reason for not accessing sexual and reproductive health-care services. Those fears are founded in attitudinal barriers raised by health-care providers, including common practices of violation of reproductive rights and abuse of persons with disabilities, such as involuntary sterilization and hysterectomies. Women and girls with disabilities are at an increased risk of violence and abuse, requiring adequate and effective measures to prevent and eliminate such threats.
- 14. Gaps in access to health services are due to the physical, financial, attitudinal, informational and communication barriers faced by persons with disabilities when they try to access health-care services. Physical barriers such as inaccessible buildings and lack of access to medical diagnostic and treatment equipment are often cited as problems. Moreover, in the broader environment, issues of inaccessible or unaffordable means of transportation, poorly paved roads and lack of rural health facilities create obvious obstacles for people with sensory, mobility and cognitive impairments. When sign language communication is not available, communication barriers between patients with hearing impairments and physicians have also been shown to have a negative impact on the quality of health care, including less use of preventive services. Alternative, augmentative communication and other digital and informational accessibility solutions needed to access general, specialist and emergency health-care services are not available in most low- and middle-income countries. In some countries, more than 30 per cent of persons with disabilities indicate that health facilities are not accessible for them. 10
- 15. The reasons that persons with disabilities have more unmet health-care needs vary depending on the context of each country, but in many countries, health-care costs are a major challenge. The cost of health services, compounded with the unavailability of health services within the public health sector and unavailability of health insurance, prevents persons with disabilities from accessing the health services they need or continuing a course of treatment once it has begun. Globally, households with persons with disabilities tend to have higher medical expenditures compared with other households. Such costs escalate in the case of persons with chronic illness, non-communicable diseases, rare diseases and life-long health-care support needs. However, the extra expenses are not always covered by available private or public

⁷ Department of Economic and Social Affairs, *United Nations Flagship Report*.

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⁸ Jean-Francois Trani and others, "Assessment of progress towards universal health coverage for people with disabilities in Afghanistan: a multilevel analysis of repeated cross-sectional surveys", The Lancet Global Health, vol. 5 No. 8 (August 2017); Bright and Kuper, "A systematic review".

⁹ Neuma Chaveiro, Celmo Celeno Porto, Maria Alves Barbosa, "The relation between deaf patients and the doctor", *Brazilian Journal of Otorhinolaryngology*, vol. 75, No. 1 (Jan-Feb 2009); Michael M. McKee and others, "Impact of communication on preventive services among deaf American sign language users", *American Journal of Preventive Medicine*, vol. 41, No. 1 (July 2011); Rachel E. Hommes and others, "American sign language interpreters' perceptions of barriers to healthcare communication in deaf and hard of hearing patients", *Journal of Community Health*, vol. 43, No. 5 (October 2018).

¹⁰ Department of Economic and Social Affairs, United Nations Flagship Report.

financial support services, especially in low- and middle-income countries, resulting in disproportionate out-of-pocket expenditures for such persons. At the same time, in many instances, persons with disabilities have lower income and assets than persons without disabilities, and, therefore, are disproportionately affected by the high market prices and insurance co-payments of health-care services, which may prevent them from seeking the care that they need.

16. Many health facilities are not accessible and do not have staff trained to work effectively with persons with disabilities. At the same time, the lack of information among patients with disabilities themselves about the services available to them is also a barrier.

B. Current practices on health and disability

- 17. While there are increasing efforts to collect disability-disaggregated data as a part of national surveys, for example, through the short set of questions on disability prepared by the Washington Group on Disability Statistics, the lack of comparable data on disability remains a critical development issue. Only better, more accurate and comparable data on disability will enable an accurate understanding of the health-care needs of persons with disabilities and make it possible to meet such needs and monitor and evaluate progress in that regard.
- 18. Only a small minority of countries have made systematic legal and policy reforms that directly address access to health-care services. Countries have adopted different basic approaches to ensure through legal means access to health-care services.
- 19. Despite the fact that 176 countries and the European Union have ratified the Convention on the Rights of Persons with Disabilities, as of 2014, the right to health was guaranteed to persons with disabilities in the national constitutions of only 10 per cent of Member States, and only six countries had an explicit law guaranteeing access to health care for persons with disabilities. Anti-discrimination laws and regulations applicable to all are common, regardless of whether they mention access to health care; however, they are general and do not explicitly target any disability-specific barriers. At best, they give a person with disabilities the option of launching legal action against the State. Finally, national disability laws or policy plans and laws concerning specific health conditions (e.g. spinal cord injuries) or specific populations (e.g. veterans) guaranteeing access to health care are common, but take a wide variety of forms.
- 20. The community-based rehabilitation approach, which is aimed at enhancing the social inclusion of persons with disabilities and their families while reversing the vicious cycle of poverty and disability, was launched by the World Health Organization in the 1980s. Community-based rehabilitation initiatives are currently being implemented in over 90 countries throughout the world, mostly in developing countries. Guidelines on community-based rehabilitation and a matrix were developed to provide a common framework as well as practical implementation strategies for programmes. A key component of the common framework is health, as community-based rehabilitation can be a means of bringing health services to persons with disabilities. In recent years, broader concepts such as disability-inclusive policies and community-based inclusive development, in which rehabilitation is recognized as one element among others, also provide valuable

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The guidelines, which were developed by WHO, the International Labour Organization, the United Nations Educational, Scientific and Cultural Organization and the International Disability and Development Consortium, are available at www.who.int/disabilities/cbr/guidelines/en/.

means of improving access for persons with disabilities to good-quality, effective and affordable health services.

IV. The way forward: leaving no one behind

- 21. Despite the increasing number of States ratifying the Convention on the Rights of Persons with Disabilities and the steps those countries have taken to implement article 25 thereof, persons with disabilities continue to experience more barriers to the full enjoyment of their right to health and to accessing health information and services in comparison with the general population.
- 22. Failure to provide access to good-quality, effective and affordable health information and services to persons with disabilities can compromise their health status and have wide ranging impacts in other areas of implementation of the Convention, such as the right to participate in all aspects of life and education and the right to work. In order for persons with disabilities to achieve the highest attainable standard of health, the following actions could be considered:
- (a) Strengthening national legislation and policies on health care in line with the Convention. The process of assessing existing laws and policies should involve all relevant stakeholders, including organizations of persons with disabilities, and be based on information about health inequalities and involve evidence-based assessments of the gaps in health-care service delivery and of the policy and legal barriers to accessing health-care services. To optimize access to health-care services, national strategies could focus on providing wider, general protections of the right to the highest attainable standard of health, either through constitutional, anti-discrimination or other national disability legislation, after which the more detailed issues of accessibility could be addressed by means of regulations and guidelines at the community level;
- (b) Aligning global frameworks and guidance on health with the Convention. The process of developing such tools could involve all relevant stakeholders, including organizations of persons with disabilities, while due attention should be given to meeting the health needs of persons with disabilities.
- (c) Empowering persons with disabilities to take control of their own health-care decisions, on the basis of free and informed consent. Countries should ensure access to and the accessibility of health-related information, including by making alternate means of communication accessible to persons with disabilities. Countries could also disseminate health information by training persons with disabilities and providing peer support, so that persons with disabilities are better prepared to make decisions about their own health and become aware of the health-care services they can benefit from;
- (d) Addressing discriminatory practices in health insurance and promoting health insurance schemes offering coverage for assistive devices and rehabilitation services. Countries should address the issue of private and public insurance schemes that limit the availability of coverage for pre-existing conditions, since such discriminatory practices disproportionately affect persons with disabilities. In addition, discriminatory practices on the basis of disability should be prohibited. Countries should promote health insurance schemes that address the needs of persons with disabilities, in particular for assistive devices and rehabilitation services;
- (e) Identifying and eliminating obstacles and barriers to accessing health-care facilities. In consultation with persons with disabilities, countries could develop national accessibility guidelines for health-care facilities. They could also conduct assessments of the accessibility of medical facilities and make use of crowd-sourced

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information and user feedback to collect information on accessibility through a bottom-up process. They should also ensure that persons with disabilities are provided with accessible and affordable transportation to health-care facilities;

- (f) Improving health-care coverage and affordability for persons with disabilities as part of universal approaches to health care. Countries could implement universal health coverage by identifying national actions, in consultation with persons with disabilities, to progressively close the gap in health-care service utilization, improve the quality and range of health-care services and reduce health-care costs for persons with disabilities;
- (g) Investing in health-care personnel and improving service delivery for persons with disabilities. Countries should integrate disability-inclusive education into the curricula and training for health professionals. They could involve persons with disabilities in the design and provision of training, increase the number of rehabilitation professionals and expand and improve training opportunities for health-care personnel as well as the recognition and retention of such personnel;
- (h) Improving research and data to monitor, evaluate and strengthen health systems to ensure the inclusion of persons with disabilities and the delivery of health services to them. Countries could conduct further research on the need for high-quality health-care services, on ways to promote public health services and on disease prevention programmes and the barriers that persons with disabilities encounter in accessing such services. Countries could establish health system monitoring and evaluation mechanisms that track the outcomes of health system reforms that address barriers to accessing health services for persons with disabilities. In addition, more studies are needed to understand the reasons that persons with disabilities self-report poorer health and have higher morbidity and mortality. Countries could also invest in sex- and disability-disaggregated data to better understand the gender- and disability-based barriers and to put in place mechanisms to overcome them. They should ensure that disability questions are integrated into existing data collection instruments, such as demographic and health surveys, to allow for disaggregation by disability status so that, among other things, outcomes for people with disabilities and people without disabilities could be compared;
- (i) Harnessing the potential of innovative technologies. Countries could harness such potential as a way to realize the right to health and achieve the Sustainable Development Goals related to health. In this context, innovative, inclusive and multi-stakeholder initiatives and partnerships focused on researching, developing and facilitating access to health technologies could be highlighted.
- 23. The above actions could be supported in a valuable way by cross-cutting efforts to raise awareness among decision-makers, health-care professionals and communities of the rights of persons with disabilities to access health services and of their needs in that regard.

V. Suggested questions for consideration

- 24. The following questions are presented for consideration at the round-table discussion:
- (a) What factors need to be considered to improve access for persons with disabilities to good-quality, non-discriminatory and affordable health-care services?
- (b) What actions, laws and policies are needed for Governments to ensure respect for the right to free and informed consent, to further raise awareness among health professionals of disability-inclusive health services and facilities and to

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empower persons with disabilities themselves to make free and informed health-care decisions?

- (c) In view of existing inequalities in society, how can Governments and other stakeholders address the disparities in access to health technologies and ensure appropriate access to essential health care so that the highest attainable standard of physical and mental health can be achieved for all, including persons with disabilities?
- (d) Why and how have community-based rehabilitation and inclusive development helped to make health facilities and services more accessible to and inclusive of persons with disabilities?
- (e) What specific measures can be taken by Governments, international organizations and civil society to increase opportunities for all persons with disabilities to have their health-care needs met?

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