# Advance Edited Version

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**Annual report of the United Nations High Commissioner**
**for Human Rights and reports of the Office of the**
**High Commissioner and the Secretary-General**

**Promotion and protection of all human rights, civil**
**political, economic, social and cultural rights,**
**including the right to development**

## Support systems to ensure community inclusion of persons with disabilities, including as a means of building forward better after the coronavirus disease (COVID-19) pandemic

### Report of the Office of the United Nations High Commissioner for Human Rights

*Summary*

In the present report, submitted pursuant to Human Rights Council resolution 49/12, the Office of the United Nations High Commissioner for Human Rights examines the main elements of support systems to ensure community inclusion of persons with disabilities, including as a means of building forward better after the coronavirus disease (COVID-19) pandemic.

The report provides a conceptual framework for gender-responsive and disability-inclusive support and care systems to enable the full inclusion of all persons with disabilities to live independently in their communities.

# Contents

## I. Mandate and scope

1. In its resolution 49/12, the Human Rights Council requested the Office of the United Nations High Commissioner for Human Rights (OHCHR) to prepare a thematic study on support systems to ensure community inclusion of persons with disabilities, including as a means of building forward better after the coronavirus disease (COVID-19) pandemic; and a subsequent study on good practices of support systems enabling community inclusion of persons with disabilities. Stakeholders' contributions and an Easy Read version of the present report will be made available on the OHCHR website.[1]

2. The COVID-19 pandemic has accelerated discussions on care systems; such discussions recognize the need to transform traditional care models so that they protect equally the rights of those receiving and providing care. In the present report, OHCHR highlights the human right of persons with disabilities to be included in the community[2] within the current global developments on care, addressing in this context the specific support needs of persons with disabilities for community inclusion. The focus in chapter II is on the support approach to care, problematizing traditional care models and explaining how the COVID-19 pandemic has acted as a catalyser for rethinking care systems. Chapters III and IV contain a discussion of human rights standards and development considerations on the issue. In chapters V and VI, OHCHR addresses the current discussions on care and key aspects needed for them to reflect disability inclusion. Chapter VII contains conclusions and recommendations.

## II. Support and care systems as a precondition for disability inclusion

3. Support and care systems are essential for persons with disabilities to fully, actively and meaningfully participate in society, with choices equal to others, and to live with dignity, autonomy and independence, as recognized by the Convention on the Rights of Persons with Disabilities. They allow children with or without disabilities to develop, grow up in a family, learn and play; enable adults with disabilities to make their own decisions, exercise rights and live independently in their communities; provide for the active participation in society of older persons with or without impairments; fundamentally reduce gender inequalities; and allow carers to enjoy the right to education, health, work and social security.[3] For persons with high support needs, support and care systems are an indispensable precondition for carrying out activities of daily living. Without such systems, persons with disabilities can be at risk of falling into poverty and exclusion, violence, exploitation and abuse, living in isolation or being institutionalized.

4. Everyone acts as a support for, and needs support from, someone. Within the disability context, the term "support" refers to the provision of assistance to enable persons with disabilities to carry out activities of daily living and actively participate in their communities.[4] Support systems refer to a network of persons, products and services, both formal and informal, that provide for such assistance. Under the Convention on the Rights of Persons with Disabilities support is not limited to human support.[5]

5. "Care" is an umbrella term with multiple meanings for different groups and in different contexts.[6] It may refer to the activity of providing assistance to a person, an ethical or moral orientation, or an emotional state or relationship. Care encompasses various

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[1] See www.ohchr.org/en/disabilities/reports. OHCHR received 25 responses from States, 2 from intergovernmental organizations and 8 from civil society organizations.

[2] Committee on the Rights of Persons with Disabilities, general comment No. 5 (2017), para. 16 (b).

[3] Magdalena Sepúlveda Carmona and Kate Donald, "What does care have to do with human rights? Analysing the impact on women's rights and gender equality", *Gender & Development*, vol. 22, No. 3 (October 2014), pp. 441–457.

[4] A/HRC/34/58, paras. 13–16.

[5] General comment No. 5 (2017), paras. 38, 60, 62, 76 and 84.

[6] Kirstein Rummery and Michael Fine, "Care: a critical review of theory, policy and practice", *Social Policy & Administration*, vol. 46, No. 3 (June 2012), pp. 321–343.

activities that enhance individuals' physical and mental well-being in the short and the long term, covering a wide range of aspects such as social care, household care and care for those who rely on another person for support, including persons with disabilities. The various forms of care are commonly categorized under the social identity of the persons receiving care (e.g. childcare, elder care or disability care) or the employment status of the carer (e.g. paid and unpaid care work or formal and informal care work).[7]

## A. Traditional care models and the disability rights' support approach

6. Traditional care models developed in the 1950s, 1960s and 1970s are characterized as carer-centred, and commonly place care receivers as passive recipients of care, with no agency to control and direct the care that they receive, leading to a loss of autonomy, economic disempowerment, and segregation and isolation from the rest of the community in institutions or in family homes. They portray care receivers as "dependants", a societal "burden", who impose negative consequences on society, in line with stereotypes linked to ableist views based on charity and medical approaches to disability. Moreover, traditional care models operate on the stereotypical assumption that men earn income and women provide care for free or low cost, undermining the equal enjoyment of human rights by women and girls, including their equal participation in education, economic activities, public life and rest and leisure. They negatively affect women with disabilities twice, both as caregivers and care receivers.[8]

7. The disability community is critical of traditional care models, claiming back agency and autonomy with the necessary support, when needed. Based on the human rights-based model of disability, it can be argued that caregiver-centred systems create a power imbalance between the caregiver and the person receiving care, leading to paternalistic practices and attitudes that create an environment that heightens the risk of violence, exploitation and abuse.[9] Similarly, carers' organizations and feminist movements oppose traditional care models for being detrimental to gender equality and undermining women's rights. This led to campaigning for the recognition of care as a necessity for the existence and reproduction of societies, which needs to be valued and, as consequence, collectively shared through a system that redistributes care work through co-responsibility among all persons, particularly men and women, and among families, communities and the State.[10]

8. Traditional care models create a tension between carers and care receivers, as they frame care as a competition between each of these "constituencies" to maximize care time according to their own interests. On the one hand, carers searching for systems that reduce the "burden of care" and, on the other, care receivers seeking access to the support necessary to meet their needs and preferences. This false dichotomy creates a risk of system incoherence and fragmentation, in which policymakers are positioned to make value judgments on who has the greater claim when deciding how to allocate limited resources.[11]

9. Care is relational; the rights of caregivers and care receivers are inextricably linked. Overburdening unpaid or underpaid caregivers necessarily affects the quality of care that they can provide, while a caregiver-centred system risks obscuring the agency and autonomy of care receivers.[12] Current discussions on care acknowledge the negative legacy of traditional care models and advocate for the equal and full realization of the rights of both caregivers and care receivers.[13] A rights-based approach to support and care is needed to harmonize multiple perspectives, ensure the structuring of co-responsibilities that respects the rights of

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[7] Yvette Maker, *Care and Support Rights After Neoliberalism: Balancing Competing Claims Through Policy and Law* (Cambridge, United Kingdom, Cambridge University Press, 2022), p. 1.

[8] Ibid., pp. 9 and 25–30.

[9] A/HRC/34/58, paras. 23–28.

[10] International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work* (Geneva, 2018).

[11] Maker, *Care and Support Rights After Neoliberalism*, p. 79.

[12] A/68/293, para. 11.

[13] See, for example, https://alianzadecuidados.forogeneracionigualdad.mx/acerca/?lang=en.

all those involved, and guarantees that those who receive and provide support and care, and self-care, do so under conditions of equality.

10. Families and carers play a fundamental role in supporting persons with disabilities to realize their right to live independently and be included in the community. Women, older persons and other adults with disabilities, among others, can be both care providers and receivers of care and their rights and experiences cannot be approached from a single perspective only as one or the other.

## B. COVID-19 pandemic and support and care systems

11. The COVID-19 pandemic has accelerated debates on support and care systems. Lockdowns, school closures, disproportionate deaths in isolating conditions in psychiatric and social care institutions, and the overburdening of health systems have all highlighted the important role of community support and care for the well-being of individuals, economies and societies. Worldwide disruptions in the functioning of community support networks and services have exacerbated existing levels of poverty, exclusion and disadvantage.[14] Persons with disabilities living in institutions have faced extreme situations of abandonment, violence and isolation, particularly older persons with disabilities.[15] In addition, the pandemic has heightened the gender and economic inequalities stemming from the organization of care work, largely operating under traditional care models.[16]

12. In particular, the COVID-19 pandemic has focused attention globally on the precarious and neglected conditions of unpaid and underpaid care workers, including long hours and heavy workloads, disproportionally borne by young women from poor and disadvantaged backgrounds. The pandemic has also underscored the fact that a large number of households depend heavily on domestic workers to provide for their care needs.[17]

13. The COVID-19 pandemic has also engendered significant repercussions on gender equality among support and care workers. The majority of care work across the globe is carried out by unpaid or underpaid caregivers, the latter comprising mostly women and girls from socially disadvantaged backgrounds, including migrants, members of ethnic minorities and women with disabilities.[18] Women carry out 76.2 per cent of the total amount of unpaid care work while men perform only 23.8 per cent of this work.[19] Women's engagement in unpaid care work determines whether they enter into and remain in employment and affects the quality of the jobs that they perform, thereby leaving them in a disadvantaged socioeconomic position. At the same time, women are overrepresented in paid care work in precarious conditions for which they earn little. Despite the greater participation of women in the labour market, a traditional division of unpaid care work persists, even in dual-earning households. These realities have accordingly rooted the focus of care discussions on advancing gender equality through the full participation of women in the economy.[20]

14. There is also greater awareness of the demographic and socioeconomic shifts affecting care contexts, including population ageing, shrinking families, the reduction in the active workforce, women's growing participation in the labour force and globalization of work, which highlight the need to invest in comprehensive support and care systems. As the population grows older, the percentage of chronic diseases and related impairments also

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[14] COVID-19 Disability Rights Monitor, *Disability Rights During the Pandemic: A Global Report on Findings of the COVID-19 Disability Rights Monitor* (2020), pp. 28–29.

[15] Martin Knapp and others, *Crystallising the Case for Deinstitutionalisation: COVID-19 and the Experiences of Persons with Disabilities* (London, London School of Economics and Political Science, 2021), pp. 3 and 42.

[16] See, for example, United Nations Entity for Gender Equality and the Empowerment of Women (UN-Women) and the Economic Commission for Latin America and the Caribbean, "Care in Latin America and the Caribbean during the COVID-19. Towards comprehensive systems to strengthen response and recovery" (Santiago, 2020), p. 4.

[17] Ibid., pp. 10–11.

[18] International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work*, p. 72.

[19] Ibid., p. 53.

[20] Ibid., p. 327.

increase, resulting in higher demand for support and care.[21] Ageing populations, in combination with lower fertility rates, also result in the relative growth of the number of older persons compared with younger persons.[22] The resultant decline in the workforce places greater pressure on women, including older women, to provide unpaid support and care while simultaneously working to generate income. These demographic and socioeconomic changes result in a situation in which there are more persons who need support and care and fewer persons available to provide it, which, in combination with stereotypical gendered roles of care and inadequate societal, policy and economic structures, is leading to a global crisis in support and care.[23] This crisis is not only exacerbating gender inequality but exposing those in need of support to higher risks of abandonment.

15.     The pandemic also draws attention to financing. Levels of investment remain low worldwide, particularly in low-income countries in which Governments do not fund support services and networks, leaving persons with disabilities to rely almost exclusively on family support. Family support is commonly unrecognized, leaving families unsupported to provide quality care, including lack of financial support, capacity-building and disproportionate care demands.[24] This creates material conditions for unwanted practices from families, such as overprotection of persons with disabilities and limitation of autonomy.[25]

16.     Despite these challenges, there are a number of opportunities to advance support and care systems capable of responding adequately and appropriately to the needs of persons with disabilities. Evidence shows that investing in support and care systems has broader long-term benefits for the economy and society. It can result in economic growth linked to employment creation.[26] Investment could also reduce the gender gap in employment and promote gender equality.[27] Furthermore, improving the status and conditions of care workers, together with an increase in the number of care jobs with better working conditions and qualifications, has the potential to attract more men to the field, thus contributing to a reduction in gender inequality in the overall labour market.[28] Finally, ensuring access to support and care will facilitate greater inclusion of persons with disabilities in education, the labour market and economic activities.[29]

## III.  Support and care systems and relevant international human rights frameworks

17.     Access to appropriate support and care systems is embedded in international human rights law.[30] Regional human rights instruments have also recognized the obligation to provide persons with disabilities with access to support and care systems.[31] Article 7 of the Inter-American Convention on the Protection of the Human Rights of Older Persons

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[21] World Health Organization, *Lessons for Long-Term Care Policy* (Geneva, 2002), p. 11.

[22] Claire Kumar and others, *Migration and the Future of Care. Supporting Older People and Care Workers* (London, Overseas Development Institute, 2022), pp. 6–7.

[23] World Health Organization, *Lessons for Long-Term Care Policy*.

[24] See A/HRC/35/12.

[25] Ibid.

[26] Jerome De Henau, *Costs and Benefits of Investing in Transformative Care Policy Packages: A Macrosimulation Study in 82 Countries*, International Labour Organization Working Paper 55 (Geneva, 2022), p. 46.

[27] Ibid., pp. 47–48.

[28] International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work*, p. 332.

[29] General comment No. 5 (2017), paras. 88 and 91.

[30] See the relevant provisions in the human rights treaties, including the International Covenant on Economic, Social and Cultural Rights (arts. 3, 6–7 and 9–13); the Convention on the Elimination of All Forms of Discrimination against Women (preamble and arts. 1–2, 5, 11–14 and 16); and the Convention on the Rights of the Child (arts. 3, 7, 18–19, 23–25, 38 and 40).

[31] See the revised European Social Charter (art. 15); the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (Protocol of San Salvador, art. 18); and the African Charter on Human and Peoples' Rights (art. 18 (2) and (4)). See also the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities in Africa (arts. 3 (h), 4 (h), 5–7, 8 (2) (b), 9 (2) (b), 10 (2) (d), 11 (1), 14, 15 (d), 16 (3) (d), 18 (c), 20 and 30 (2) (d)), which is not yet in force.

establishes an obligation to provide support and care to older persons, including older persons with disabilities.

18. The Committee on the Elimination of Discrimination against Women noted that support and care systems were required to achieve gender equality, challenge stereotypes and harmful practices and guarantee women's rights to work, social protection, health and education.[32] Similarly, the Committee on the Rights of the Child underlined that appropriate support and care was necessary to prevent family separation, protect children deprived of their family environment, ensure an adequate standard of living, support children with disabilities and their families, and prevent violence, abuse and neglect.[33] The Committee on Economic, Social and Cultural Rights emphasized the role of support and care systems in achieving equality between men and women, advancing the deinstitutionalization of children with and without disabilities, enabling persons with disabilities and older persons to live in the community, and guaranteeing the rights to work and social protection of caregivers.[34]

19. The Human Rights Council has adopted numerous resolutions on the issue of support and care to enable persons with disabilities to live in the community. These include resolutions 28/4 on the right of persons with disabilities to live independently and be included in the community on an equal basis with others; 40/14 on empowering children with disabilities for the enjoyment of their human rights, including through inclusive education; 43/13 on mental health and human rights; and 47/15 on preventing and responding to all forms of violence against women and girls with disabilities. During its fiftieth session, the Human Rights Council also held a panel discussion on human rights-based and gender-responsive care and support systems, as part of the annual full-day discussion on the human rights of women.

20. The former Special Rapporteur on the rights of persons with disabilities addressed these concerns in numerous reports,[35] and the current mandate holder addressed this issue in his report on service transformation.[36] Other special procedure mandate holders of the Human Rights Council, such as the Independent Expert on the enjoyment of all human rights by older persons, the Special Rapporteur on extreme poverty and human rights, the Special Rapporteur on adequate housing as a component of the right to an adequate standard of living, and on the right to non-discrimination in this context, and the Working Group on discrimination against women and girls, have also addressed support and care in their work.[37]

21. Access to support and care by persons with disabilities is also essential for ensuring that no one is left behind in the implementation of the 2030 Agenda for Sustainable Development, and is specifically recognized as a means to achieve gender equality in target 5.4 and in Our Common Agenda.[38] The provision of support and care is a prerequisite for the realization of a number of Sustainable Development Goals, including ending poverty in all its forms everywhere (Goal 1); ensuring healthy lives and promoting well-being for all at all ages (Goal 3); ensuring inclusive and equitable quality education and promoting lifelong learning opportunities for all (Goal 4); achieving gender equality and empowering all women and girls (Goal 5); promoting sustained, inclusive and sustainable economic growth, full and productive employment and decent work for all (Goal 8); reducing inequality within and among countries (Goal 10); and making cities and human settlements inclusive, safe, resilient and sustainable (Goal 11).

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[32] CEDAW/C/ECU/CO/10, paras. 31–32 and 36–38; CEDAW/C/UZB/CO/6, paras. 19–20 and 35–36; and CEDAW/C/KGZ/CO/5, paras. 37–38.

[33] CRC/C/GRC/CO/4-6, paras. 30–31 and 33; CRC/C/CYP/CO/5-6, paras. 26–28 and 30; and CRC/C/MDG/CO/5-6, paras. 27–28 and 30.

[34] E/C.12/MDA/CO/3, paras. 15–16 and 25; and E/C.12/CZE/CO/3, paras. 28–31.

[35] See A/70/297, A/71/314, A/73/161 and A/74/186; and A/HRC/31/62, A/HRC/34/58, A/HRC/37/56 and A/HRC/40/54.

[36] See A/HRC/52/32.

[37] See A/HRC/30/43, A/68/293, A/72/128 and A/HRC/44/51.

[38] A/75/982, para. 39.

## IV. Support and care systems in the Convention on the Rights of Persons with Disabilities

22. The Convention on the Rights of Persons with Disabilities provides a comprehensive framework for the implementation of support and care systems. Support is a cross-cutting obligation under the Convention.[39] It further reflects the Convention's model of "inclusive equality", which embraces four intertwined dimensions: (a) a fair redistributive dimension to address socioeconomic disadvantages; (b) a recognition dimension to combat stigma, stereotyping, prejudice and violence and to recognize the dignity of human beings and their intersectionality; (c) a participatory dimension to reaffirm the social nature of individuals as members of social groups and the full recognition of humanity through inclusion in society; and (d) an accommodating dimension to make space for difference as a matter of human dignity.[40]

23. Support is included as part of the general obligations, particularly under article 4 (1) (g) and (h). The Convention makes reference to support in relation to various rights, including equal recognition before the law (art. 12); access to justice (art. 13); freedom from exploitation, violence and abuse (art. 16); living independently and being included in the community (art. 19); personal mobility (art. 20); freedom of expression and opinion, and access to information (art. 21); respect for home and the family (art. 23); education (art. 24); habilitation and rehabilitation (art. 26); work and employment (art. 27); an adequate standard of living and social protection (art. 28); and participation in cultural life, recreation, leisure and sport (art. 30). Articles 12 and 19 of the Convention, central to the purpose of the treaty, require States parties, respectively, to provide access by persons with disabilities: to the support that they may require in exercising their legal capacity; and to a range of community support services, including personal assistance, to prevent isolation or segregation from the community.

24. Support is present in the jurisprudence of the Committee on the Rights of Persons with Disabilities.[41] For example, in a recent case, the Committee underscored that failure to provide support services to families of persons with disabilities was discrimination by association, which violated the rights of persons with disabilities to family life, to live independently and to an adequate standard of living.[42] Support-related obligations are addressed in the Committee's general comments.[43] Likewise, in its concluding observations, the Committee has called upon States parties to ensure that persons with disabilities have access to the support that they need in various domains.[44]

25. The Committee's work has been central to developing the standards related to access to, and provision of, support. For example, recognizing support as a right;[45] the diversity of support arrangements (both informal and formal support of varying types and intensity);[46] its characteristics and scope (respect for the will and preferences of persons with disabilities, allowing for personal choice and control and flexibility to adapt to the requirements of people and not the other way around); and related obligations (support should be available, accessible, acceptable, affordable and adaptable; and be person-centred, age- and gender-sensitive and culturally appropriate). Eligibility criteria and procedures for accessing support must be non-discriminatory and focus on the requirements of the person rather than the impairment. The Committee has also underlined the role of support systems and networks, including family members, friends, neighbours and other trusted persons who provide

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[39] A/HRC/34/58, para. 37.
[40] Committee on the Rights of Persons with Disabilities, general comment No. 6 (2018), para. 11.
[41] *Gröninger et al. v. Germany* (CRPD/C/D/2/2010), paras. 6.3 and 7; and *H.M. v. Sweden* (CRPD/C/7/D/3/2011), paras. 8.7 and 8.9.
[42] See *Bellini et al. v. Italy* (CRPD/C/27/D/51/2018).
[43] General comment No. 1 (2014), paras. 15–16; general comment No. 5 (2017), paras. 13, 15, 88 and 91; and general comment No. 8 (2022), paras. 19, 69–70, 73 and 77.
[44] See, for example, CRPD/C/IDN/CO/1, CRPD/C/CHN/CO/2-3 and CRPD/C/NZL/CO/2-3.
[45] General comment No. 5 (2017), para. 28.
[46] General comment No. 1 (2014), paras. 17–18.

support. It has also called upon States to closely consult persons with disabilities and their representative organizations in policy design, implementation and monitoring.[47]

## V. A conceptual framework for gender-responsive and disability-inclusive support and care systems

26.     Different stakeholders – from grass-roots to international organizations – are proposing new models of organizing care work to address the care crisis, grounded in gender equality and social justice.[48] An important development in these new models is that they are based on the so-called right to care.

27.     The calls for recognition of care as both a human right and a development issue are gaining strength at international and national levels, with care being increasingly recognized as a right in regional forums and national legislation.[49] The right to care has three dimensions of equal standing.[50] The first dimension is the right to provide care, which acknowledges that, as social beings with multiple and intersecting identities, all persons provide support and care to others and need to be supported to do so without being exposed to inequalities and denial of rights. The second dimension is the right to receive care, which, in a human rights-based approach, considers recipients of support and care as rights holders who are entitled to exercise their autonomy and agency in relation to the support that they receive, rather than as passive beneficiaries. The third dimension is the right to self-care, which recognizes the importance of having time, space and resources to take care of oneself.[51]

28.     A proposal for transforming traditional care models is the Triple R framework, which involves recognizing and redistributing care work and reducing unpaid care work.[52] Recognition entails valuing care work and recognizing it as essential for social reproduction, economic and social well-being and sustainable development. Redistribution involves a fairer and more balanced distribution of care responsibilities in society, particularly between men and women, and co-responsibility for care among households, communities, the private sector and the State. Finally, reduction is about addressing the inequalities of unpaid care work through public investment in quality support and care services, social policies, and accessible and inclusive basic infrastructure.[53] The International Labour Organization and the United Nations Entity for Gender Equality and the Empowerment of Women (UN-Women) have further proposed a 5R framework, adding to the Triple R framework, "reward" and "representation" for paid care workers by promoting decent work, including for migrant workers, and guaranteeing their representation, social dialogue and collective bargaining.[54]

29.     These conceptual frameworks facilitate a social, political and administrative organization of care systems applicable in all contexts through a model of social co-responsibility, which demands a combination of efforts from families, communities, markets and the State.[55] According to the frameworks, States play a fundamental role in guaranteeing care as a right, organizing the distribution of care work through legislation, creating regulatory frameworks and incentives to guide profit and not-for-profit quality support services, and assigning context-specific roles to each of these responsible constituencies.

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[47]  General comment No. 7 (2018), paras. 22–23 and 55.

[48]  See https://alianzadecuidados.forogeneracionigualdad.mx/acerca/?lang=en.

[49]  Economic Commission for Latin America and the Caribbean, *The Care Society: A Horizon for Sustainable Recovery with Gender Equality* (Santiago, 2022), pp. 24 ff; and Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on the European care strategy – COM(2022) 440.

[50]  Buenos Aires Commitment, adopted at the fifteenth session of the Regional Conference on Women in Latin America and the Caribbean, para. 8.

[51]  Economic Commission for Latin America and the Caribbean, *The Care Society*, pp. 24 ff.

[52]  Diane Elson, "Recognize, reduce, and redistribute unpaid care work: how to close the gender gap", *New Labour Forum*, vol. 26, No. 2 (Spring 2017), pp. 52–61.

[53]  International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work*, p. 154.

[54]  International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work*; and UN-Women, "A toolkit on paid and unpaid care work: from 3Rs to 5Rs" (New York, 2022).

[55]  International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work*, p. 25.

30.     The private sector has an important role to play in social co-responsibility for care, including by investing in quality support and care services and infrastructure, providing decent care work and fostering gender equality and disability inclusion in the workplace. Not-for-profit organizations further complement public and private efforts by harvesting community resources and improving access to support and care services for underserved populations.[56]

31.     Current conversations on care have specific policy objectives aimed at addressing, among other issues, the structural inequalities that women face because of unpaid care work. Hence, advocacy efforts call for time to provide quality care or "time for care"; compensation for the provision of care or "cash for care"; and substitution of the free provision of care with service provision. These policy objectives are compatible with policy objectives framed by the Convention on the Rights of Persons with Disabilities.[57]

32.     The transformation of support and care systems also calls for the participation of not only all stakeholders providing support and care, but also of all persons who may require support or care at some point or throughout their lives.[58] It means that women and men with disabilities of all ages, including children, and young and older persons with disabilities, should participate actively and meaningfully in policy discussions and reform efforts, together with other rights holders.

**A disability rights-based approach to support and care systems**

33.     Current calls for transformative care systems require that traditional care models be replaced by rights-based models. They address a long-standing demand by persons with disabilities for transformative care systems that provide a platform to implement human rights obligations under the Convention on the Rights of Persons with Disabilities, beyond disability-specific programmes, in the larger context of care and infrastructure strategies. They can contribute to building dialogue across movements of persons with disabilities of all ages and the women's rights movement under a common platform and on equal terms.

34.     The three dimensions of the right to care are well reflected in the Convention on the Rights of Persons with Disabilities, particularly the rights to receive care and self-care with agency and dignity. The influence and inertia of traditional care models, vested financial interests and structural economic factors have denied these dimensions an opportunity to be properly reflected in law and policy.[59]

35.     Recognizing care work, including the role of support networks and family support, requires that support to live independently and be included in the community with agency and dignity be an integral part of support and care systems. Such systems should reflect the diversity of support needs of persons with disabilities and their families, beyond human assistance, throughout the life cycle.

36.     Redistribution of care in society, particularly among men and women, families, communities and the State, is necessary to ensure integral solutions that build on the capacities of each responsible constituency. Redistribution also means challenging power relations and dismantling social norms and gender stereotypes that make women and girls in all their diversity the primary providers of unpaid support and care work.[60]

37.     Support and care systems for community living should integrate mainstream and disability-specific programmes. In high-income countries, social protection systems often meet support costs through a combination of cash transfers, health insurance, long-term care insurance, as well as direct service provision, albeit insufficiently and commonly through charity and medical models.[61] In low- and middle-income countries, in which fiscal capacity

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[56]  See A/HRC/52/32.

[57]  Maker, *Care and Support Rights After Neoliberalism*, p. 179.

[58]  International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work*, p. 117.

[59]  Maker, *Care and Support Rights After Neoliberalism*, pp. 243–245.

[60]  Valeria Esquivel, "Care in households and communities: background paper on conceptual issues" (London, Oxfam, 2013).

[61]  European Association of Service Providers for Persons with Disabilities, "Funding of disability services in Europe: a state of play" (Brussels, 2020).

is limited, social protection schemes resort to cash transfers to individuals and families from low-income households, reducing administrative costs.[62] In this context, it is necessary to recognize and develop the skills of unpaid care workers, especially since they are an integral part of the provision of support services to persons with disabilities. Unpaid care workers need visibility, guidance, training and support services.

38.     Addressing social and economic barriers that limit the participation in society of persons with disabilities is essential in reducing unpaid support and care work. There is a direct relationship between barriers concerning the environment, transportation, information and communication, and the need for support and care. Similarly, the lack of inclusion of the rights of persons with disabilities within the design and implementation of social policies, such as those on education, health and social protection, has a multiplier effect on support and care needs. For example, exclusion from education forces families to take on full-time care responsibilities, which affects not only the household's income and opportunities, but also the development and autonomy of children with disabilities.[63]

39.     Policies that recognize and provide time for care also need to be designed and implemented from a human rights-based approach to disability. Leave policies and flexible working arrangements enable workers, including those with disabilities, to take time off work to assist family members with disabilities. Accommodations in education, the workplace and society generally are also needed for persons with disabilities who receive support, including to organize the support that they receive. Additionally, persons with disabilities need time for self-care and to participate in nurturing activities and relationships. The extra time that persons with disabilities spend in carrying out activities of daily living is seldom acknowledged, exposing them to "time poverty".[64]

40.     Money for care is one of the most widespread strategies for the provision of support and care to persons with disabilities. However, in some countries, cash transfers are directed only to caregivers and households instead of to persons with disabilities themselves, creating a complex power relationship within households, particularly when such funding is not complemented by poverty reduction schemes to cover basic needs.[65] Financial support directed to persons with disabilities increases their choice and control over the support and care that they obtain, allowing them to pay for different combinations of formal and informal support. Such cash transfers should acknowledge disability-related extra costs and self-care activities.[66] Furthermore, payments should be sufficient to offer meaningful choice to both persons with disabilities and carers, and offer decent and secure work.[67] Governments should consider additional financial support for caregivers, but that should not be at the expense of the independence of persons with disabilities.

41.     A disability rights-based approach to support and care systems requires service transformation towards a care model that ensures personalized, rights-based and community-based support and care. In most parts of the world, there is a dearth of formal services offering alternatives to unpaid care work. In situations in which public or not-for-profit services are available, they are often provided in a medicalized, segregated or institutionalized way, or are not based on the will and preferences of the individual, which is contrary to a rights-based approach. In many countries, institutions are the primary service provided to persons with

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[62] Daniel Mont and others, "Estimating the extra costs for disability for social protection programs" (United Nations Partnership on the Rights of Persons with Disabilities and others, 2022), p. 39.

[63] United Nations Children's Fund, *Seen, Counted, Included: Using Data to Shed Light on the Well-Being of Children with Disabilities* (New York, 2021).

[64] Clair Vickery, "The time-poor: a new look at poverty", *Journal of Human Resources*, vol. 12, No. 1 (Winter 1977), pp. 27–48.

[65] Alberto Vásquez Encalada and others, "The disability support gap: community support systems for persons with disabilities in low- and middle-income countries" (Centre for Inclusive Policy and others, forthcoming).

[66] General comment No. 5 (2017), para. 62.

[67] Maker, *Care and Support Rights After Neoliberalism*, p. 92.

disabilities and their families, in spite of their documented negative effects.[68] In many cases, moreover, support is not personalized, flexible, sufficient or sustainable.[69]

42.     Public investment in transformative support and care services and networks is important in enabling persons with disabilities to participate and be fully included in the community and to reduce and redistribute unpaid care work. Support services should be developed in accordance with the human rights-based model of disability, respecting the will and preferences of persons with disabilities and supporting their inclusion in the community.[70] As part of these efforts, States should consider implementing deinstitutionalization strategies.[71] In addition, they should invest in peer support, self-advocacy, circles of support, independent living centres, and other support networks and arrangements. Family carers should also have access to adequate support services, including respite care services, counselling services, social support, financial support and other support options.[72] Information and training on understanding the rights-based approach to disability and the role of families in supporting and nurturing the agency of persons with disabilities is essential.

43.     The concept of choice and control is fundamental to the rights of persons with disabilities and should feature as an integral component of the exercise of autonomy in support and care systems. By exercising choice and decision-making, persons with disabilities retain control over their lives and support and care arrangements that affect their daily living. Choice and control for support and care presupposes that there is a range of options available to the individual, including those relating to time, money and services; arrangements cannot be imposed; and individuals retain the freedom to modify and reject arrangements that do not suit them.[73]

44.     In some countries, there has been a shift towards "personalization" of support and care to increase user choice and control through direct payments and personal budgets, which allow persons with disabilities to "purchase" services that best meet their needs. While personalization is a well-recognized strategy, research shows some negative aspects, including a reduction in public expenditure, the commodification of support and care, the burden of financial self-management, a decrease in the quality of services, a deterioration in the working conditions of carers and a deepening of gender inequality.[74] For personalization schemes to be effective and equitable, States need to increase efforts to regulate services, markets and working conditions, and ensure flexibility to meet all individual needs, including the need for support in managing schemes.[75] The rise of technology-based services also demands greater regulation and oversight.[76]

45.     Community mobilization and partnerships are also central to the provision of support and care. Despite the gradual move towards personalization, mobilizing community resources remains necessary, particularly in low- and middle-income countries. In situations in which social networks and solidarity are an integral part of life, community and family mobilization are an important way of maximizing resources in a culturally acceptable manner.[77] Organizations of persons with disabilities, not-for-profit organizations, community-based organizations and volunteer networks are all part of the community structures that need to be strengthened, for example, through sustained government funding,

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[68]  Knapp and others, *Crystallising the Case for Deinstitutionalisation*, pp. 15–16.

[69]  See A/HRC/52/32.

[70]  Ibid.

[71]  General comment No. 5 (2017), para. 49.

[72]  *Bellini et al. v. Italy*, para. 7.6.

[73]  General comment No. 5 (2017), paras. 25–27 and 36.

[74]  Gemma Carey, Brad Crammond and Eleanor Malbon, "Personalisation schemes in social care and inequality: review of the evidence and early theorising", *International Journal for Equity in Health*, vol. 18 (2019); and Fiona Macdonald, *Individualising Risk: Paid Care Work in the New Gig Economy* (Singapore, Palgrave Macmillan, 2021).

[75]  Macdonald, *Individualising Risk: Paid Care Work in the New Gig Economy*, pp. 91–109.

[76]  World Health Organization and United Nations Children's Fund, *Global Report on Assistive Technology* (2022), p. 38.

[77]  Vásquez Encalada and others, "The disability support gap: community support systems for persons with disabilities in low- and middle-income countries", p. 20.

to enable them to provide community support and care for persons with disabilities. Families should also be involved in community mobilization efforts, including through funding. In the design and implementation of these arrangements, it is crucial to ensure agency and choice for persons with disabilities, and not to exacerbate gender inequalities in the distribution of care.

46.     Throughout the life cycle, persons with disabilities have diverse support and care needs. These include the need for financial support in the form of cash transfers to meet the extra costs associated with disability; human support, such as personal assistance services, sign language interpretation and peer support groups; assistive technology, including digital support; support to overcome barriers in accessing public transportation, including point-to-point and paratransit solutions, and transport subsidies; and support to access adequate housing, such as programmes and services to find, afford and adjust accessible housing. These support and care tools complement each other. For example, assistive technologies reduce the need for human support and facilitating transportation reduces higher costs in mobility devices. Support and care systems need to be comprehensive and integral to cover these diverse support needs, as well as age appropriate, covering the whole life-cycle approach.

47.     Gender, intersectional and intercultural perspectives should be integrated into the design and implementation of support and care systems in order to ensure that persons with disabilities, in all their diversity, can receive tailored support and care arrangements. Support and care should be embedded in specific local and cultural contexts. However, this should not impede the choice and control of the individuals concerned about the support that they receive.

## VI.    Cross-cutting implementation measures

### A.    Governance

48.     Effective governance is necessary to ensure comprehensive support and care systems. Governance entails the establishment of effective legal and policy frameworks as well as institutional frameworks. Legal recognition of the rights of persons with disabilities, as an integral part of support and care systems, is fundamental. Legislation should include disability rights-based definitions, principles and provisions to ensure that persons with disabilities are properly included in support and care systems. When addressing sector-specific areas, such as social protection, human support, assistive technologies, transportation and housing, health and education measures, legislation and policies also need to be based on the rights reflected in the Convention on the Rights of Persons with Disabilities.

49.     Institutional frameworks and architecture should include functions, powers and oversight mechanisms that underpin the governance of support and care systems. Frameworks must be based on inter-institutional coordination that prioritizes a person's rights and leverages the capacities and resources of the State and the community.[78] States must devise effective methods to decentralize the provision of support and ensure effective coordination and implementation mechanisms, sufficient budget allocations to local authorities and other entities responsible for the provision of support, as well as a system for monitoring the effectiveness of the provision of support services.[79]

50.     Persons with disabilities, through their representative organizations, must participate in decision-making processes concerning issues related to them,[80] which includes the design, implementation, monitoring and evaluation of support and care systems. Persons with disabilities possess in-depth knowledge from lived experiences about the types of support

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[78]  See Julio Bango and Patricia Cossani, *Towards the Construction of Comprehensive Care Systems in Latin America and the Caribbean: Elements for Implementation* (Santiago, UN-Women and the Economic Commission for Latin America and the Caribbean, 2021).
[79]  A/HRC/34/58, para. 59.
[80]  Convention on the Rights of Persons with Disabilities, art. 4 (3).

that they require, as well as about how to manage that support. Support and care systems can also benefit from the experience of organizations of persons with disabilities.[81]

## B.  Measuring support and care needs

51.    Information and knowledge management are an integral part of the design of quality and inclusive support and care systems. Information that is relevant for policy planning and implementation, including case management, needs to be tracked and collected. Maintaining effective information systems also facilitates the sharing of information on support requirements across programmes and for emergency preparedness. Data collection efforts should seek to identify limitations and barriers experienced by persons with disabilities, including those based on their age and gender, in carrying out activities of daily living and participating in social contexts.[82]

52.    It is important to conduct support needs assessments to inform the design and development of individualized support and care systems that respond adequately and appropriately to the needs of persons with disabilities as both care receivers and caregivers. States should take measures to improve the identification, assessment and certification of persons with disabilities. While current disability assessments can play a crucial role in the design of support and care systems, these commonly ignore support requirements.[83]

53.    Time-use surveys measure the amount of time spent on various activities, including household and family care, personal care, paid work, and social and leisure activities, for the purpose of informing policy. These surveys can be useful in understanding the type of activities performed in providing and receiving care, and self-care, how they are performed and the amount of time it takes to perform them. This information is necessary for the development and implementation of policies and programmes with a focus on disability inclusion and gender equality. Indicator 5.4.1 of the Sustainable Development Goals does not provide for data disaggregation by disability, assuming that persons with disabilities are only care receivers.[84]

## C.  Social protection

54.    Persons with disabilities and their families incur disability-related extra costs. Some of these are direct costs that result from having an impairment, such as the purchase of assistive technology, the procurement of support services, as well as higher health, transportation and housing costs. Other costs are indirect, because of reduced earning capacity due to limited access to education and employment, as well as the opportunity costs of foregone income for family carers.[85] Disability-related extra costs are determined by various factors, including the type of impairment, environmental barriers and socioeconomic participation. Persons with disabilities and their families often encounter out-of-pocket expenditure related to support and care. These costs must be accounted for to ensure that persons with disabilities and their households enjoy similar standards of living to others. Social protection plays an important role in meeting disability-related extra costs. Worldwide, social protection, if available, hardly ever considers disability-related extra costs and, when social protection exists, it is limited to a poverty reduction scheme.[86]

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[81]  A/HRC/34/58, para. 64.
[82]  A/HRC/49/60, para. 18.
[83]  Ibid., paras. 25–29.
[84]  See https://unstats.un.org/sdgs/metadata/files/Metadata-05-04-01.pdf.
[85]  See Mont and others, "Estimating the extra costs for disability for social protection programs".
[86]  International Labour Organization, *World Social Protection Report 2020–22: Social Protection at the Crossroads – In Pursuit of a Better Future* (Geneva, 2021), p. 148–149.

## D.  Workforce

55.     There is a shortage of skilled care workers in most parts of the world, which affects the availability and quality of support and care that persons with disabilities receive. This does not only put additional pressure on those providing unpaid care, but also facilitates the recruitment of unskilled and underpaid care workers, including migrant workers, under precarious conditions, who face significant inequalities related to gender, class, race and nationality. Greater investments by States are required to ensure that the job market for support and care is attractive to young workers and that they can benefit from improved labour regulation and control to ensure fair, safe and decent working conditions. Furthermore, in those occupations that require specialization, such as sign language interpretation or augmentative and alternative communication, States should take proactive measures to facilitate the training, accreditation and recognition of these workers.

## E.  Financing

56.     Various funding mechanisms may be relied upon for financing support and care for persons with disabilities. Tax-funded financing is the most common form of public financing for support and care. Other financing mechanisms include social insurance, private insurance and direct subsidies to service providers. These financing models are not mutually exclusive and can be combined to suit the economic and political conditions of each country. In order to build well-resourced and sustainable systems, States should consider expanding fiscal space to generate the adequate levels of resources needed in line with their obligation to mobilize the maximum of available resources to progressively achieve the full realization of economic, social and cultural rights.[87] As the International Labour Organization has noted, comparative work in 40 countries with a similar income and socioeconomic status displays different care policies and related outcomes, which underlines the importance of political willingness and clearly defined policy priorities.[88]

57.     International cooperation is key to financing support and care systems, particularly in low-resourced settings and in the aftermath of the COVID-19 pandemic. In addition to providing funding for the development of support and care systems, international cooperation can also play an important role in channelling investment towards innovative support systems, services and practices that capitalize on public and community resources, promote gender equality and foster choice and control. It is important that discussions on the care economy[89] at the international level emphasize disability inclusion and gender equality, in line with the human rights-based approach, as well as the 2030 Agenda. International donors should consult with local organizations of persons with disabilities and ensure that their investments in support and care are useful to fulfil the life plans of such persons in a culturally appropriate manner.

## VII.  Conclusions and recommendations

58.     The COVID-19 pandemic has highlighted the shortcomings of traditional care models and accelerated discussions towards new rights-based support and care models that are gender-responsive and disability inclusive. New care models are emerging through integral systems and infrastructure strategies that reflect the rights of caregivers and care receivers, reconciling long-standing tensions. The Convention on the Rights of Persons with Disabilities provides a comprehensive framework for the development of support and care systems. Further international action is needed to integrate these models into policy. **It is important that the Human Rights Council consider paying specific attention to the issue of support and care. Relevant stakeholders, including States, international and regional organizations, international, bilateral and multilateral development aid agencies,**

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[87]  Principles for Human Rights in Fiscal Policy, principle 10.
[88]  International Labour Organization, *Care Work and Care Jobs for the Future of Decent Work*, pp. 111–159.
[89]  Ibid., pp. 6 ff.

**representative organizations of persons with disabilities, and service providers, are encouraged to support the efforts towards transformative and inclusive support and care systems.**

59.     Efforts to recognize and redistribute care work and reduce unpaid care work need to pay increased attention to the intersection of gender-responsive and disability-inclusive frameworks and to delivering relevant support and care systems for all rights holders. **Support and care systems should reflect the rights of carers and care receivers, integrating a disability, gender, intersectional and intercultural perspective.**

60.     Care systems do not commonly integrate the human rights of persons with disabilities in governance. A cross-sectoral institutional framework that facilitates participation of persons with disabilities and their representative organizations in policy design, implementation and monitoring is lacking. **States should consider incorporating the rights of persons with disabilities in law, policy and programmes regulating support and care systems, including dedicated funding for disability inclusion. These revised frameworks should reflect the rights of persons with disabilities, safeguard against the negative effects of traditional care models, recognize their roles as carers and care receivers and promote their autonomy and independence.**

61.     Traditional care models commonly have a fragmented approach to age-based needs, disrupting access to support and care throughout the life cycle. In addition, they rarely reflect an intersectional approach, leaving policy gaps when addressing the situation of caregivers and care receivers, with their multiple identities and experiences. **States should take steps towards adopting a life-cycle approach to the design of policies that recognize the multiple needs that people experience according to their specific realities, including a culturally sensitive perspective.**

62.     Persons with disabilities are underserved by policies promoting time-for-care, cash-for-care and care services. Funding of care systems is commonly directed to services that fail to recognize the capacity of persons with disabilities to decide on the support and care that they receive and overly rely on unsupported families, creating conducive conditions for undesirable practices. **In this context, time-for-care, cash-for-care and disability-inclusive services need to be based on the human rights-based model of disability, guided by inclusive equality standards, ensuring agency and choice and control. Furthermore, the mobilization of community resources must be prioritized.**

63.     Traditional care models and social protection systems do not commonly take into account disability-related extra costs, hence exposing persons with disabilities and their households to higher risks of poverty and exclusion. **Disability assessments need to be in place to properly define the support needs of all persons with disabilities and of their support networks. Time-use surveys need to disaggregate, at a minimum, by disability, gender and age to inform disability-inclusive policy design. However, a lack of data collection should not preclude or delay States from taking steps towards establishing rights-based care systems.**

64.     There is currently limited funding for support and care policies and services that fully recognize the rights of persons with disabilities of all ages. **States should take steps, including through international cooperation, towards enabling policy frameworks that promote support and care systems that are gender responsive and disability inclusive, directing funding to innovation for transformation of care systems, particularly attending to policy objectives related to time for care, cash for care and services that address the human rights of persons with disabilities and that contribute to overcoming development concerns.**