A/HRC/34/58

Support Services
to ensure the inclusion of persons with disabilities

UN Special Rapporteur
on the rights of persons with disabilities

Figure 1Photo by Christian Tasso. text: Support services to ensure the inclusion of persons with disabilities.

Contents

What is support?

Giving and receiving support is part of the human experience for all of us. All communities have ways of providing help or assistance in both formal and informal ways, which are naturally integrated into society. Some persons with disabilities require specific forms of support for daily activities and social participation. These range from activities like bathing, dressing and eating, to living independently, getting around and working. Governments have a key role to play in providing support to persons with disabilities. In this report, we set out principles and guidance for how this can be done in a rights-based way.

Support for persons with disabilities is particularly relevant in:

- Decision-making and exercising legal capacity.
- Communication through alternative modes, means and formats.
- Personal mobility and transportation.
- Performing daily activities and personal assistance.
- Living independently in the community.
- Access to general services, such as education, justice, and health, among others.

Why is support important?

Persons with disabilities make up 15% of the world population. Currently, most of them rely on informal means of support, from families and personal networks, which are insufficient to meet their needs.

The lack of options and appropriate support services puts persons with disabilities at risk. It has negative consequences on their ability to choose for themselves and have control of the way they live. Lack of formal support systems puts more pressure on persons with disabilities, their family and communities. It also increases the risk of institutionalization and segregation. A better understanding and more commitment by policymakers and all other stakeholders are required to meet the support needs of persons with disabilities.

Context of Support

Support should move away from traditional ideas of care and caregiving that see persons with disabilities as passive recipients of assistance. Often this style of providing care has led to segregation and disempowerment of persons with disabilities. Support should be based on persons with disabilities having choice and control over their own lives. Independent living is not based on self-sufficiency, but rather on having this choice and control over one's own life.

Accessibility and support are related, but the responsibilities lie with different actors. Accessibility is related to the physical environment, transportation, information and communications. Some of these areas overlap with those where support may be needed. The difference is that support is linked to assisting individuals, whereas accessibility is about environmental change. Like accessibility, support is required under the United Nation's Convention for the Rights of Persons with Disabilities.

Provision of support should consider the diversity of persons with disabilities. Services should respond to the needs, and respect the rights of, women and girls with disabilities. Children with disabilities and their families are in particular need of support services in education and health. Older persons with disabilities may need support through personal assistance, assisted living arrangements and palliative care. Policies and programmes for support should take into account multiple discrimination as well as the specific needs of different disabilities.

Elements of good support

1. **Availability.** Appropriate support services should be available to all persons with disabilities in sufficient quantity, through whichever means they are provided.

2. **Accessibility.** There should be no barriers or discrimination in the access to services for all persons with disabilities. Among its dimensions, accessibility includes affordability and geographic reach.

3. **Acceptability.** All programmes should be provided on a voluntary basis and respect the rights and dignity of persons with disabilities.

4. **Choice and control.** Persons with disabilities should have the opportunity to plan and direct their own support. Existing services often do not comply with this standard.

<div style="border:1px solid">

Recommendations for Governments

A. **Take a national approach to providing support, ensuring resources and mainstreaming in all policies and programmes.**

B. **Provide quality community-based support services and phase out institutionalization.**

C. **Ensure participation, choice and control of persons with disabilities.**

D. **Ensure non-discrimination, monitoring and safeguards.**

E. **Develop international cooperation on support services.**

</div>

II. Introduction

This 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.

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 describes the activities she carried out in 2016 and contains 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, Ethiopia 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.

A. What is support?

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, which is at the basis of all our social networks. Everyone needs support from others at some stage in their life, if not throughout, to participate in society and live with dignity. Being recipients of support and supporters 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 the one required by persons with disabilities, are still marginal.[1]

> **Being recipients of support and supporters to others are roles we all share as part of our human experience.**

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

For most persons with disabilities, access to quality support is a necessary precondition to live and fully participate in the community, with 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 conducive to the realisation of the full spectrum of human rights and enables persons with disabilities to achieve their full potential, thus contributing to the overall wellbeing and diversity of the communities in which they live. Moreover, for many persons with disabilities, support represents an essential precondition to ensure their active and meaningful participation in society, while preserving their dignity, autonomy and independence.

The existence of social and environment barriers contributes significantly to create support needs. For example, persons with disabilities who live in inaccessible communities might require greater support than if they lived in accessible ones. Individual support needs also vary according to personal factors, including 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 participate in the community on an equal basis with others.

B. The importance of support

Persons with disabilities constitute 15 percent of the world population, approximately one billion people. Many of them require different forms of support, including for basic day-to-day activities, such as getting up, bathing, dressing, and eating.[2] The sustained aging of the global population, particularly in high-income countries, has also had a substantial impact in the demand for disability-related support, as older persons tend to be overrepresented in the disability community.[3] Other socio-political factors such as conflict and migration increase the demand for support, as support networks tend to fall apart in such situations.

---

[1] See Tom Shakespeare, *Help*, Birmingham, Venture Press, 2000.
[2] World Health Organization (WHO) and World Bank, *World Disability Report*, 2011, p. 29.
[3] Ibid, pp. 34-35.

Despite the rising demand, most persons with disabilities worldwide do not have their support needs met. Evidence indicates that in most developed and developing countries, the majority of persons with disabilities have limited access to support services.[4] There is a shortage of community support services for persons with disabilities requiring personal assistance. In many countries, only between 5 to 15 percent of those in need of assistive devices and technologies are able to obtain them. 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, such as in the areas of 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.

> The sustained aging of the global population increases demands for disability-related support, as older persons tend to be overrepresented in the disability community.

Regretfully, there is little public and political interest and 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.[5] Moreover, while in many high-income countries there are some forms of formal support for persons with disabilities, it 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.

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

The absence of appropriate support systems increases the risk of segregation and institutionalization. When families do not get the necessary support, there is a high pressure to place their family member 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 and the lack of support within the family put persons with disabilities at risk of suffering neglect, violence and abuse.

States should therefore adopt and implement policies and programmes on support that enable persons with disabilities to participate in decisions affecting their lives and to participate fully in the life of their communities. The protection and promotion of human rights of persons with

---

[4] Ibid, p. 139-140.
[5] WHO and World Bank, *World Disability Report*, 2011, pp. 144-147.

disabilities should be at the centre of these policy efforts, rather than focusing on charitable and medical approaches.

C. Rethinking care and assistance

For a long time, responses to 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 been historically 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 source of '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.

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 into institutions, the loss of control of their lives (under the power of care providers), and their ultimate objectification. Therefore, for many persons with disabilities the notion of care bears a heavy historical connotation associated with oppression and invalidation.[6]

The disability community has challenged the traditional concept of care from a social understanding of disability. The social model of disability draws its 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.

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 it takes into account the interdependency of human experiences and accepts the reliance on others as a fundamental aspect of it, thus moving away from narrow interpretations of independence that conflate it with self-sufficiency and self-reliance.[7] In this regard, support must ensure that persons with disabilities are able to have choice and control over their own lives, irrespective of their physical, sensory, mental

> **Support must ensure that persons with disabilities have choice and control over their own lives and views, rather than having to follow the views of those looking after their needs.**

and intellectual impairments, and over their own views, rather than having to follow the views of those looking after their needs.

At the same time, there is a need to recover the personal experience of impairment to adequately inform the support needs that persons with disabilities have to participate in society, which may have been rendered marginal in the disability-rights debate.[8] The acceptance of

---

[6] Teppo Kroger, *Care research and disability studies: Nothing in common?*, 2009, University of Jyväskylä, Finland, 29(3), pp. 398-420, see /www.sagepub.co.uk/.

[7] Jenny Morris, *Impairment and disability: Constructing an ethics of care that promote human rights*, 2001, Hypatia, 16(4), pp. 1-16.

[8] Ibid.

persons with disabilities as part of human diversity should influence the way societies perceive and respond to individuals' support requirements.

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.

III. Support to persons with disabilities in international human rights law

A. State obligation to ensure access to support

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 to promote and protect 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 (article 23).

Regional human rights instruments have further recognized support to persons with disabilities. The Revised European Charter 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 (article 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 (article 18). While the African Charter on Human and People's Rights establishes a general obligation to facilitate "special protection measures" for persons with disabilities (article 18 paras 2 and 4), the current draft Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities explicitly recognizes support as a necessary measure to enable the realisation of the rights of persons with disabilities (articles 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 (2013-2022) considers community inclusion and support as part of its policy direction. Its goal 4 on strengthening social protection includes a target on enhancing services and programmes, including for personal assistance and peer counseling, that supports persons with disabilities in living independently in the community.

> Ensuring access to support must be distinguished from the obligation to provide accessibility: accessibility is related to the physical environment, transportation, information and communications, while support is an obligation linked to the individual.

The absence of the explicit mention of support measures for persons with disabilities in the core international human rights treaties does not imply that the obligation did not exist before 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, for example, has recognized that support and 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.

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 realisation 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 *de facto* exercise their human rights on an equal basis with others and, therefore, to live with dignity and autonomy in the community.

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, what is sought 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, both are complementary obligations enabling persons with disabilities to live independently and to participate fully in all aspects of life.

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 not imposing 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

The Convention on the Rights of Persons with Disabilities firmly grounds support in a complex substantive equality model that takes into account the diversity of the human experience. 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.

> States are called by the CRPD to provide support to persons with disabilities in different aspects of life. Support to exercise legal capacity is one among the specific forms of support that are subject to immediate realization.

The Convention does not define support, but refers to it in several of its provisions. According the Committee on the Rights to Persons with Disabilities, "support" is a broad term that encompasses both informal and formal support arrangements, of varying types and intensity. All forms of support should be provided while respecting the general principles of the Convention (article 3).

Support is a crosscutting 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 (article 4(1)(a)). States must also undertake or promote research and development of, and promote the availability and use of, devices and assistive technologies (article 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 (article 4(1)(h)).

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

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. More specifically, in its general comment no. 1 on article 12 (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.

Many forms of support, such as the support required to exercise legal capacity, are subject to immediate realization. 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.

The Convention challenges traditional approaches of care and has the potential to redress its legacy of disempowerment and paternalism. Furthermore, the notion of support in the Convention 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.[9] These innovations can and should be translated across to all existing human rights instruments.

C.   Multiple and intersectional approach to support

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 or other status. States need to address the specific support needs of individuals throughout their lifecycle.

---

[9] Gerard Quinn and Anna Arstein-Kerslake, *Restoring the 'human' in 'human rights': personhood and doctrinal innovation in the UN disability convention*, The Cambridge Companion to Human Rights Law (Cambridge University Press, 2012), pp. 36-55.

1. Women and girls with disabilities

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. Oftentimes male staff are assigned to provide assistance, which may not fulfil 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 interfering 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.

> The design and implementation of support systems must consider systemic and multiple discrimination faced by women and girls with disabilities, by children and older people as well as by persons with disabilities from disadvantaged communities.

2. Children with disabilities

Children with disabilities and their families require different types of support services, especially in the education and health sectors. Those 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 available at all, which resulted in widespread segregation, institutionalization and neglect. Instead, States must organize support services and measures that foster their wellbeing, and enable them to realize their full potential. Families need help to understand disability in a positive way and to know how to support their children to be autonomous and independent. Limited understandings 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

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 dementia, which is increasing the risk of institutionalization among older persons with disabilities. Importantly, older women with disabilities are more likely to be institutionalized due to the different life expectancies between men and women. The provision of in-home support services, including personal assistance and help with household chores has the potential to avoid such practices and to improve the quality of life of older persons by enabling them to stay at home. [10]

4. Disadvantaged groups

Persons with disabilities belonging to historically discriminated or disadvantaged groups (such as indigenous peoples, ethnic minorities and persons living with HIV/AIDS) are disproportionately

---

[10] A/HRC/30/43, para. 72.

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 racial and cultural minorities, and experiencing coercion and institutionalization.[11] 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.

Policies and programmes to ensure access to support should respond to the heterogeneous needs of the diversity of the disability community, such as 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 be 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 actually exclude others.

D.   Unpacking the obligation to provide access to support

Following the standards developed by the Committee on Economic, Social and Cultural Rights,[12] the Special Rapporteur has identified four interrelated and essential elements of the obligation to provide support to persons with disabilities. These elements can vary according to different conditions and types of support arrangements.

1.   Availability

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.[13]

Support systems should ensure the availability of a an adequate number of functioning programmes and services to provide the fullest possible range of support to the diversity 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, 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.

---

[11] Ruchika Gajwani et al, *Ethnicity and detention: Are black and minority ethnic (BME) groups disproportionately detained under the Mental Health Act 2007?* (2016), Social Psychiatry and Psychiatric Epidemiology, 51(5), pp. 703–711.

[12] E/C.12/1999/10, E/C.12/2000/4 and E/C.12/GC/19.

[13] See A/HRC/28/37, paras. 35-36.

2. Accessibility[14]

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 diversity of the 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 be also ensured.

Support must be affordable for all persons with disabilities. Support services represent a significant cost for persons with disabilities, preventing them from getting 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. Qualifying conditions for accessing support must be reasonable, proportionate and transparent, and should not be limited to those protected by social insurance schemes.[15] Additionally, States should include the provision of essential assistive devices and technologies in the coverage of national health insurance and/or social protection schemes, based on the World Health Organization priority assistive products list.[16] States should also consider waiving import duties and taxes on assistive devices and technologies that are not produced domestically.[17]

3. Acceptability

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.

States must ensure that 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, and set up monitoring mechanisms to assess the adequacy of support services and arrangements, and prevent abuses and violence in its provision.

4. Choice and control

States must design support services and arrangements in a way 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 even overridden by professionals and family

---

[14] 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.

[15] E/C.12/GC/19, para. 24.

[16] A/70/297, para. 9.

[17] Ibid, para. 48.

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, directly impacts 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.

> ## States must guarantee to persons with disabilities the opportunity to plan and direct their own support. Allowing professionals or family members to override their decisions denies their legal capacity and is a human rights violation.

Individual funding is a suitable way to ensure choice and control by persons with disabilities. These personalization schemes allow persons with disabilities to directly hire support, 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 the will receive the adequate support. The implementation of these schemes, however, should not 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.

IV. Ensuring access to support for persons with disabilities

A. General State obligations

1. Legal and policy frameworks

States must establish legal and policy frameworks ensuring that support services and arrangements, including assistive technologies, are available, accessible, adequate and affordable. Many national legal frameworks do not contemplate support services at all, or only for the exercise of certain rights (e.g., inclusive education or mobility). Moreover, when legislation considers these services, often States 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.

> ## Legal framework should be based on human rights principles, consider equality between men and women, and the rights of most disadvantaged and marginalized groups.

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.

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 was 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 or control over support services and arrangements. States should enhance their internal coordination mechanisms to address support needs in a comprehensive manner and ensure that regional and local authorities receive adequate budget and effectively implement and monitor the provision of support services. 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

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 been traditionally the main source of formal support, either through their centralized healthcare or social protection systems, or through local authorities. In many cases, States fund and contract non-profit organizations and private organizations to carry out those interventions. In low-income countries, charities and international non-governmental organizations are the main providers of formal support, often with limited sustainability and low quality standards. 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 organisations and private actors. In such cases, States must adopt a comprehensive regulatory and monitoring framework that involve a due diligence obligation.

In 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 approach enables stakeholders — family, friends, neighbors, 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 community 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 of 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.

> **Community participation improves service delivery, enabling cost-effective policy responses in countries with limited resources.**

In the last 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 the re-familiarization and feminization of support.[18] 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. Supports to families should never be in place of supports to individuals.

3.   Participation and collaboration

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 closely consult 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 (article 4 (3)). My thematic study on the right of persons with disabilities to participate in decision-making provides specific guidance in this regard.

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 sub-national and operational level. 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, which facilitate support for decision-making and community living.

4.   Non-discrimination

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 that 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 my thematic study on the right of persons with disabilities to social protection (A/70/297).

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 perpetuate their isolation, forced treatment and institutionalization. State should not bundle access to support with such requirements, including accepting certain residential arrangements or undergoing medical treatment. Stigma and discrimination also impact negatively on the access to support services by persons with disabilities. Misconceptions about them often results in 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 survive instead in dire conditions.

---

[18] 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 Rummery, Kirstein, *A Comparative Analysis of Personalisation: Balancing an Ethic of Care with User Empowerment* (2011), Ethics and Social Welfare, 5(2), pp. 138-152.

5. Sustainability

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 mainly funded and provided by families, charities and international non-governmental organizations, many high- and middle-income countries are reducing their direct public investment in support and turn 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.

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. Processes of participatory budgeting, when they are inclusive of persons with disabilities, can also help to expand the allocation of public funds to support of persons with disabilities. Social protection systems can also constitute a powerful strategy to facilitate access to support for persons with disabilities.

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. Reduction and caps on direct payments, on 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

International cooperation can play a crucial role in the implementation of support systems. Donor countries and international organizations should consider increasing funding to design and develop 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.

International cooperation must be provided in a manner that is consistent with the human rights of persons with disabilities, and 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-profits, charities and others 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.

The United Nations, including all its programmes, funds and specialized agencies, should increase the awareness and expertise of its staff in relation to the implementation of support systems, so as to be able to cooperate more effectively with States, including through technical guidance, information, and capacity building.

7. Accountability and monitoring

States must monitor effectively the access of persons with to appropriate support. For that purpose, States should build, within their national legal and policy frameworks, clear accountability mechanisms, with indicators and benchmarks against which State authorities should be held responsible. The governmental focal points and coordination mechanisms for the implementation of the Convention on the Rights of Persons with Disabilities, as required by

article 33 (1) of the same, should be considered as the mechanisms for overseeing this implementation. To prevent the occurrence of all forms of exploitation, violence and abuse in the provision of support, States must ensure the independent monitoring of all the facilities and programmes providing services to persons with disabilities, as well as the establishment of appropriate and effective safeguards.

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 on the rights of persons with disabilities should be mandated to carry out inquiries and investigations (article 33 (2)), as well as providing assistance to persons with disabilities in accessing legal remedies.

B.   Obligations related to specific types of support

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

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 (article 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, advance directives, among others. In its general comment No. 1 (2014), the Committee on the Rights of Persons with Disabilities provides guidance on how to ensure access to support in decision-making.

> States must replace substitute decision-making with supported decision-making regimes, that respect the rights, will and preferences of persons with disabilities.

Since the adoption of the Convention on the rights of persons with disabilities, it is encouraging to note that many countries, including Argentina, Costa Rica, Czech Republic 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

Some persons with disabilities may need support to overcome communication 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 in 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 on the rights of persons with disabilities. This includes professional sign language interpretation, display of text, Braille, tactile communication, large print, 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 communication technology.

Contributions to this 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

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

Article 20 of the Convention on the rights of persons with disabilities 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. My thematic report on disability-inclusive policies 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

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 on the rights of persons with disabilities. 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 couple of hours a week, depending on their individual needs.

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 related to the provision of personal assistance.

5. Living independently in the community

Article 19 (2) of the Convention on the rights of persons with disabilities requires States 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 and 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.

> Persons with disabilities should have the right to choose where and with whom to live, and not be confined to psychiatric hospitals, nursing homes or other institutions.

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 for providing them 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 this report show a growing interest from States towards 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 out of the 15 regions of the country.

States should close all congregate living arrangement for persons with disabilities of any size, which 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 admission in 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.[19]

6. General services

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

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.

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

---

[19]   WHO and World Bank, *World Disability Report*, p. 149.

disabilities. For example, in South Africa, the University of Pretoria has provided research, training and direct services to different national authorities on how to ensure access to justice for persons with disabilities through augmentative and alternative communication support.

V. Conclusion and recommendations

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 fully live 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.

The Special Rapporteur makes the following **recommendations to States** to develop and implement support arrangements and services for persons with disabilities:

A. Take a national approach to providing support, ensuring resources and mainstreaming in all policies and programmes.
- Recognize the obligation to provide access to different forms of support to persons with disabilities to carry out daily activities and participate in society in domestic legislation;
- Guarantee that all national policies and programmes take into account and allocate budget for support services and arrangements for persons with disabilities;
- 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;
- 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;

B. Provide quality community-based support services and phase out institutionalization.
- Ensure that persons with disabilities have access to community-based support services and arrangements that are available, accessible, adequate and affordable;
- 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;
- Establish clear timelines and concrete benchmarks for the deinstitutionalization of persons with disabilities, and adopt a moratorium on new admissions to institutions;

C. Ensure participation, choice and control of persons with disabilities.
- Actively involve and consult with persons with disabilities and their representative organizations in all decision-making processes related to the provision of and access to support;

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

D. Ensure non-discrimination, monitoring and safeguards.

- Ensure that eligibility criteria for accessing support do not discriminate against persons with disabilities on any grounds.
- Ensure that disability assessments, when established, take into consideration the barriers affecting a person's participation and not only her or his impairment;
- Ensure appropriate safeguards at and independent monitoring of all public and private facilities and programmes providing support to persons with disabilities;

E. Develop international cooperation on support services.

Encourage international cooperation actors, including international governments and non-profit 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.

The United Nations, its programmes, funds and specialized agencies, should 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 should increase its capacities to provide technical guidance in this regard.

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.