**Submission from the** [**International Disability and Development Consortium (IDDC)**](https://www.iddcconsortium.net/) **to the OHCHR Call for Input: Human Rights Council resolution 54/6 on the centrality of care and support from a human rights perspective (11th April 2024; for further information, contact: Sarah Collinson:** **scollinson@sightsavers.org****)**

1. **In your country, regional or at the global level, how are the following rights recognized and protected under national, regional and/or international law?**

- Under CRPD article 19, States Parties recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

- States Parties to the CRPD also have the obligation to ensure that all persons with disabilities have access to the range of community support services they require to participate in society, with dignity and autonomy (articles 9, 12, 14, 19(b), 20 and 28(2)).[[1]](#footnote-1)

- Under CRPD article 12 all persons with disabilities, including persons with mental health conditions and psychosocial disabilities, must be allowed to exercise legal capacity on an equal basis with others,[[2]](#footnote-2) prohibiting practices such as forced admission and treatment, guardianship, and other forms of substitute decision-making. Article 12 recognizes and promotes the concept of “supported decision-making,” wherein people are provided with access to support to make decisions and choices for themselves, including the support of people they. A person may need support to understand the information, assess options and potential consequences, and communicate their decisions to others.[[3]](#footnote-3)

- Under CRPD article 25, States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. General Comment 14 on the right to health confirms that the right to the highest attainable standard of health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life; in this regard, access to quality care and support services is essential to realise the right to health for many persons with disabilities. At the same time, improving the health-outcomes and functioning of a person can foster their autonomy, alleviating a need for caregiving.[[4]](#footnote-4)

- Under CRPD article 26, States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes; they shall also promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services, and they shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

Under article 23 of the Convention on the Rights of the Child, States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child. Such care shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.

Limited attention is given to the rights of older persons with disabilities in the CRPD or in other international human rights instruments. More broadly, the failure to clearly articulate how human rights apply in older age in international human rights law, including for older persons with disabilities, contributes to violations of the rights of older persons with disabilities, including in relation to the provision and receipt of care and support.

1. **Concrete policy or programmatic measures taken to promote and ensure the rights of caregivers and recipients of care and support in national care and support systems**

Support services such asinterpreters, care staff, support workers and personal assistants are fundamental to meeting basic needs and realising the human rights of persons with disabilities.[[5]](#footnote-5)

**Re. organizations of persons with disabilities (OPDs)**: OPDs can play an important role in providing community support, disseminating information, creating social and peer support networks; providing input into policy and planning (particularly re. social protection and linked services), delivering localised community-based support programmes; and providing a platform for persons with disabilities to engage with other key stakeholders in developing community support services. However, there is a need for further evidence on the role of OPDs in needs assessment and provision of, community support.[[6]](#footnote-6)

**Re. Universal health coverage (UHC):** UHC means that all people have access to the full range of quality health services they need, when and where they need them, without financial hardship. It covers the full continuum of essential health services, from health promotion to prevention, treatment, rehabilitation and palliative care. To deliver UHC, countries need to have strong, efficient and equitable health systems that are rooted in the communities they serve; primary health care (PHC) is fundamental to achieving this in order to ensure that all those needs are identified, prioritized and addressed in an integrated way; that there is a robust and equipped health and care workforce; and that environmental and socio-economic factors that affect health and well-being are addressed. For example, in low and middle-income countries (LMICs), [ReLAB-HS](https://sightsavershh-my.sharepoint.com/personal/scollinson_sightsavers_org/Documents/Human%20rights/HRC%20care%20and%20support%20systems%20for%20persons%20with%20disabilities/ReLAB-HS) is strengthening service delivery and supporting the integration of rehabilitation and AT into primary health care by training primary health care workers and community health workers to identify individuals who require rehabilitation and refer them to specialized services as needed. Primary care doctors and nurses are receiving additional training on the provision of basic rehabilitation and AT services. ReLAB-HS is also supporting the provision of simple assistive products at the primary care level (e.g., walking canes, crutches, and toilet and shower chairs) by working with local stakeholders to establish procurement mechanisms that will secure a steady supply of products.[[7]](#footnote-7)

**Re. Deinstitutionalisation and community-based support for persons with psychosocial disabilities**: Deinstitutionalisation and moving to community-based models of care is important for improving the quality of life for persons with psychosocial disabilities and protecting them from a wide range of human rights violations; it is also more cost–effective since it leads to better recovery outcomes.[[8]](#footnote-8) The WHO [QualityRights initiative](https://www.who.int/publications/i/item/who-qualityrights-guidance-and-training-tools) uses a multicomponent framework and strategies to promote mental health systems, services, and practices that prioritize respect for human rights, in line with the CRPD. As part of the this initiative, WHO has developed a comprehensive package of training and guidance materials which can be used to build capacity among mental health practitioners, people with psychosocial, intellectual and cognitive disabilities, people using mental health services, families, care partners and other supporters, NGOs, organizations of persons with disabilities and others on how to implement a human rights and recovery approach in the area of mental health in line with the CRPD and other international human rights standards.[[9]](#footnote-9) WHO [guidance on community mental health services](https://www.who.int/publications/i/item/9789240025707) published in 2021provides a detailed description of person-centred, human rights-based and recovery-oriented approaches in mental health, and showcases examples of good practice services around the world, including examples of integrated regional and national networks of community-based mental health services.[[10]](#footnote-10) Deinstitutionalisation and QualityRights continue to be implemented in in many countries across the world. In Buenos Aires, Argentina, for example, a mental health reform conducted between 2020 and 2021 resulted in the number of people in institutions falling from 1810 to 1391 through a halt to long-term admissions, transfer subsidies to support discharge and provision of housing support and community-based mental health services.[[11]](#footnote-11) Yet, while community-based services are widely regarded as the best approach for providing mental health care, most LMICs spend the majority of their scarce resources for mental health on managing people with mental health conditions in institutions,[[12]](#footnote-12) meaning that significant challenges remain in achieving rights-based mental health services in the community.[[13]](#footnote-13)

**Re. legal capacity and the right to decide:** Many persons with disabilities (particularly persons with psychosocial, cognitive or intellectual disabilities and older persons with disabilities) often experience challenges in exercising their right to legal capacity (enshrined in the CRPD). As part of its QualityRights initiative, WHO has developed a core training on legal capacity and the right to decide, as well as on supportive decision-making for countries in strengthening their policies. A human rights-based approach to supported decision-making can enable persons with disabilities to have access to trusted support persons of their choosing who can assist them in understanding the options available to them; help them to consider the advantages and disadvantages of particular choices and decisions and in communicating their will and preferences in relation to the support and services they receive. *(23, 24)*.[[14]](#footnote-14)

**Re. support for persons with intellectual disabilities**: Australia’s [National roadmap for improving the health of people with intellectual disability](https://www.health.gov.au/our-work/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability)represents a positive example of a national policy approach that aims to improve support for persons with intellectual disabilities. The roadmap aims to improve support for persons with intellectual disabilities, their families and carers, develop better models of care, support health and care workers to deliver quality care for persons with intellectual disabilities, and ensure that their needs are considered and met in emergency plans and responses. The roadmap was developed in close consultation with persons with intellectual disabilities, family members and carers.[[15]](#footnote-15)

**Re. support providers:** WHO has also developed ‘[iSupport for Dementia’](https://www.who.int/publications/i/item/9789241515863) as a knowledge and skills training programme for support providers of people living with dementia. This tool includes information on how to deal with behavioural changes such as memory loss and getting lost; how to provide support for a person’s everyday activities; or how to manage an individual’s own physical and mental health.[[16]](#footnote-16)

**Re. social protection and cash transfers**: The provision of non-contributory cash transfers can be seen as promoting community support for persons with disabilities in many countries. However, it is often not clear whether services linked to social protection programmes are accessible or appropriate for the self-identified support needs of persons with disabilities at community level. In Cambodia, the social protection system is underpinned by the involvement of organizations of persons with disabilities that use the social protection system as a vehicle for awareness-raising and inclusion campaigns. Cash transfers delivered on mobile platforms, such as those being developed in Gambia, Morocco, and Togo, have the potential to link beneficiaries easily to other sources of support. In other settings, more comprehensive social protection programmes are being developed which also incorporate a range of linked services. Thailand and Tunisia are developing personal assistance service schemes which have the potential to link individuals to social networks. In Vietnam, functioning-based protocols have been introduced as opposed to purely medical-based assessments, and applications for all forms of social protection are conducted at the local commune-level of People’s Committees, one of the lowest administrative units, and automatically link beneficiaries to local infrastructure, and a shift from a previous, more centralised, system. Research shows that this decentralised approach has been seen to improve coverage under disability-targeted programmes. In Cambodia, all persons who qualify for disability cash transfers automatically qualify for free health insurance. Many informal social protection initiatives, such as savings and loans groups, have been documented at the community level, in many countries, including in Uganda, although the precise role these play in providing material resources for community support among persons with disabilities merits further research.[[17]](#footnote-17)

1. **Main challenges faced at the national level in creating robust, resilient and gender-responsive, disability-inclusive and age-sensitive care and support systems with full respect for human rights.**

In LMICs, formal community support services for persons with disabilities are commonly under-developed, under-resourced, or do not exist, leaving persons with disabilities to rely primarily on family members to have their needs met; in most LMICs, families and informal carers are the only source of support for people with mental health conditions and psychosocial disabilities. Family members and caregivers may not have the necessary knowledge or skills; they too often take on these roles because there are few options for formal social support or trained support persons; this situation is further exacerbated in health emergencies when support services that are already limited become disrupted, further increasing the demands on families and other informal networks.[[18]](#footnote-18) The lack of choice and over-reliance on families and informal carers leads to loss of autonomy and privacy and infringement of rights for those receiving support, and to gender-based inequalities due to the feminization of caring responsibilities.[[19]](#footnote-19) The lack of support services is also a contributing factor to deteriorated health among family members and caregivers of persons with disabilities who may often develop mental health conditions such as depression or anxiety.[[20]](#footnote-20)

Consequently, persons with disabilities commonly have a range of unmet needs in relation to accessing formal services in the community, getting disability-related information, developing strategies for daily living, receiving support for childcare among parents of children with disabilities, accessing social support and other social resources, finding support for communication and socialisation, and being able to pursue employment opportunities in line with personal preferences.A major gap is in establishing linkages between persons with disabilities and available resources for care and support at community level.[[21]](#footnote-21)

The additional costs of living associated with disabilityrepresent an increase of around a third of the average income for those with moderate disability, and by more than 40% of an average income for those with significant disability. These include costs associated with health care, housing, transportation, personal assistance, and assistive products. Because of these higher costs, persons with disabilities experience *inter alia* reduced access to timely care and support, inability to pay for necessary assistive devices and increased reliance on support from family members. All these factors have an inevitable negative effect on their health resulting in increased mortality and morbidity, and decreased functioning, and significantly higher levels of poverty on average.[[22]](#footnote-22)

Where formal support structures exist, providers are commonly overworked, and services are stretched because of lack of funding and personnel with relevant training in community support work for persons with disabilities.[[23]](#footnote-23) Health and care workers may hold negative attitudes and beliefs about persons with disabilities which can lead to discriminatory practices, a lack of understanding and respect, and negative assumptions about the capacity of individuals with disabilities to engage in or make decisions about their own care and support, undermining their autonomy and independence. The lack of knowledge and skills or miscommunication of health and care workers is linked directly to several factors including hindered access to services and poor quality of care and support, leading to poor outcomes. In particular, negative and false beliefs concerning persons with psychosocial disabilities can lead to coercive practices including involuntary admission, treatment, seclusion and restraint. Examples exist of interventions to increase awareness, knowledge and skills on disability-related issues among health and care workers, but very little is known about their effectiveness; interventions are often developed and delivered by health practitioners without the involvement of persons with disabilities and may not reflect a rights-based approach that is aligned with the CRPD.[[24]](#footnote-24) Furthermore, there do not appear to be many programmes for caregivers that look at persons with disabilities’ participation as a key outcome.[[25]](#footnote-25)

A lack of formal community support services is also reflected in persistently high numbers of persons with disabilities living in institutions or special homes; in many countries, the health provision for individuals with psychosocial disabilities is still predominantly provided in psychiatric or social care institutions. Persons with disabilities frequently enter these institutions as children or adolescents, often against the wishes of their parents, and remain for their entire lives. Institutionalisation, particularly for persons with psychosocial, intellectual and cognitive disabilities, is associated with poor quality services, inadequate living conditions, loneliness and isolation, and exposure to a range of human rights violations including forced treatment and coercive practices, and psychological, physical, and sexual abuse or violence. Persons with autism or learning disabilities are often detained long-term in institutions or inpatient facilities located far from their families where they can be subjected to abusive, restrictive and inhumane practices.[[26]](#footnote-26) Inadequate provision of formal community support and housing can also lead to homelessness among persons with disabilities if deinstitutionalisation is not conducted through a regulated and systemic process with appropriate support and access to affordable accommodation.[[27]](#footnote-27)

Institutionalisation can also expose persons with disabilities to higher risks relating to infectious disease outbreaks and associated health emergencies, as reflected in elevated rates of mortality from COVID-19 among persons with disabilities in long-term care institutions, largely because of poor living conditions and the inability to ensure prevention measures. Where persons with disabilities are supported in the community, multisectoral preparedness and coordination mechanisms are also needed to reduce the additional risks for persons with disabilities in health emergencies resulting from response measures such as lockdowns and physical distancing requirements, and disruptions to care and support services.[[28]](#footnote-28)

1. This obligation has been further developed in the Committee on the Rights of Persons with Disabilities General Comments on articles 9, 12 and 19; see [Community 2030 Narrative (2023)](https://www.cbm.org/fileadmin/resourcespace/community_2030_narrative_artwork_accessible.pdf). [↑](#footnote-ref-1)
2. Committee on the Rights of Persons with Disabilities, General Comment No. 1, Article 12: Equal Recognition before the Law, UN Doc. CRPD/C/GC/1 (2014), discussed in Funk M, Bold ND (2020) [‘WHO's QualityRights Initiative: Transforming Services and Promoting Rights in Mental Health’](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7348459/#r4), Health Hum Rights. 2020 Jun;22(1):69-75. PMID: 32669790; PMCID: PMC7348459. [↑](#footnote-ref-2)
3. Funk and Bold (2020), [*op cit*.](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7348459/#r4), citing WHO (2019) [*Legal capacity and the right to decide: WHO QualityRights Core training; Mental health and social services*](https://iris.who.int/bitstream/handle/10665/329539/9789241516716-eng.pdf).  [↑](#footnote-ref-3)
4. <https://www.hi.org/sn_uploads/document/Rehabilitation-through-a-gender-lens-ReLABHS-Factsheet-2021.pdf> [↑](#footnote-ref-4)
5. World Health Organization (WHO) (2022) [*Global report on health equity for persons with disabilities*](https://www.who.int/publications/i/item/9789240063600), p.112. [↑](#footnote-ref-5)
6. Hunt X., Bradshaw M., Vogel S.L., Encalada A.V., Eksteen S., Schneider M., Chunga K., Swartz L. ‘[Community Support for Persons with Disabilities in Low- and Middle-Income Countries: A Scoping Review](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9319493/)’ (2022) Int J Environ Res Public Health. 2022 Jul 6;19(14):8269. doi: 10.3390/ijerph19148269. PMID: 35886121; PMCID: PMC9319493. [↑](#footnote-ref-6)
7. <https://relabhs.org/wp-content/uploads/2023/12/Article-ReLAB-HS-Rehabilitation-in-UHC_Final-Formatted-.pdf> [↑](#footnote-ref-7)
8. WHO (2022), [*op cit.*](https://www.who.int/publications/i/item/9789240063600), p.202. [↑](#footnote-ref-8)
9. Funk and Bold, [*op cit*](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7348459/#r4). [↑](#footnote-ref-9)
10. WHO (2021) [*Guidance on community mental health services: Promoting person-centred and rights-based approaches*](https://www.who.int/publications/i/item/9789240025707). [↑](#footnote-ref-10)
11. WHO (2022),[*op cit.*](https://www.who.int/publications/i/item/9789240063600), p.202, citing Ministerio de Salud de Argentina (2021) *Monitoreo de los procesos de atencion y de adecuacion de los hospitales neuropsiquiatricos publicos de la provincia de Buenos Aires*, Informe Año 2021. [↑](#footnote-ref-11)
12. WHO (2022),[*op cit.*](https://www.who.int/publications/i/item/9789240063600) , p.202. [↑](#footnote-ref-12)
13. Funk and Bold (2020), [*op cit*](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7348459/#r4) . See also: Mion ABZ, Ventura CAA. ‘The WHO QualityRights Initiative and its use worldwide: A literature review’, *International Journal of Social Psychiatry*. 2023;0(0). doi:[10.1177/00207640231207580](https://doi.org/10.1177/00207640231207580). [↑](#footnote-ref-13)
14. WHO (2019) ‘[Legal capacity and the right to decide: WHO QualityRights core training: mental health and social services: course guide’](https://iris.who.int/bitstream/handle/10665/329539/9789241516716-eng.pdf); and WHO (2019) ‘[Supported decision-making and advance planning. WHO QualityRights specialized training. Course guide](https://iris.who.int/handle/10665/329647).’; see also WHO (2022), [*op cit.*](https://www.who.int/publications/i/item/9789240063600), p.171. [↑](#footnote-ref-14)
15. Australian Government Department of Health and Aged Care (2021), [*National roadmap for improving the health of people with intellectual* disability](https://www.health.gov.au/our-work/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability); cited in WHO (2022) [*op cit*](https://www.who.int/publications/i/item/9789240063600)*.,* p.71. [↑](#footnote-ref-15)
16. WHO (2019) ‘[iSupport for Dementia: training and support manual for carers of people with dementia](https://www.who.int/publications/i/item/9789241515863)’. [↑](#footnote-ref-16)
17. Hunt, Bradshaw et al. (2022), [*op cit*](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9319493/) and various sources cited therein. [↑](#footnote-ref-17)
18. WHO (2022), [*op cit.*](https://www.who.int/publications/i/item/9789240063600) , p.98. [↑](#footnote-ref-18)
19. WHO (2021) [*Guidance on community mental health services: Promoting person-centred and rights-based approaches*](https://www.who.int/publications/i/item/9789240025707), p.188; Hunt, Bradshaw et al. (2022), [*op cit*](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9319493/); WHO (2022), [*op cit*](https://www.who.int/publications/i/item/9789240063600)., p.40; <https://relabhs.org/wp-content/uploads/2023/12/Article-ReLAB-HS-Rehabilitation-in-UHC_Final-Formatted-.pdf> [↑](#footnote-ref-19)
20. Ibid. [↑](#footnote-ref-20)
21. Hunt, Bradshaw et al. (2022), [*op cit*](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9319493/). [↑](#footnote-ref-21)
22. WHO (2022), [*op cit.*](https://www.who.int/publications/i/item/9789240063600) , p.4 and various sources cited therein. [↑](#footnote-ref-22)
23. Hunt, Bradshaw et al. (2022), [*op cit*](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9319493/). [↑](#footnote-ref-23)
24. WHO (2022), [*op cit.*](https://www.who.int/publications/i/item/9789240063600), pp.92-3. [↑](#footnote-ref-24)
25. Hunt, Bradshaw et al. (2022), [*op cit*](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9319493/). [↑](#footnote-ref-25)
26. WHO (2022), [*op cit.*](https://www.who.int/publications/i/item/9789240063600) , p.78, 112 & 202, citing *inter alia*: UK Parliament, House of Commons Health and Social Care Committee (2021) The treatment of autistic people and people with learning disabilities; Drew N, Funk M, Tang S, et al. (2011) ‘Human rights violations of people with mental and psychosocial disabilities: an unresolved global crisis’, Lancet. 2011;378:1664–75; Human Rights Watch (2018) ‘“They stay until they die”. A lifetime of isolation and neglect in institutions for people with disabilities in Brazil’; & Cohen A, Minas H. (2017) ‘Global mental health and psychiatric institutions in the 21st century’, Epidemiol Psychiatr Sci. 2017;26:4–9. [↑](#footnote-ref-26)
27. WHO (2022), [*op cit.*](https://www.who.int/publications/i/item/9789240063600) , p.77, citing WHO (2022) [*World mental health report*](https://www.who.int/publications/i/item/9789240049338). [↑](#footnote-ref-27)
28. WHO (2022), [*op cit.*](https://www.who.int/publications/i/item/9789240063600), p.36, citing *inter alia*: WHO (2021) ‘Second round of the national pulse survey on continuity of essential health services during the COVID-19 pandemic’ & Jesus TS, Bhattacharjya S, et al. et al. (2021) ‘Lockdown-related disparities experienced by people with disabilities during the first wave of the COVID-19 pandemic: scoping review with thematic analysis’, Int J Environmental Res Public Health. 2021;18:6178. [↑](#footnote-ref-28)