 ****

**Regional Expert meeting on support services for persons with disabilities**

6-7 September 2016

Addis Ababa- Ethiopia

**Background note**

1. **Introduction**

Persons with disabilities constitute 15 percent of the world population, approximately one billion people. However, despite the recent commitment by State parties to the Convention on the Rights of Persons with Disabilities to promote and protect the human rights of all persons with disabilities (including those who require more intensive support), the majority continues to face barriers to their participation as equal members of society, are side-lined from decision-making processes, denied the opportunity to lead independent lives and be included in the community, or, in some cases, deprived of their right to make independent decisions. The unavailability of assistance and support, or the poor quality of existing services, partly explains this exclusion of persons with disabilities from their communities.

The obligation to provide support services to persons with disabilities is closely related to the realisation of their civil, cultural, economic, social, and political rights. In fact, under certain circumstances, access to support services is a necessary precondition to guarantee the full exercise and equal enjoyment of all human rights and fundamental freedoms. For instance, article 12 of the Convention explicitly recognizes that States have an obligation to provide persons with disabilities with access to support in the exercise of their legal capacity.

Support services are conducive to the realisation of the full spectrum of human rights and represent an essential precondition, for most persons with disabilities, to ensure that they can actively and meaningfully participate in society, while preserving their inherent dignity, autonomy and independence. Moreover, the provision of adequate support services also helps them valorise their full potential and thus contribute to the overall well-being and diversity of the communities in which they live.

Support services can cover a wide range of formal and informal interventions, including:

* support in decision-making;
* communication support, such as readers, sign language interpreters;
* mobility support, such as assistive technology, service animals;
* personal assistance;
* living arrangements services, such as housing, household care; and
* community services.

An individual’s need for support depends on environmental and personal determinants, and may differ across a person’s lifespan.

Despite their importance, evidence indicates that many persons with disabilities have limited access to support services. In many countries, support is not part of national legislation and policies, and when available, services are scare, underfunded and do not match people’s needs.[[1]](#footnote-1) Moreover, while formal organized support services and programmes for persons with disabilities are increasingly common in high-income countries, they are a fairly new concept in many low- and middle-income countries. In the latter countries, the majority of persons with disabilities rely on spontaneous support, primarily from their families and personal networks.

Even where support services are in place, the type of support provided may not be human rights compliant. For instance, services provided in the framework of a “charity model” tend to be guided by the thinking that persons with disabilities only need a decent shelter, adequate meals, comfort and personal contact. Likewise, services developed within a medical model framework often aim at reforming behaviour, “fixing” or “adjusting” an individual to a perceived standard of “normality”, or at protecting communities against individuals and marginalised groups that do not “seem to fit in”. Therefore, considerable work remains to be done to promote a rights-based approach to disability and support services.

1. **International normative framework**

The Convention on the Rights of Persons with Disabilities, the highest international standard to promote and protect the rights of persons with disabilities, is the first human rights treaty that clearly stipulates the obligation of States to deliver a wide range of support services to persons with disabilities, providing a comprehensive framework for its implementation.

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 should 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, as well as 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 27 (work and employment), article 28 (adequate standard of living and social protection) and article 30 (participation in cultural life, recreation, leisure and sport).

Moreover, the equality model enshrined in the Convention, which highlights the interaction between the individual and the social context, highlights the importance of adopting all appropriate measures to support the full and effective participation of persons with disabilities in society. Therefore, the obligation to provide the necessary and appropriate support to persons with disabilities is a precondition for achieving equality in practice.

In many of its concluding observations, the Committee on the Rights of Persons with Disabilities has called upon States to provide support to persons with disabilities in different aspects of life.[[2]](#footnote-2) 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.[[3]](#footnote-3) Thus, the need to ensure the choice and control of persons with disabilities over the different types and levels of support they may need.

Other United Nations treaty bodies have also highlighted the importance of proving support to persons with disabilities. The Committee on Economic, Social and Cultural Rights, for example, has recognized that support services 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.[[4]](#footnote-4) Similarly, the Committee on the Rights of the Child urged States parties to the Convention on the Rights of the Child to recognize assistance to children with disabilities as a matter of high priority and to invest to the maximum extent of available resources in the elimination of discrimination against children with disabilities and towards their maximum inclusion in society.[[5]](#footnote-5)

Support to persons with disabilities has been further recognized in regional human rights instrument. Article 18 of the African Charter on Human and People’s Rights recognizes that States have an obligation to support families as well as facilitate special protection measures in keeping up with the physical and moral needs of persons with disabilities.[[6]](#footnote-6) The draft Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Persons with Disabilities also explicitly recognizes support as necessary measure to enable the realisation of the rights of persons with disabilities.[[7]](#footnote-7) In the European context, article 15 of 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.

In her thematic report on social protection, the UN Special Rapporteur on the rights of persons with disabilities has stressed that social protection systems can constitute a powerful strategy to facilitate access to support services for persons with disabilities.[[8]](#footnote-8) More recently, in her upcoming report to the General Assembly on disability-inclusive policies,[[9]](#footnote-9) the Special Rapporteur recommended States to establish a policy framework to ensure access of persons with disabilities to assistive technologies and support services that are available, accessible, adequate and affordable and within a community-based approach. The Special Rapporteur particularly stressed the need to adopt guidelines and criteria to regulate the delivery of assistance and support services, including standards for training and certification, as well as the need to ensure that services are designed in a way that they enable direct choice and control of users over services providers, including the way in which support is provided.

1. **Challenges in law and practice regarding the provision of support to persons with disabilities**

Access to appropriate support is extremely limited for persons with disabilities worldwide. The majority of persons with disabilities in both developed and developing countries do not have their needs for assistance met in everyday activities.[[10]](#footnote-10) Moreover, in many countries only 5 to 15 percent of those in need of assistive devices and technologies are able to obtain them.[[11]](#footnote-11) While all persons with disabilities face different challenges in accessing support, those with high-support needs, psychosocial disabilities, and intellectual disabilities are disproportionately affected by the lack of appropriate support services.

Several factors impede access to support services by persons with disabilities.

1. The legal and policy framework in many countries does not contemplate support services for the exercise of certain rights (e.g., equality before the law, live independently in the community) or simply does not uphold these rights. Moreover, when legislation considers these services, often States are yet to adopt appropriate policies and programmes to ensure implementation. For instance, if having access to support services is considered as an intrinsic part of the right to inclusive education, then this right should be entrenched in national laws. The State should therefore spell out what it means specifically, in policy terms, to ensure the equal enjoyment of the right to education for persons with disabilities, including the appropriate institutional arrangements for the delivery of services that correspond to the variety and complexity of support needs. Moreover, a human rights approach to support services presupposes and requires State accountability.
2. Practices that are non-compliant with the Convention represent a great impediment. Many States continue to rely on institutional and residential care, with support services being predominantly provided in those settings.[[12]](#footnote-12) Furthermore, the existence of guardianship and other regimes for substitute decision-making present great challenges for persons with intellectual and psychosocial disabilities in accessing support services. Such practices not only deprive individuals of the possibility to choose their supports, but also contribute to perpetuate their isolation, forced treatment and institutionalization.
3. Most countries also rely excessively on informal support. While informal care or naturally occurring community support can be efficient, cost effective and promote inclusive societies,[[13]](#footnote-13) to rely exclusively on informal support networks can have adverse consequences on the lives of families and friends of persons with disabilities – including stress, reduced employment opportunities, and excessive demand on women and children[[14]](#footnote-14) – and on the privacy and independence of persons with disabilities themselves. Consequently, informal support is not a reliable, consistent or sustainable solution in the long term.
4. The lack of a community-based approach to the implementation of services poses another challenge. Relevant services are rarely provided in the community where the person lives or are culturally relevant. Moreover, often persons with disabilities do not participate in the decision-making processes related to the design and provision of these services. Further, existing social networks and community resources are not recognized as partners for the optimal and efficient delivery of services.
5. Existing services are often not designed to enable the direct choice and control by persons with disabilities. An individual’s choice is often limited due the lack of options of service providers. In addition, in many countries a user’s decision can be overridden by a doctor’s decision. When people are left without a choice, in practice they have no control over support services.
6. Discriminatory targeting and eligibility criteria can also impact negatively on the access to support. In many countries, including in low- and middle-income countries, a medical assessment is the basic criteria used for accessing services, and the “severity” of the impairment determines the beneficiaries of support and assistance. Such narrow scope often fails to meet the individual needs of persons with disabilities and the human rights-based approach to disability. Moreover, in some countries, groups such as persons with intellectual and psychosocial disabilities are expressly excluded from schemes that promote autonomy and independence.
7. The sustainability of services poses another challenge, especially in developing countries where support is mainly funded and provided by charities and international non-governmental organizations. This is the case of many community-based rehabilitation projects and “care homes” and special schools established to support children with disabilities, in most cases against their best interest.
8. Finally, stigma and discrimination also impacts negatively on the access to support services by persons with disabilities. Misconceptions about them contributes to hiding persons with disabilities at home, and even attacks against them, such as in the case of persons with albinism. [[15]](#footnote-15) As a result, many persons with disabilities fail to receive the necessary support and instead survive in dire conditions.

**IV. Questions for consideration**

* What barriers inhibit access to support services in Africa?
* What are the main challenges and gaps in designing and implementing effective support systems in Africa?
* What approach does your country follow (charity, medical, or human rights-based approach) to give direction to the service policies?
* How to develop adequate support services in situations of competing interests, scarce resources and insufficient funding?
* Are there any good practices or lessons, at either the local or national level, in the design and implementation of effective support systems in Africa? How can these practices be scaled up?
* What concrete measures should States, UN agencies, civil society and academic institutions take to facilitate and ensure the establishment of effective support systems in Africa?
1. WHO and World Bank, World Report on Disability, pp. 144-147. [↑](#footnote-ref-1)
2. See, for example, CRPD/C/DEU/CO/1, CRPD/C/SWE/CO/1, CRPD/C/AUT/CO/1, and CRPD/C/BEL/CO/1. [↑](#footnote-ref-2)
3. CRPD/C/GC/1, para. 18. [↑](#footnote-ref-3)
4. E/1995/22, para. 33. [↑](#footnote-ref-4)
5. CRC/C/GC/9, para 14(a). [↑](#footnote-ref-5)
6. Article 18(2) and (4). [↑](#footnote-ref-6)
7. Articles 2(h), 8, 10, 12, 13, 14, 16, 17, 20, 23, 25 and 26. [↑](#footnote-ref-7)
8. A/70/297, para. 9. [↑](#footnote-ref-8)
9. A/71/314, available as of October 2016. [↑](#footnote-ref-9)
10. WHO and World Bank, World Report on Disability, p. 139-140. [↑](#footnote-ref-10)
11. See: <http://www.who.int/disabilities/technology/activities/en/> [↑](#footnote-ref-11)
12. See, for instance, CRPD/C/AUS/CO/1, CRPD/C/CRI/CO/1, CRPD/C/AZE/CO/1, CRPD/C/KOR/CO/1, CRPD/C/LTU/CO/1. [↑](#footnote-ref-12)
13. OHCHR, Thematic study on the right of persons with disabilities to live independently and be included in the community, A/HRC/28/37, para. 35. [↑](#footnote-ref-13)
14. WHO and World Bank, World Report on Disability, p.142. [↑](#footnote-ref-14)
15. See A/HRC/31/63, paras. 14-44. [↑](#footnote-ref-15)