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# **Report of the Special Rapporteur on the rights of persons** with disabilities

# Note by the Secretariat

The Secretariat has the honour to transmit to the Human Rights Council the report of the Special Rapporteur on the rights of persons with disabilities, pursuant to Council resolution 26/20. In her report, the Special Rapporteur provides an overview of the activities undertaken in 2016, as well as a thematic study on access to support by persons with disabilities. The study includes guidance for States on how to ensure the provision of different forms of rights-based support and assistance for persons with disabilities, in consultation with them.





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# **Report of the Special Rapporteur on the rights of persons** with disabilities

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# I. Introduction

1. The Special Rapporteur on the rights of persons with disabilities, Catalina Devandas Aguilar, submits the present report to the Human Rights Council pursuant to its resolution 26/20. It contains a description of the activities she carried out in 2016 and a thematic study on access to support by persons with disabilities. In preparing the study, the Special Rapporteur convened a regional expert consultation in Addis Ababa in September 2016 and analysed the responses to a questionnaire sent to Member States, national human rights institutions, agencies of the United Nations system, civil society organizations and persons with disabilities and their representative organizations. As at 5 December 2016, she had received 114 responses.<sup>1</sup>

# II. Activities of the Special Rapporteur

## A. Country visits

2. In 2016, the Special Rapporteur visited Zambia from 18 to 28 April (see A/HRC/34/58/Add.2) and warmly thanks the Government for its cooperation prior to, during and after the visit. The planned visit to Morocco (18 to 28 July) was postponed at the last moment at the request of the Government and has not been rescheduled.

3. The Special Rapporteur has agreed to undertake a visit to France during the course of 2017 and has requested invitations to visit Cuba, the Philippines, Qatar and Viet Nam.

## B. Conferences, meetings and engagement with stakeholders

4. During the year the Special Rapporteur participated in numerous conferences and expert meetings, which allowed her to exchange information, share good practices and raise awareness of disability-related issues. She participated, inter alia, in the fifty-fourth session of the Commission for Social Development in New York (February), the annual interactive debate on the rights of persons with disabilities at the Human Rights Council (March), the World Humanitarian Summit in Istanbul, Turkey (May) and the Social Forum of the Human Rights Council (October), which focused on the rights of persons with disabilities in the context of the tenth anniversary of the adoption of the Convention on the Rights of Persons with Disabilities. She also attended a meeting of the Human Dimension Committee of the Organization for Security and Cooperation in Europe, the Forum on Human Rights organized by the Department of Foreign Affairs and Trade of Ireland and several expert consultations on social protection, disability assessment and mental health organized by other United Nations experts, agencies, organizations of persons with disabilities or academia.

5. In June, the Special Rapporteur participated in the ninth session of the Conference of States Parties to the Convention on the Rights of Persons with Disabilities, held in New York, and its parallel events. As mandated by the General Assembly, she also engaged with the United Nations Statistical Division, the Inter-Agency and Expert Group on Sustainable Development Goal Indicators and with several United Nations agencies to advocate for the

<sup>&</sup>lt;sup>1</sup> See www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/Provisionofsupporttopersons withdisabilities.aspx.

disaggregation of data by disability in the implementation of the Sustainable Development Goals.

6. In July, together with the Special Rapporteur on the rights of indigenous peoples, she organized an expert meeting on indigenous persons with disabilities, which convened for the first time the main United Nations and other international experts from both constituencies, as well as indigenous persons with disabilities. The meeting informed the panel discussion on the situation of indigenous persons with disabilities that took place during the ensuing meeting of the Expert Mechanism on the Rights of Indigenous Peoples.

7. On 26 October, the Special Rapporteur presented her annual report to the General Assembly on disability-inclusive policies (A/71/314). The report was made available in accessible formats. She also contributed to the report of the Secretary-General titled "Towards the full realization of an inclusive and accessible United Nations for persons with disabilities" (A/71/344 and Corr.1) and other reports of other United Nations bodies.

8. To mark the International Day of Persons with Disabilities, the Special Rapporteur, together with other United Nations experts, United Nations agencies and disability advocacy organizations, organized several awareness-raising activities in Geneva on 2 December under the campaign to embrace diversity called "A day for all".

9. In June, the Special Rapporteur became a member of the Coordination Committee of Special Procedures and she continues to collaborate closely with other mandate holders, including the Special Rapporteur on the right to adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context, the Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health, the Special Rapporteur on the rights of indigenous peoples, the Independent Expert on the enjoyment of all human rights by older persons, the Independent Expert on the enjoyment of human rights by persons with albinism, the Working Group on the issue of discrimination against women in law and in practice and a number of country mandate holders. Moreover, she has engaged with other United Nations experts, including the Special Envoy of the Secretary-General on Disability and Accessibility and the Special Representative of the Secretary-General on Violence against Children, and with the United Nations Partnership to Promote the Rights of Persons with Disabilities, the Committee on the Rights of Persons with Disabilities, the Committee on the Rights of the Child and the Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. In November 2016, she was appointed a member of the advisory board of the global study on children deprived of liberty that has been commissioned by the Secretary-General at the invitation of the General Assembly.

10. The Special Rapporteur also held consultations with several United Nations agencies and other stakeholders, such as the World Health Organization, the International Labour Organization, the United Nations Educational, Scientific and Cultural Organization, representatives of national human rights institutions, numerous persons with disabilities and their representative organizations, other non-governmental organizations, academics and ambassadors.

## C. Communications

11. Summaries of communications sent and replies received during the period covered by the present report are available in the communications reports of special procedures (A/HRC/31/79, A/HRC/32/53 and A/HRC/33/32 and Corr.1).

# III. Support services for persons with disabilities

12. The present report aims to raise awareness and provide guidance to States on how to ensure access to different forms of support for persons with disabilities inclusive of a human rights-based approach.

# A. What is support?

13. Support is the act of providing help or assistance to someone who requires it to carry out daily activities and participate in society. Support is a practice, deeply embedded in all cultures and communities, that is at the basis of all our social networks. Everyone needs support from others at some stage, if not throughout their life, to participate in society and live with dignity. Being a recipient of support and offering support to others are roles we all share as part of our human experience, regardless of impairment, age or social status. However, while some forms of support have been naturally integrated into social design, others, such as that required by persons with disabilities, are still marginal.<sup>2</sup>

14. Support for persons with disabilities encompasses a wide range of formal and informal interventions, including live assistance and intermediaries, mobility aids and assistive devices and technologies. It also includes personal assistance; support in decision-making; communication support, such as sign language interpreters and alternative and augmentative communication; mobility support, such as assistive technology or service animals; living arrangements services for securing housing and household help; and community services. Persons with disabilities may also need support in accessing and using general services, such as health, education and justice.

15. For most persons with disabilities, access to quality support is a necessary precondition for living and fully participating in the community on the basis of choices equal to others. Without adequate support, persons with disabilities are at risk of falling into neglect and institutionalization. The provision of appropriate support is necessary to the realization of the full spectrum of human rights and enables persons with disabilities to achieve their full potential, thus contributing to the overall well-being and diversity of the communities in which they live. For many persons with disabilities, support represents an essential precondition for their active and meaningful participation in society, while preserving their dignity, autonomy and independence.

16. The existence of social and environmental barriers creates the need for support. For example, persons with disabilities who live in inaccessible communities may require greater support than if they lived in accessible ones. Individual support needs also vary according to personal factors, including level of impairment, age, socioeconomic status and ethnic origin. While the existence of strong non-discrimination legal frameworks and fully accessible general environments significantly facilitate the participation of persons with disabilities, many of them may still require support measures to be able to participate in the community on an equal basis with others.

# **B.** The importance of support

17. Persons with disabilities constitute 15 per cent of the world population, approximately one billion people. Many of them require different forms of support,

<sup>&</sup>lt;sup>2</sup> Tom Shakespeare, *Help* (Birmingham, United Kingdom of Great Britain and Northern Ireland, Venture Press, 2000).

including for basic day-to-day activities such as getting up, bathing, dressing and eating.<sup>3</sup> The sustained ageing of the global population, particularly in high-income countries, has also had a substantial impact on the demand for disability-related support, as older persons tend to be overrepresented in the disability community.<sup>4</sup> Other sociopolitical factors such as conflict and migration increase the demand for support, as support networks tend to fall apart in such situations.

18. Despite the rising demand, the support needs of most persons with disabilities worldwide are not being met. Evidence indicates that in most developed and developing countries, the majority of persons with disabilities have limited access to support services.<sup>5</sup> There is a shortage of community support services for persons with disabilities who require personal assistance. In many countries, only 5-15 per cent of those in need of assistive devices and technologies are able to obtain them.<sup>6</sup> Deaf and deafblind persons frequently face difficulties in accessing trained interpreters, particularly in rural or isolated communities. Persons with psychosocial and intellectual disabilities are overrepresented among the homeless because of the lack of support for living in the community and for decision-making. Furthermore, general public services in such areas as education and employment do not envision support measures to ensure the full participation of persons with disabilities. While all persons with disabilities face challenges in accessing support, those with high support needs are disproportionately affected by the lack of appropriate services.

19. Regretfully, there is little public and political interest or attention to the support needs of persons with disabilities. In many countries, support is not included in national legislation and policies and, when available, it is an underfunded residual service with scarce provision that does not match people's needs.<sup>7</sup> Moreover, whereas there are some forms of formal support for persons with disabilities in many high-income countries, this is not the case in many low- and middle-income countries. Consequently, the majority of persons with disabilities have to rely on informal forms of support, primarily from their families and personal networks.

20. Support is a normal part of community life, with families serving as the first source of support for everyone. For many persons with disabilities, family support serves as a bridge to access other assistance needed to fully enjoy their human rights. However, when no other options are available and families are the sole source of support, the autonomy of persons with disabilities and their family members is reduced. Those being supported have no choice or control over the assistance they require to pursue their life plans, and questions of overprotection and conflict of interest commonly arise. Families — especially the poorest — are also under significant pressure as unpaid familial support also affects social relationships, income levels and the general well-being of the household. Women and girls are disproportionately affected, as in practice they are the main providers of support within the household, reducing their freedom and choices to pursue their own life plans.

21. The absence of appropriate support systems increases the risk of segregation and institutionalization. When families do not get the necessary support, there is great pressure to place their family member with a disability in an institution. In addition, service providers in many countries continue to claim that institutions are the best way to support persons with disabilities. Thus, the only way a family can get any support for accessing basic services is by placing their family member in an institution. Both institutionalization

<sup>&</sup>lt;sup>3</sup> World Health Organization (WHO) and World Bank, *World Report on Disability 2011*, p. 29.

<sup>&</sup>lt;sup>4</sup> Ibid., pp. 34-35.

<sup>&</sup>lt;sup>5</sup> Ibid., pp. 139-140.

<sup>&</sup>lt;sup>6</sup> See who.int/disabilities/technology/activities/en/.

<sup>&</sup>lt;sup>7</sup> WHO and World Bank, *World Report* on *Disability 2011*, pp. 144-147.

and the lack of support within the family put persons with disabilities at risk of neglect, violence and abuse.

22. States should therefore adopt and implement policies and programmes that enable persons with disabilities to obtain the support they need to participate in decisions affecting their lives and in the life of their communities. The protection and promotion of human rights of persons with disabilities should be at the centre of these policy efforts, rather than focusing on charitable and medical approaches.

## C. Rethinking care and assistance

23. For a long time, responses to the assistance needs of persons with disabilities have been framed in terms of care. While care as a concept can be understood and used in several ways, the disability community has historically been critical of the idea of "being cared for" and of the traditional role of caregivers. Service models of care have traditionally treated persons with disabilities as passive objects or recipients of care, or as a "burden" for family and society, rather than as active holders of rights. Whether in formal or informal settings, care services have traditionally regarded persons with disabilities as dependents, which in most cases has not enabled them to fully participate in decisions affecting their lives.

24. Care services also have a legacy of segregation and disempowerment of persons with disabilities. In fact, most services were built under the medical and assistentialist models, which prompted the confinement of persons with disabilities in institutions, leading to the loss of control of their lives and their ultimate objectification. Therefore, for many persons with disabilities the notion of care bears a heavy historical connotation associated with oppression and invalidation.<sup>8</sup>

25. The disability community has challenged the traditional concept of care on the basis of a social understanding of disability. The social model of disability draws attention to the interaction between an individual's perceived or actual impairment — be it physical, sensory, mental or intellectual — and the disabling barriers that hinder people from participating in society. Therefore, it is critical to enable inclusive societies that support persons with disabilities to participate and have the freedom and opportunities to live lives they value. This means replacing the legacy of paternalism, dependency and stigma that exist behind traditional approaches to care with the concept of support as a State obligation arising from human rights, equality and social justice.

26. The philosophy of independent living, which outlines the need for persons with disabilities to have autonomous and independent lives, reinforces the notion of support. However, independence needs to be framed in a way that takes into account the interdependence of human experiences and accepts reliance on others as a fundamental aspect of that interdependence, thus moving away from narrow interpretations of independence that conflate it with self-sufficiency and self-reliance.<sup>9</sup> In this regard, support must ensure that persons with disabilities are able to exercise choice and control over their own lives, irrespective of their physical, sensory, mental and intellectual impairments, and over their own views, rather than having to follow the views of those looking after their needs.

<sup>&</sup>lt;sup>8</sup> Teppo Kroger, "Care research and disability studies: nothing in common?", *Critical Social Policy*, vol. 29, No. 3 (2009), pp. 398-420.

<sup>&</sup>lt;sup>9</sup> Jenny Morris, "Impairment and disability: constructing an ethics of care that promotes human rights", *Hypatia*, vol. 16, No. 4 (November 2001), pp. 1-16.

27. At the same time, there is a need to recover and acknowledge the personal experience of impairment that informs the support needs that persons with disabilities have in order to participate in society, experiences that may have been rendered marginal in the disability-rights debate.<sup>10</sup> The acceptance of persons with disabilities as part of human diversity should influence the way societies perceive and respond to individuals' support requirements.

28. Against this background, States must move away from the assistentialist and medical approaches and rethink their policy and practice of care from a human rights perspective. The provision of access to support is essential for the implementation of the Sustainable Development Goals. While the debates on political and social economy of care are receiving increasing attention from activists, researchers, States and international actors, they do not adequately address the rights of persons with disabilities. Discussions on care in the 2030 Agenda for Sustainable Development must be inclusive of persons with disabilities and incorporate a human rights-based approach to disability. The enjoyment by all persons with disabilities of all human rights and fundamental freedoms should be at the centre of any model of support and assistance.

# IV. Support to persons with disabilities in international human rights law

#### A. State obligation to ensure access to support

29. International human rights law requires States to provide persons with disabilities access to appropriate support to carry out daily activities and participate in society. The Convention on the Rights of Persons with Disabilities — the highest international standard on promotion and protection of the rights of persons with disabilities — clearly stipulates the obligation of States to ensure access to a wide range of support services to persons with disabilities, and provides a comprehensive framework for its implementation. The Convention on the Rights of the Child also recognizes the obligation of States to ensure the assistance required by children with disabilities for achieving their fullest possible social integration and individual development (art. 23).

30. Regional human rights instruments have also recognized support to persons with disabilities. The European Social Charter (revised) enshrines the right of persons with disabilities to independence, social integration and participation in the life of the community, calling on States to facilitate access to technical aids and support services (art. 15). The Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador) establishes an obligation to adopt measures to assist persons with disabilities to achieve the greatest possible development of their personality, including the implementation of programmes specifically aimed at providing them with the resources and environment needed for attaining this goal (art. 18). While the African Charter on Human and Peoples' Rights establishes a general obligation to facilitate "special protection measures" for persons with disabilities (art. 18 (2) and (4)), the draft protocol to the African Charter on Human and Peoples' Rights on the rights of persons with disabilities adopted by the African Commission on Human and Peoples' Rights in April 2016 explicitly recognizes support as a necessary measure to enable the realization of the rights of persons with disabilities (arts. 2 (h), 8, 10, 12, 13, 14, 16, 17, 20, 23, 25 and 26). Finally, the Incheon Strategy to "Make the Right Real" for Persons with Disabilities in Asia and the Pacific considers community inclusion and

<sup>&</sup>lt;sup>10</sup> Ibid.

support as part of its policy direction. Its goal 4, Strengthen social protection, includes a target on enhancing services and programmes, including for personal assistance and peer counseling, that support persons with disabilities in living independently in the community.

31. That the core international human rights treaties do not explicitly mention support measures for persons with disabilities does not imply that the obligation did not exist prior to the adoption of the Convention of the Rights of Persons with Disabilities. Support is a human rights obligation arising from various rights, including the right to an adequate standard of living, the right to social protection, the right of everyone to the enjoyment of the highest attainable standard of physical and mental health and the right to education. The Committee on Economic, Social and Cultural Rights, in paragraph 33 of its general comment No. 5 (1994) on persons with disabilities, recognized that support and an adequate standard of living are interconnected and that the provision of necessary support services to persons with disabilities, including assistive devices, increases their level of independence in their daily living and to exercise their rights.

32. Support can also be derived from the basic principles of human rights, such as dignity, universality, individual autonomy, equality and non-discrimination, participation and inclusion. The universal nature of human rights provides an obligation on States to promote the full realization of rights for all people. Persons with disabilities should enjoy all human rights and fundamental freedoms on an equal basis with others. Access to adequate support is indeed a precondition for persons with disabilities to effective exercise of their human rights on an equal basis with others and, therefore, to live with dignity and autonomy in the community.

33. The State obligation to ensure access to support to persons with disabilities must be distinguished from the obligation to provide accessibility. While accessibility is an obligation related to the physical environment, transportation, information and communications — a requirement for barrier-free, inclusive societies — support is an obligation linked to the individual. Instead of transforming the environment, the goal is to assist the individual in a range of different activities, from communication to mobility. Whereas the level of accessibility may increase or decrease the need for support, the two are complementary obligations enabling persons with disabilities to live independently and to participate fully in all aspects of life.

34. Similarly, the right to reasonable accommodation is distinct from, although complementary to, the obligation to provide support. States are required to make all necessary and appropriate modifications or adjustments that do not impose a disproportionate or undue burden to allow persons with disabilities to exercise their rights. Such modifications or adjustments may include support measures tailored to the needs of an individual in a particular case. However, the obligation to ensure access to support is not limited by the qualification of disproportionate or undue burden.

## B. Support in the Convention on the Rights of Persons with Disabilities

35. In the Convention on the Rights of Persons with Disabilities support is firmly grounded in a complex substantive equality model introduced by the Convention. The treaty underlines the importance of taking the diversity of the human experience into account. The Convention underlines the importance of adopting all appropriate measures to support the full and effective participation of persons with disabilities in society on an equal basis with others. Its rights-based approach also places persons with disabilities at the centre of all decisions affecting them, including decisions about support and assistance.

36. The Convention does not define support, but refers to it in several of its provisions. According to the Committee on the Rights of Persons with Disabilities, "support" is a broad

term that encompasses both informal and formal support arrangements, of varying types and intensity.<sup>11</sup> All forms of support should be provided while respecting the general principles of the Convention (art. 3).

37. Support is a cross-cutting obligation under the Convention. As part of the general obligations provided in article 4, States parties have an obligation to adopt all appropriate measures to implement the rights recognized in the treaty, including the provision of support services when necessary (art. 4 (1) (a)). States must also undertake or promote research and development, and promote the availability and use, of devices and assistive technologies (art. 4 (1) (g)), and provide accessible information to persons with disabilities about mobility aids, devices and assistive technologies, including new technologies, and other forms of assistance, support services and facilities (art. 4 (1) (h)).

38. The provision of specific forms of support is further referred to in articles 9 (accessibility), 12 (equal recognition before the law), 13 (access to justice), 16 (freedom from exploitation, violence and abuse), 19 (living independently and being included in the community), 20 (personal mobility), 21 (freedom of expression and opinion, and access to information), 23 (respect for home and the family), 24 (education), 26 (habilitation and rehabilitation), 27 (work and employment), 28 (adequate standard of living and social protection) and 30 (participation in cultural life, recreation, leisure and sport).

39. In many of its concluding observations, the Committee on the Rights of Persons with Disabilities has called upon States to provide access to support to persons with disabilities in different aspects of life.<sup>12</sup> More specifically, in its general comment No. 1 (1994) on equal recognition before the law, the Committee stressed that support must respect the rights, will and preferences of persons with disabilities, and that the type and intensity of support to be provided will vary significantly from one person to another owing to the diversity of persons with disabilities.

40. Many forms of support, such as the support required to exercise legal capacity, are subject to immediate realization.<sup>13</sup> While full realization of other forms of support may be achieved progressively, States have an obligation to take immediate steps to the maximum of their available resources, including those made available through international assistance and cooperation, to ensure support for persons with disabilities, including the adoption of legislative and policy frameworks and budgetary measures.

41. The Convention challenges traditional approaches to care and has the potential to redress the legacy of disempowerment and paternalism. Furthermore, the notion of support in the Convention also has the potential to override traditional understandings of care and assistance for other groups, such as older persons and children. The Convention restores the importance of the "human being" in the human rights discourse by emphasizing the individual and social aspects of the human experience.<sup>14</sup> These innovations can and should be incorporated into the implementation of all existing human rights instruments.

<sup>&</sup>lt;sup>11</sup> General comment No. 1 (2014) on equal recognition before the law, para. 17.

 $<sup>^{12} \ \</sup> See \ www.ohchr.org/EN/HRBodies/CRPD/Pages/CRPDIndex.aspx.$ 

<sup>&</sup>lt;sup>13</sup> General comment No. 1, para. 30.

<sup>&</sup>lt;sup>14</sup> Gerard Quinn and Anna Arstein-Kerslake, "Restoring the 'human' in 'human rights': personhood and doctrinal innovation in the UN disability convention", in *The Cambridge Companion to Human Rights Law* (Cambridge University Press, 2012), pp. 36-55.

# C. Multiple and intersectional approach to support

42. In providing support to persons with disabilities, States need to acknowledge the different layers of identities within the disability community. Persons with disabilities comprise a very heterogeneous group with a wide range of impairments as well as identity markers such as race, colour, sex, sexual orientation, gender identity, language, religion, national, ethnic, indigenous or social origin, age and other status. States need to address the specific support needs of individuals throughout their life cycle.

#### 1. Women and girls with disabilities

43. Women and girls with disabilities face significant difficulties in accessing support throughout their lives. On average, they are less likely to study and work; they earn less than men and thus have fewer opportunities to access appropriate support. Moreover, existing support services are frequently not responsive to the needs, nor respectful of the rights, of girls and women with disabilities. Male staff are often assigned to provide assistance, which may not respond to their preferences and create a heightened risk of abuse. In this regard, support cannot be addressed in gender-neutral terms. When designing and implementing policies and interventions on support, States must take into account the systemic and multiple discrimination faced by women and girls with disabilities. They must remove all barriers that interfere with access by women and girls to comprehensive support arrangements and provide appropriate assistance to those women with disabilities who perform care and support responsibilities as parents, without reinforcing patterns of discrimination and negative stereotyping.

#### 2. Children with disabilities

44. Children with disabilities and their families require different types of support services, especially in the education and health sectors. They include assistive technology, communication support and individualized education plans, and information and assistance to families of children with disabilities in need. For too long, children and adolescents with disabilities have been mere recipients of "special care", when this is available at all, which resulted in widespread segregation, institutionalization and neglect. Instead, States must organize support services and measures that foster their well-being and enable them to realize their full potential. Families need help to understand disability in a positive way and to know how to help support their children to be autonomous and independent. Limited understanding of care can hinder their right to express their views freely on all matters affecting them, in accordance with their age and maturity, and to be provided with disability- and age-appropriate assistance to realize that right.

#### 3. Older persons with disabilities

45. Older persons with disabilities also have difficulties in accessing support arrangements for daily life, such as personal assistance, assisted living arrangements and palliative care. While families are the most common source of support for older persons with disabilities in most countries, there is an increasing demand for institutional care, especially from family members and other informal supporters of persons with disabilities. Importantly, older women with disabilities are more likely to be institutionalized owing to the different life expectancies of men and women. The provision of in-home support services, including personal assistance and help with household chores, can avoid institutionalization and improve the quality of life of older persons by enabling them to stay at home (see A/HRC/30/43, para. 72).

#### 4. Disadvantaged groups

46. Persons with disabilities belonging to groups that have been historically discriminated against or disadvantaged (such as indigenous peoples, ethnic minorities and persons living with HIV/AIDS) are disproportionately affected in accessing support arrangements and services. This also applies to migrants, persons living in conflict situations, internally displaced persons, refugees, asylum seekers, stateless persons and prisoners with disabilities, as humanitarian responses tend to overlook their support needs. Moreover, there is a strong link between belonging to a racial and cultural minority and experiencing coercion and institutionalization.<sup>15</sup> Policies and programmes to ensure access to support must seek to overcome the impact of the multiple and aggravated forms of discrimination faced by persons with disabilities belonging to these groups in accessing support.

47. Policies and programmes to ensure access to support should respond to the heterogeneous needs of the diverse disability community, which includes deaf, deafblind and autistic persons, persons with psychosocial and intellectual disabilities and persons with albinism. For example, in Kazakhstan new regulations provide that all blind and deafblind persons are entitled to personal assistance. Nonetheless, while impairment-specific considerations may be necessary to provide targeted support services for specific groups, States should carefully assess whether the adoption of specific measures that benefit certain groups may exclude others.

## **D.** Unpacking the obligation to provide access to support

48. Following the standards developed by the Committee on Economic, Social and Cultural Rights, <sup>16</sup> the Special Rapporteur has identified four interrelated and essential elements of the obligation to provide support to persons with disabilities. These elements can vary in accordance with different conditions and types of support arrangements.

#### 1. Availability

49. Appropriate support services and arrangements must be available to all persons with disabilities in sufficient quantity within countries. States should consider establishing a system, under domestic law, to ensure access to a wide range of support measures. This system can be composed of a single scheme or a variety of schemes, both formal and informal. States have a duty to ensure that support is available for persons with disabilities, regardless of whether it is actually provided by public service providers, civil society, families, communities, or a combination of public and private actors. While the support provided by family, friends and the broader community is extremely important and should be encouraged and enabled, it is not always a reliable or sustainable solution in the longer term (see A/HRC/28/37, paras. 35-36).

50. Support systems should ensure the availability of an adequate number of functioning programmes and services to provide the fullest possible range of support to the diverse population of persons with disabilities, including communication support, support in decision-making, mobility support, personal assistance, living arrangements services and community services. Ensuring the availability of a reliable, skilled and trained workforce,

<sup>&</sup>lt;sup>15</sup> Ruchika Gajwani and others, "Ethnicity and detention: are black and minority ethnic (BME) groups disproportionately detained under the Mental Health Act 2007?", *Social Psychiatry and Psychiatric Epidemiology*, vol. 51, No. 5 (May 2016), pp. 703-711.

<sup>&</sup>lt;sup>16</sup> General comments No. 13 (1999) on the right to education, No. 14 (2000) on the right to the highest attainable standard of health and No. 19 (2007) on the right to social security.

including sign language interpreters, interpreters for the deafblind, personal assistants and other intermediaries, is a critical component of ensuring the availability of support. Assistive devices and technologies for persons with disabilities should also be available.

#### 2. Accessibility<sup>17</sup>

51. Support services and arrangements should be accessible to all persons with disabilities, especially the most disadvantaged ones, without discrimination of any kind. States must ensure that support is available within safe physical and geographical reach for everyone, including those living in institutions. All facilities and services providing support, public and private, including information and communications technologies and systems, must be accessible for the diverse disability community. States must take positive measures to ensure that persons with disabilities living in rural and remote areas also have access to support services and arrangements. Dissemination of information about existing services and social protection schemes must also be ensured.

52. Support must be affordable for all persons with disabilities. Support services represent a significant cost for persons with disabilities, preventing them from climbing out of poverty. States must ensure that support is available at nominal or no cost to the maximum extent of their available resources, and take into account the gender disparity in income and access to financial resources. Social protection systems can constitute a powerful strategy to facilitate access to support services for persons with disabilities (see A/70/297, para. 9). Qualifying conditions for accessing support must be reasonable, proportionate and transparent, and should not be limited to those persons protected by social insurance schemes.<sup>18</sup> Additionally, States should include the provision of essential assistive devices and technologies in the coverage of national health insurance and/or social protection schemes, on the basis of the World Health Organization priority assistive products list (ibid.). States should also consider waiving import duties and taxes on assistive devices and technologies that are not produced domestically (ibid., para. 48).

#### 3. Acceptability

53. States must take all appropriate measures to ensure that support programmes incorporate a rights-based approach, are provided on a voluntary basis and respect the rights and dignity of persons with disabilities. All support services and arrangements must be culturally appropriate; sensitive to gender, impairment and life-cycle requirements; and designed to respect the privacy of those concerned. Community-based approaches for the provision of support constitute an effective strategy to ensure the provision of responses that take into account geographical, social, economic and cultural issues.

54. States must ensure that the support made available is of good quality. This requires, inter alia, the implementation of person-centred approaches and the adoption of guidelines and criteria to regulate the delivery of assistance and support services, including standards for training and certification. States should also train and assist families and communities providing informal support, set up monitoring mechanisms to assess the adequacy of support services and arrangements and prevent abuses and violence in its provision.

<sup>&</sup>lt;sup>17</sup> It is important to differentiate between the concept of accessibility as defined by the Committee on Economic, Social and Cultural Rights, which relates to the capacity of systems to ensure access to services, and accessibility as a human rights principle as referred to in the Convention on the Rights of Persons with Disabilities.

<sup>&</sup>lt;sup>18</sup> Committee on Economic, Social and Cultural Rights, general comment No. 19 (2007), para. 24.

#### 4. Choice and control

55. States must design support services and arrangements so that they enable direct choice and control by persons with disabilities. Existing services often do not comply with this standard. In many instances the decisions of users can be overridden by professionals and family members. States must guarantee to persons with disabilities the opportunity to plan and direct their own support: who provides it and how, and whether it is provided in disability-specific services or in services offered to the general public. The denial or restriction of legal capacity, a widespread human rights violation worldwide, has a direct impact on the possibility for persons with disabilities to exercise choice and control over the support they receive and contributes to the imposition of services that are contrary to their dignity and rights.

56. Individual funding is a suitable way to ensure choice and control by persons with disabilities. Personalized schemes allow persons with disabilities to hire support directly, either from formal service providers or informal carers, or a combination of both. In this way, persons with disabilities can decide who provides them support and the type and level of support they wish to receive, and thus are much more empowered to ensure that they will receive adequate support. The implementation of such schemes should not, however, result in States relinquishing their primary responsibility to ensure access to appropriate support for persons with disabilities. On the contrary, States have a significant role to play in its management and monitoring.

# V. Ensuring access to support for persons with disabilities

## A. General State obligations

#### 1. Legal and policy frameworks

57. States must establish legal and policy frameworks that ensure that support services and arrangements, including assistive technologies, are available, accessible, adequate and affordable. Many national legal frameworks do not include support services at all, or only for the exercise of certain rights (e.g., inclusive education or mobility). Moreover, when legislation does consider these services, States often do not have the appropriate policies and programmes in place to ensure implementation. States should review existing legislation and policies on support to ensure that they are compatible with the requirements of the Convention on the Rights of Persons with Disabilities.

58. States should also consider establishing a comprehensive system to coordinate the effective access to support of persons with disabilities. The system should be anchored in the human rights-based approach to disability; take into account equality between men and women and the rights of the most disadvantaged and marginalized groups; and cover all support needs across all sectors of society throughout one or more schemes, formal and informal. Such a system could bring coherence and coordination across programmes, actors and levels of government responsible for the provision of support. Within this system, States should take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities from all forms of exploitation, violence and abuse, including their gender-based aspects. States should also consider integrating as many assistance and support services as possible into their existing mainstream policies and programmes. Persons with disabilities and their representative organizations should participate in all decision-making processes concerning this system, including design, implementation and monitoring.

59. Decentralizing the provision of support is a major challenge for many States. Contributions to the present report illustrate that where responsibility for the provision of support has been delegated to regional or local authorities, support is often underfunded and fragmented, allowing for regional disparities and inequitable access within the country. This situation gives persons with disabilities little certainty and limited choice of or control over support services and arrangements. States should enhance their internal coordination mechanisms to address support needs in a comprehensive manner, ensure that regional and local authorities receive adequate budget, and implement and monitor the provision of support services effectively. Persons with disabilities should be able to retain the support they receive when they move to another region in their country.

#### 2. Service delivery arrangements

60. Support is usually delivered by a mixture of providers, including State agencies, private organizations, non-profit organizations, charities and families. In high- and middle-income countries, States have traditionally been the main source of formal support, either through their centralized health-care or social protection systems or through local authorities. In many cases, States fund and contract non-profit organizations and private organizations to carry out these interventions. In low-income countries, charities and international non-governmental organizations are the main providers of formal support, often with limited sustainability and low standards of quality. Regardless of the type of service delivery arrangement, States have an obligation to ensure that persons with disabilities have access to and receive quality services and adequate support, including when service provision is delegated to non-profit organizations and private actors. In such cases, States must adopt a comprehensive regulatory and monitoring framework that involves a due diligence obligation.

61. In the light of article 19 of the Convention on the Rights of Persons with Disabilities, States must adopt a community-based approach to the provision of support, either directly or through intermediaries. Such an approach enables stakeholders — family, friends, neighbours, peers and others — to play a significant role in supporting persons with disabilities in daily life activities and participating in the community. This allows the provision of culturally sensitive services in the communities where persons with disabilities live, building on existing social networks and community resources. In the case of indigenous peoples, for example, community-based approaches could reduce the risk of assimilation. When services are not made available within the community, there is limited participation by persons with disabilities in their design and provision, and there is an increased risk of segregation and institutionalization. Importantly, by benefiting from local skills and resources, community participation in the provision of support facilitates the optimal and efficient delivery of services, enabling a cost-effective policy response in countries with limited resources.

62. In recent decades, many high- and middle-income countries have shifted their support policies towards personalization, to enable persons with disabilities to hire the support they require within the existing market. Different models of personalization have been implemented, including direct payments and personal budgets. While these models can potentially empower persons with disabilities, States need to adopt a set of measures to enhance their effectiveness. Such measures include, for instance, building the capacities of beneficiaries to manage their own funding and support (including supported decision-making); having a wide range of providers that respond to the diversity of support needs, particularly for those who live in rural and remote areas; preventing precariousness in the work conditions of supporters; and avoiding channelling personal budgets through the

family rather than directly to the persons with disabilities, and the feminization of support.<sup>19</sup> It is important to note that allowances that are paid directly to "informal carers" of adults with disabilities can compromise the capacity of persons with disabilities to exercise choice and control over their support. Support to families should never replace support to individuals.

#### 3. Participation and collaboration

63. Persons with disabilities and their representative organizations must participate in all decision-making processes related to the design, implementation, monitoring and evaluation of support services and arrangements. Persons with disabilities know best what type of support they require and the barriers they face in accessing it. The Convention on the Rights of Persons with Disabilities explicitly requires States to consult closely with and actively involve persons with disabilities, including children with disabilities, in the development and implementation of legislation and policies concerning issues relating to them (art. 4 (3)). The Special Rapporteur's thematic study on the right of persons with disabilities to participate in decision-making (A/HRC/31/62) provides specific guidance in this regard.

64. States should promote collaboration and partnerships between public authorities and civil society organizations, including representative organizations of persons with disabilities, in the area of provision of support, particularly at the subnational and operational levels. In this way, support systems can benefit from the outreach capacity of organizations of persons with disabilities, their knowledge of local contexts and their mobilization and advocacy capacity. For instance, in Kenya the Government funds organizations of persons with psychosocial disabilities to run peer support groups in seven counties that facilitate support for decision-making and community living.

#### 4. Non-discrimination

65. States must ensure that all persons with disabilities enjoy equal access to quality support without discrimination. Public and private service providers and agencies cannot deny access to support on the basis of disability, whether directly or indirectly, and they must ensure the provision of reasonable accommodation to all those who may require it. States should review all eligibility criteria and assessments from a human rights perspective to ensure they are not discriminatory, in line with the recommendations included in the Special Rapporteur's thematic study on the right of persons with disabilities to social protection (A/70/297).

66. States must abolish discriminatory practices in the provision of support. For instance, many States continue to rely on institutional and residential care and provide support services predominantly in those settings. Furthermore, the existence of guardianship and other substitute decision-making regimes present great challenges for persons with disabilities in accessing support services. These practices not only deprive them of the possibility to choose their supports, but also contribute to perpetuating their isolation, forced treatment and institutionalization. States should not bundle access to support with such requirements as accepting certain residential arrangements or undergoing medical treatment. Stigma and discrimination also have a negative impact on access to support services by persons with disabilities. Misconceptions about them often result in

<sup>&</sup>lt;sup>19</sup> Evidence also shows that, if well designed, personalization schemes can increase the protection of those who provide support, both in the formal and informal sector. See Kirstein Rummery, "A comparative analysis of personalisation: balancing an ethic of care with user empowerment", *Ethics* and Social Welfare, vol. 5, No. 2 (2011), pp. 138-152.

hiding persons with disabilities at home, and even attacks against them, such as in the case of persons with albinism. Consequently, many persons with disabilities fail to receive the necessary support and instead survive in dire conditions.

#### 5. Sustainability

67. The sustainability of support services and arrangements represents a major challenge in both developing and developed countries. Whereas in most low-income countries support is funded and provided mainly by families, charities and international non-governmental organizations, many high- and middle-income countries are reducing their direct public investment in support and are turning to non-profit organizations and community networks to take charge of these services. States usually invoke the scarcity of resources and economic difficulties to justify their failure to provide support services and arrangements to persons with disabilities.

68. States have an obligation to mobilize resources to their maximum availability to ensure access to support for persons with disabilities. Earmarked funds aimed at covering support, close collaboration and engagement with civil society and increasing efficiency can contribute to greater sustainability of support systems. Participatory budgeting processes, when they are inclusive of persons with disabilities, can also help to expand the allocation of public funds to support persons with disabilities. Social protection systems can also constitute a powerful strategy to facilitate access to support for persons with disabilities (see A/70/297, paras. 4-9).

69. States must refrain from adopting retrogressive measures that affect their obligation to ensure access to support for persons with disabilities. In times of crisis, more support is needed, rather than cuts (ibid., para. 85). Reduction and caps on direct payments, personal budgets and other benefits; stricter eligibility criteria; the elimination or reduction of subsidies and tax credits; and reduced expenditures on community support services, such as in-home services and personal assistance, affect the right to live independently and be included in the community and to an adequate standard of living. States should ensure sufficient resources for individual funds to enable persons with disabilities to access appropriate support.

#### 6. International cooperation

70. International cooperation can play a crucial role in the implementation of support systems. Donor countries and international organizations should consider increasing funding for the design and development of sustainable national support systems and securing the necessary funds to implement development aid inclusive of the support arrangements required by persons with disabilities. For example, when funding national education systems, donors should take into account the obligation to provide support to children and adolescents with disabilities within the general education system to facilitate their effective education.

71. International cooperation must be consistent with the human rights of persons with disabilities and provided in a sustainable and culturally appropriate manner. To this end, international assistance should not support practices contrary to the human rights-based approach to disability. International organizations, non-profit organizations, charities and other organizations operating in national contexts should refrain from implementing projects that are not sustainable or that violate the rights of persons with disabilities, such as "care homes" and special schools.

72. The United Nations, including all its programmes, funds and specialized agencies, should increase the awareness and expertise of its staff on the implementation of support

systems to be able to cooperate more effectively with States, including through technical guidance, information and capacity-building.

#### 7. Accountability and monitoring

73. States must monitor effectively the access of persons with disabilities to appropriate support. For that purpose, States should build, within their national legal and policy frameworks, clear accountability mechanisms, with indicators and benchmarks for measuring the accountability of State authorities. The governmental focal points and coordination mechanisms for the implementation of the Convention on the Rights of Persons with Disabilities, as required by its article 33 (1), should be considered as the mechanisms for overseeing implementation. To prevent the occurrence of all forms of exploitation, violence and abuse in the provision of support, States must ensure independent monitoring of all the facilities and programmes that provide services to persons with disabilities as well as the establishment of appropriate and effective safeguards.

74. Persons with disabilities should have access to effective judicial or other appropriate remedies when States fail to meet their obligation to ensure access. Similarly, States must guarantee that all persons with disabilities who have experienced any form of exploitation, violence or abuse in the context of support received have access to justice and effective remedies. These remedies should include adequate reparations, including restitution, compensation, satisfaction and guarantees of non-repetition, as appropriate. National human rights institutions and independent mechanisms to promote, protect and monitor the implementation of the Convention should be mandated to carry out inquiries and investigations (art. 33 (2)) as well as provide assistance to persons with disabilities in accessing legal remedies.

## B. Obligations related to specific types of support

75. There is a diversity of forms of support services and arrangements for persons with disabilities. These include, but are not limited to, the different types of support measures described in the following paragraphs. While the classification is useful for identifying specific obligations and particularities, in practice most forms of support overlap in significant ways.

#### 1. Decision-making

76. Some persons with disabilities may want support to make decisions, hence to exercise their legal capacity. The Convention on the Rights of Persons with Disabilities explicitly recognizes that States have an obligation to provide persons with disabilities with access to support in the exercise of their legal capacity (art. 12 (3)). States must replace regimes of substitute decision-making with regimes of supported decision-making that respect the rights, will and preferences of persons with disabilities, such as support agreements, peer support groups, self-advocacy support and advance directives, among others. In its general comment No. 1 (2014) on equal recognition before the law, the Committee on the Rights of Persons with Disabilities provides guidance on how to ensure access to support in decision-making.

77. Since the adoption of the Convention, it is encouraging to note that many countries, including Argentina, Costa Rica, Czechia and Ireland, have revised their legal frameworks to recognize the right of persons with disabilities to access support to exercise legal capacity. In order to uphold a real paradigm shift, the implementation of supported decision-making systems must be accompanied by the abolishment of all substitute decision-making regimes.

#### 2. Communication

78. Some persons with disabilities may need support to overcome barriers that limit their ability to communicate and be understood. While the provision of accessible information and communication can reduce the need for support of persons with disabilities, many of them may still require support with communication. The situation of children with disabilities with limited or no speech capacity is particularly alarming, since their communication needs are usually neglected within the education system and in their communities, despite the existence of low-cost resources and materials. In this regard, States must take all appropriate measures to ensure that persons with disabilities, whatever their communication skills or type of impairment, can access the communication support they need through different forms of communication, as defined in article 2 of the Convention. This includes professional sign language interpretation, display of text, Braille, tactile communication, large print and accessible multimedia, as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means and formats of communication, including accessible information and communications technology.

79. Contributions to the present report illustrate different ways in which States provide support in the area of communication. For example, Cuba has certified 455 sign language interpreters who work in coordination with the National Association of the Deaf, the Ministry of Education and the Ministry of Higher Education, while Colombia has set up an online relay centre that facilitates the communication of deaf persons with anyone in the country through interpretation services. Deaf persons can also learn to use information and communications technology and be trained as interpreters.

#### 3. Mobility

80. A variety of persons with disabilities may require support to ensure their personal mobility with the greatest possible independence, including through mobility aids, devices and assistive technologies and forms of live assistance and intermediaries. In particular, persons with disabilities who live in rural and remote areas face significant challenges in accessing different forms of mobility support, which significantly limits their access to such basic services as health care and education.

81. Article 20 of the Convention requires States to facilitate the personal mobility of persons with disabilities in the manner and at the time of their choice, facilitate their access to assistive technologies and forms of mobility assistance and intermediaries, and provide training in mobility skills to persons with disabilities and staff working with them. It also encourages entities that produce mobility aids, devices and assistive technologies to take into account all aspects of mobility for persons with disabilities. The Special Rapporteur's thematic report on disability-inclusive policies (A/71/314) provides guidance to States on how to establish a policy framework that ensures access to assistive devices and technologies to persons with disabilities.

#### 4. Personal assistance

82. States have an obligation to ensure that persons with disabilities have access to the personal assistance necessary to support living and inclusion in the community, as provided by article 19 (b) of the Convention. Personal assistance encompasses a broad range of arrangements designed to assist a person with disabilities to perform daily activities, including getting up, bathing, dressing, getting ready for work, going out, cooking, cleaning and shopping. Persons with disabilities may require personal assistance for different lengths of time, from full time to a few hours a week, depending on their individual needs.

83. Independent living centres and representative organizations of persons with disabilities can play an important role in ensuring access to personal assistance. They can

disseminate information about the obligations of States and service providers, provide assistance in recruitment and budgeting, facilitate support groups and train those who wish to become assistants. They can also foster participatory processes for developing ethical principles and practice guidance. While personal assistants may not require specialized preparation, States should ensure they have adequate training in order to provide safe and quality support. For example, in the Republic of Korea, the Act on Personal Assistance Services for Persons with Disabilities specifies the qualifications, human resources and service providers relating to the provision of personal assistance.

#### 5. Living independently in the community

84. Under article 19 (2) of the Convention States are required to ensure access to a range of in-home, residential and other community support services for persons with disabilities. The ultimate aim of this provision is to support living and inclusion in the community, and to prevent isolation or segregation from the community. Persons with disabilities should have the opportunity to choose where and with whom to live, and not be obliged to live in a particular living arrangement such as psychiatric hospitals, nursing homes or other institutions. Moreover, States have an obligation to facilitate the transition of persons with disabilities from those facilities to home- and community-based residences and to provide urgent aid to persons with disabilities who are at risk of becoming homeless or being institutionalized.

85. Persons with psychosocial disabilities can benefit significantly from community support services. Peer support, for example, is an effective tool to support people experiencing severe emotional distress and prevent coercion in mental health services, as well as providing them with community-based support. In the case of persons with albinism, the provision of adequate housing and community support are essential protection measures to prevent abductions and attacks. Contributions to the present report show a growing interest on the part of States in community support. In Chile, for example, the State created a programme that funds civil society organizations to provide support services for independent living. During its first year of existence, 40 projects were financed in 13 of the 15 regions of the country.

86. States should close all group living arrangement for persons with disabilities of any size that do not allow residents to participate in the community on an equal basis with others. In particular, States must establish an immediate moratorium on new admissions to institutions and set up a policy framework to guide deinstitutionalization processes. This framework should include the adoption of a plan of action with clear timelines and concrete benchmarks, the redistribution of public funds from institutions to community services and the development of adequate community support for persons with disabilities such as housing assistance, home support, peer support and respite services. Evidence shows that, when adequately planned and resourced, community services are much more cost-effective than institutional care.<sup>20</sup>

#### 6. General services

87. General services, such as education, employment, justice and health, as well as other community services and social protection programmes, must consider the provision of support to persons with disabilities. Similarly, programmes to end domestic violence should include appropriate forms of gender- and age-sensitive assistance and support for girls and women with disabilities. States should budget and plan for such measures when designing

<sup>&</sup>lt;sup>20</sup> WHO and World Bank, World Report on Disability, p. 149.

policies and programmes to ensure that support for persons with disabilities is available from the start.

88. Consideration of persons with disabilities in national policies on adequate housing is essential to ensure community participation. In the Republic of Moldova, as part of the process of deinstitutionalization of persons with intellectual and psychosocial disabilities, the Government has introduced protected housing arrangements, where persons with disabilities are provided social housing and the support necessary for living independently in the community (see A/HRC/31/62/Add.2, para. 46).

89. Partnerships and alliances with non-profit organizations, academia and organizations of persons with disabilities can increase the capacity of general services to ensure access to support for persons with disabilities. For example, in South Africa, the University of Pretoria has provided research and training to different national authorities on how to ensure access to justice for persons with disabilities through augmentative and alternative communication support as well as direct services to that end.

# VI. Conclusions and recommendations

90. Guaranteeing access to support for persons with disabilities is not only a human rights obligation for States, but also an essential condition to ensure that no one is left behind in the implementation of the 2030 Agenda for Sustainable Development. Even if we advance in the areas of accessibility and non-discrimination, persons with disabilities will always need to have access to support. In fact, without appropriate support to carry out daily activities and participate in society, many persons with disabilities will not be able to exercise their human rights and fundamental freedoms, and will remain at risk of abuse and institutionalization. Support measures are vital to enable persons with disabilities to benefit from all policies and programmes and to live fully in the community on an equal basis with others. States should guarantee the full and equal enjoyment of human rights and fundamental freedoms of persons with disabilities in the provision of support.

91. The Special Rapporteur makes the following recommendations to States with the aim of assisting them in developing and implementing support arrangements and services for persons with disabilities. States should:

(a) Recognize in domestic legislation the obligation to provide access to different forms of support to persons with disabilities to carry out daily activities and participate in society;

(b) Implement a comprehensive system across different sectors and levels of government to ensure that persons with disabilities have access to community-based support services and arrangements that are available, accessible, adequate and affordable;

(c) Guarantee that all national policies and programmes take into account and allocate budgets for support services and arrangements for persons with disabilities;

(d) Ensure that social protection systems include the provision of access to different forms of support for persons with disabilities, including the provision of free access to essential assistive technologies, as part of the State's health coverage and social protection schemes;

(e) Ensure access by persons with disabilities to appropriate support in their communities, regardless of the type of service delivery arrangement. When available,

individual funding should enable persons with disabilities to effectively access support of appropriate quality;

(f) Design support systems so that they enable direct choice and control to be exercised by persons with disabilities;

(g) Ensure that eligibility criteria for accessing support do not discriminate against persons with disabilities on any grounds and that disability assessments, when established, take into consideration the barriers affecting a person's participation and not only her or his impairment;

(h) Adopt a plan of action with clear timelines and concrete benchmarks for the deinstitutionalization of persons with disabilities, including a moratorium on new admissions to institutions;

(i) Ensure appropriate safeguards at and independent monitoring of all public and private facilities and programmes providing support to persons with disabilities;

(j) Actively involve and consult with persons with disabilities and their representative organizations in all decision-making processes related to the provision of access to support;

(k) Progressively increase the allocation of funds to ensure access to support for persons with disabilities and refrain from adopting any retrogressive measures that directly or indirectly affect the access of persons with disabilities to support;

(1) Encourage international cooperation actors, including international nonprofit organizations, to carry out research on and provide funding and technical assistance for the provision of support for persons with disabilities, and refrain from implementing or supporting projects that contravene the Convention on the Rights of Persons with Disabilities.

92. The Special Rapporteur also recommends that the United Nations, including all its programmes, funds and specialized agencies, adequately consider the obligation to ensure access to support for persons with disabilities in all its work, including when assisting States in the implementation of mainstream policies and programmes, and to increase its capacities to provide technical guidance in this regard.