Community 2030 Narrative

Towards sustainable support systems for community inclusion of persons with disabilities

IDA International Disability Alliance

UNITED NATIONS HUMAN RIGHTS OFFICE OF THE HIGH COMMISSIONER

cbm christian blind mission

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IDDC

Why do we need an agenda on support systems for community inclusion?

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Across their life cycle and their diverse layers of identities, all persons have different support requirements, to go to school, to work, to make decisions, to take part in family, community, and public life. Discrimination, whether conscious or unconscious, towards persons with disabilities results in a lack of inclusive policies that ensure adequate supports.

Since the adoption of the United Nations Convention on the Rights of Persons with Disabilities in 2006, disability rights have gained increasing importance on the international agenda. Under the CRPD, persons with disabilities have the right to live independently in the community and decide where and with whom to live.

States 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)). This obligation has been well framed in the CRPD general comments on articles 9, 12 and 19.

In addition, the United Nations' 2030 **Agenda for Sustainable Development**, whose commitment is to leave no one behind, reaching the furthest behind first, **specifically mentions persons with disabilities** in several of its Sustainable Development Goals.

The Commission on the Status of Women[1] (CSW) has recognized that women and girls undertake a disproportionate share of unpaid care and domestic work, including childcare and support for persons with disabilities. The CSW 61st session agreed conclusions stressed the need to promote the equal sharing of responsibilities by prioritizing, inter alia, social protection policies and infrastructure development. This has been reiterated in other UN resolutions on the right to work, women in development, and violence against women, which have also called for sustained investments in the care economy.[2]

Despite these advancements at international level, support systems for persons with disabilities of all ages largely rely on families, particularly women. This way of organising support is facing a crisis in many societies as the 'breadwinner model' – traditionally based on the idea that men work and women provide care and support at home for children, persons with disabilities and older persons – is in decline.

In addition, societies are ageing and the active workforce is reducing. **Ageing societies imply a larger demand for support and care of older persons**. The reduction of the workforce is putting a larger pressure on women to work. Increasing gender parity in labor and the reduction of the workforce has led to more women working and juggling unpaid support and care demands. This is not only unfair to women but **also puts those requiring support at a higher risk of abandonment**.

Given the demographic and labor market changes, the current model of support and care is likely to evolve, and many agree that a new model is emerging. A model that recognizes the societal function that support and care play to ensure equality and dignity and economic empowerment, redistributes

1. Commission on the Status of Women Agreed Conclusions 61st session, para 30, see also para 40(t), https://www.unwomen.org/sites/default/files/Headquarters/Attachments/Sections/CSW/61/CSW Conclusions-61-WEB.pdf
2. 2 A/RES/74/235; A/HRC/RES/31/15; A/HRC/RES/26/5; A/HRC/RES/26/15

better unpaid support and care between men and women and the larger community, and reduces unpaid support and care by combining paid and unpaid support and care.

This situation has led to a strong mobilization of women's rights movements to make the support and care agenda a priority under the unpaid care and domestic work pillar of gender equality under SDG5.4. **Calls for change have been accelerated by the experiences derived from the COVID-19 pandemic**.

Persons with disabilities and the disability rights movement have been active since the beginning to promote support systems that are reflective of the right to exercise their autonomy and direct their own lives.

It is important to understand the nuances across the life cycle with regards to agency, to exercise choice and control over the support persons with disabilities receive. **Under international human rights law, children with disabilities exercise agency according to their 'evolving capacities' from an intrinsic care dependency in early childhood to gaining control into youth and adulthood. Working age adults and older persons with disabilities have full agency and 'care dependency' does not apply to them. Instead, they are entitled to support in order to perform their daily living activities**. Traditional care models do not respect this agency from youth to old age, perpetuating a dependency paradigm for youth and adults with disabilities rather than the support paradigm, based on the CRPD principle of 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons.' Regardless of the system that organizes support for persons with disabilities – long-term care, community-based care, childcare, or other – agency must always be guaranteed according to the lifecycle.

In current conversations on care systems, care is divided into three dimensions: provide care, receive care, and self-care. **The disability rights movement has explored multiple strategies for access to support, defined as the 'receive care' dimension in current conversations on the care agenda**. In addition, persons with disabilities, including older persons with disabilities, their community networks and their family members are also counted as those providing support. In current conversations on care, this is described as the 'provision of care' dimension. 'Self-care' refers to having choice and control over the type of care a person provides and manages for themselves, not only related to their daily living activities or well being, but also in relation to the time they have to do it in comparison with others (women compared to men, higher- compared to lower-income segments, persons with disabilities compared to others).

Persons with disabilities and the disability rights movement have been active since the beginning to promote support systems that are reflective of the right to exercise their autonomy and direct their own lives.

The disability rights movement proposed for human support to be organized through multiple approaches, including one-to-one support (such as personal assistance) or community-based support (peer support, supported decision-making circles, community-based mobilization). These may be paid or unpaid and are commonly combined. While accessing habilitation and rehabilitation may increase persons with disabilities' intrinsic functionality, support systems are needed to compensate for remaining functional limitations and to overcome barriers in the environment that undermine participation. This is why support and care systems from a disability rights perspective are not limited to human support but are combined with assistive technologies, including digital technologies, and transportation. In some cases, human support costs can be reduced through access to assistive technology that enhances functionality without needing as much human support. Equally, assistive technology costs can be reduced with accessible transportation.

The diversity of support strategies properly combined, adjusted to the context and responsive to the life plans of persons with disabilities is a precondition to participation in society for persons with support needs.

Inclusive societies, accessible environments and communities well prepared to engage with persons with disabilities, can reduce support needs to a certain extent. Support, then, fits between the maximum functionality a person with a disability can reach individually and the reduction of support needs that inclusive societies can provide.

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What is the situation of support and care systems?

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Despite the efforts of the disability rights movement, a support agenda as proposed by the movement has not yet been developed as a central function of social protection and health systems. Existing systems largely concentrate on family/household-based provision of support.

While some higher-income countries have developed community-based support services, globally the most common publicly-funded forms of care are still institutionalized services in which service users have little or no control (psychiatric institutions, social care homes, day-care centres, foster homes, geriatric institutions). **In lower income countries, initiatives within Community Based Inclusive Development that seek to provide support for living within the community are rarely supported by public funds, and then need to mobilize volunteers**.

The organisation of support and care, paid or unpaid, has a measurable impact on GDP. Unpaid care work is measurable and represents a significant contribution to economies. Paid support and care work motorize economies as well, although today the conditions of care workers are very precarious. Persons with disabilities, older persons and children are largely represented on the receiving end of care, and less represented in the provision of care and in self-care. The recognition of these aspects is key to improve quality of support and care.

The current conversations on support and care are usually unilateral with two clear dimensions. On one side, the women's rights movement presents three clear asks under the 5Rs framework: time for care, cash for care and redistribution of care by combining services and unpaid care. On the other side, service providers are requesting a larger investment in service provision, largely sustaining the status quo.

These dimensions **have not yet involved persons with disabilities to make sure that all these requests are presented in compliance with human rights standards applicable under the Convention on the Rights of Persons with Disabilities**. Leading voices on the care agenda, nevertheless, are eager to include persons with disabilities and their views in the conversation.[3] This represents an opportunity to be part of the broader conversation on what is currently being portrayed as a fourth pillar of social protection systems.[4]

Quality of services should be measured against human rights standards applicable to persons with disabilities, but also at the intersection of age, applying to children, youth, and older persons. A life cycle approach is also needed in the care and support agenda, to make sure that rights and services are respectful of the evolving capacities of children and that transitioning to young age, adult life and old age are not considered with a siloed approach.

Given the existing focus on institutionalized services in some contexts, service transformation should be an integral part of the support and care

3. ECLAC, UN Women, *Towards the construction of Comprehensive Care Systems in Latin America and the Caribbean*: *Elements for Implementation*. Available at: https://lac.unwomen.org/en/digiteca/publicaciones/2021/11/hacia-la-construccion-de-sistemas-integrales-de-cuidados-en-america-latina-y-el-caribe 10, 23, 37 (Accessed 30 August 2022)
4. The Global Alliance for Care made a public invitation to the international disability community to join it during COSP15; ILO Report: Care work and care jobs for the future of decent work (ilo.org), highlights the need for involving persons with disabilities.

agenda. This is currently missing in the global and regional debates on support and care as well as in the disability inclusion strategies launched by governments, with certain exceptions. Regional realities are also missing in the current discussions on support and care, including cultural aspects and financial resources. A larger reflection on the universality of the support and care agenda is needed.

The largest support and care economies continue to be in middle- and high-income countries that have stronger social protection systems. Good examples of support and care systems are coming at the legal level at least, from countries like Argentina, Costa Rica and Uruguay, in which care systems with different levels of inclusion are considering human rights-based perspectives in their design. A significant challenge in many high-income countries is that they often have well-resourced service providers acting as a strong lobby group against reform, entrenching the status quo regardless of CRPD standards.

The disability rights movement is particularly well positioned to contribute to the support and care agenda as it is, together with the women's rights movement, a first-person movement that can represent the voices of persons with disabilities across the life cycle. This is not the same situation with children that are represented through children's rights organizations, or older persons who have not yet organized as a first-person movement and whose voices are largely replaced by health and social care professionals and service providers.

Current care conceptual frameworks mirror, with a different perspective but with similar objectives, the long-standing work of the disability rights movement. To ensure that the rights of those providing and receiving care and support are respected, several vital elements need to intersect: the **demand** from persons with disabilities, children and older persons; the paid and unpaid **offer** of care provided by caregivers and support systems; the **integral dimensions** of provide care and support, receive care and support and self-care; the **policy objectives** of time for care and support, cash for care and support and redistribution between paid/unpaid care; and good **quality** care and support. This could pave the way for a new social contract to build back better after the pandemic.

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How is the international community considering the support and care agenda?

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The resolution 49/12 of the Human Rights Council acknowledged the discussion on support and care by mandating the Office of the High Commissioner for Human Rights (OHCHR) to prepare two reports on "support systems to ensure community inclusion of persons with disabilities, including as a means of building forward better after the COVID-19 pandemic".

The first report presents a human rights based approach to support and care systems based on the CRPD and the second will illustrate the first report with good practices. The Special Rapporteur on the rights of persons with disabilities presented at the 52nd session of the Human Rights Council (A/HRC/52/32) on service transformation already provides guidance on this component of the support and care agenda. The upcoming **United Nations Disability and Development Report** (launch planned for 2023) will also include a chapter on community support and care presenting data on the status of implementation.

The United Nations Secretary General in his vision on addressing the current and future challenges people face in the 21st century, "Our common agenda", has made care systems a priority. UN Women in its strategic plan made care the first point of the agenda. International cooperation agencies are mobilizing resources to support this work. **OHCHR, UNICEF, ILO, UNDP and UN Women (lead) submitted a high impact initiative to accelerate SDG5.4 implementation, currently under consideration**.

The **Global Disability Summit 2022** has highlighted the renewed commitment of States to advance the inclusion of persons with disabilities. During the summit, representatives of all stakeholder groups, including 44 countries, made approximately 1,300 commitments. **Participants recognized the need for further efforts to strengthen community inclusion**, including through inclusive social protection systems, the promotion of community-based services, and the availability and affordability of assistive technology and individual support. Without support and care systems, many persons with disabilities, particularly those with the highest support needs, are not able to participate fully in their communities and on equal terms with others. Furthermore, without adequate support, persons with disabilities are at higher risk of falling into poverty, abandonment, and institutionalization, as well as being victims of various forms of violence and abuse.

Community 2030 – Context and opportunities for a new initiative

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While making all infrastructure facilities and services inclusive and accessible is a long-term endeavour, developing community support services and systems can enable participation and inclusion by providing the support needed to overcome the consequences of functional limitations and barriers in the environment.

At the same time, the increasing attention and focus on unpaid care work, inclusion in different sectors, advances in disability data collection, social protection, and digitization, combined with greater awareness about the failures of traditional care policies, the needs of ageing populations, and the potential emergence of a more inclusive generation provide countries and stakeholders with **unprecedented opportunities to develop inclusive community support systems**.

Lessons learned from deinstitutionalization reform as well as community-based rehabilitation and inclusive development programs showed that achieving progressively universal access to such support requires mobilization and coordination of responsibilities within and among central and local authorities, organizations of persons with disabilities and their families, NGOs, private sector, development and humanitarian agencies as well as significant redistribution of public financing over time. It is important to recognize that many persons with disabilities live in institutions; data from low- and middle-income countries indicate that 4–15% of persons with disabilities currently live in institutions or special homes where they are often subjected to human rights abuses, inadequate living conditions and unregulated and poor-quality services. Yet, deinstitutionalization can itself pose risks such as homelessness or neglect for people with disabilities if conducted without a properly regulated and resourced systematic process to provide appropriate support, including access to affordable accommodation and appropriate community care, and support to carers. The CRPD Committee Guidelines on deinstitutionalization, including in emergencies is a tool that could be used to overcome the challenges related to deinstitutionalization.

In the current context, there is an important opportunity to bring global agendas and movements together in a new global partnership around the topic of community support. The Global Alliance for Care is already organised behind the women's rights goals and it can also represent an opportunity.

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Community 2030 – Proposed solution and way forward

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The "Community 2030" partnership works towards ensuring that the Post-2030 Agenda includes community-based support systems and services as an essential function of development.

Community 2030 proposes to advocate globally, regionally and nationally for the inclusion of persons with disabilities and their human rights in the care agenda and to progressively create a care and support agenda that recognizes the diversity of needs of women, children, older persons and persons with disabilities across the life cycle. To this end, it will work on the three dimensions of support and care (provide support and care, receive support and care, and self-support/self-care), addressing persons with disabilities and women of all ages, with the aim of meeting the 5Rs framework.[5] Community 2030 will contribute to defining the CRPD-compliant policy dimensions in the intersectionality of these axes:

	Provide care and support				Receive care and support				Self-care			
Time for care and support												
Cash for care and support												
Support and care services												
Groups	Women	Adults with disabilities	Children with disabilities	Older persons with disabilities	Women	Adults with disabilities	Children with disabilities	Older persons with disabilities	Women	Adults with disabilities	Children with disabilities	Older persons with disabilities

The matrix above provides an illustration of the intersectionality of the dimensions of support and care, the demands of support and care systems and the groups involved. Each box provides for one or more representative public policies.

Autonomy is at the centre of support and care, in all its dimensions. Disability support and care systems must be built on the free exercise of legal capacity, the equal recognition before the law and the right to support in decision making. Equally, they must

5. Recognize, reduce, redistribute, reward and representation. See A toolkit on paid and unpaid care work: From 3Rs to 5Rs | Publications | UN Women – Headquarters

be built on the right to liberty of person, aiming at eliminating structures that contribute to arbitrary deprivation of liberty while facilitating the reduction of arbitrary detention.

To this end, CRPD-compliant policy guidance will focus on the following thematic areas of care and support to ensure full community inclusion and independent living of persons with disabilities of all age groups and across the life cycle. These thematic areas include networks of services, people and products that enable persons with disabilities to carry out activities of daily living and to actively participate in their communities. When planning and implementing activities, "Community 2030" will focus on these core topics for all community members with specific support needs across the life cycle.

1. Social protection covering extra support costs

Social protection systems have a critical role to play in supporting inclusion of persons with disabilities across the life cycle. As specified in the Joint statement on inclusive social protection systems, states should progressively ensure access to a set of benefits in cash and in kind providing basic income security as well as coverage of support and care and disability related costs, including community care and support services. Design of cash transfers and in-kind benefits (concessions or services) should always aim at inclusion and empowerment. Social protection systems can also play a critical role in developing gatekeeping mechanisms and information systems for administrative identification of persons with disabilities and their support needs, enabling case management and policy planning.

2. Human Assistance

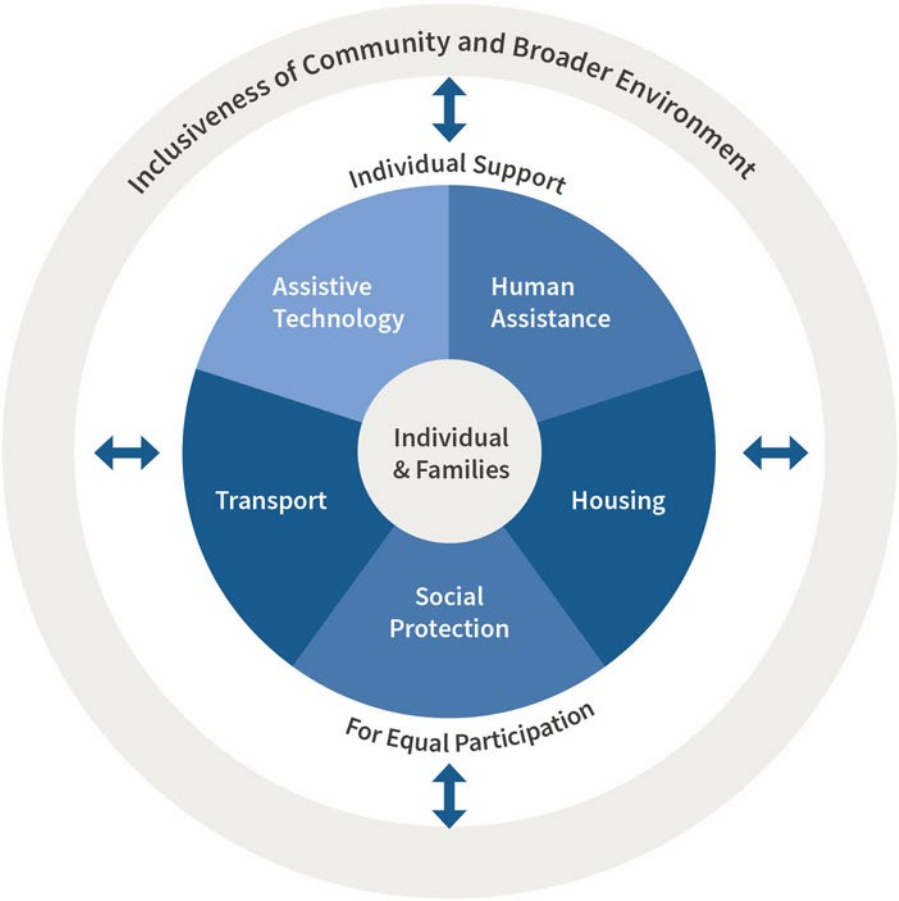
Human assistance, whether paid or unpaid, should be provided in a manner which respects voice, choice and autonomy of the person being supported, including access to decision making support. Investing in the capacity and remuneration of home and community based human supports is an essential catalyst and multiplier of other care and support solutions while strengthening the full and effective inclusion and participation of women, men, girls, boys, and older persons with disabilities. Redistributing care work among men and women, between families, communities and states, and valuing and investing in human support will ease the disproportionate burden experienced by family members, in particular women and girls in the household in low-, middle- and high-income countries and particularly compounded for women and girls living in poverty.

3. Assistive technologies

Persons with disabilities with high-support needs may never completely cease to require human support. However, assistive technologies are key to increasing individual functioning with autonomy and, in turn, reduce the demand for human support. Access to quality assistive technology facilitates inclusion in education, work, family and community life, and helps reduce health inequities, but currently only 10% of those who need an assistive product have access to it. Assistive products need to be affordable and available in all regions, with support provided for overcoming environmental barriers in the specific context where they are used. States should have the capacity to replace assistive products, maintain and replace them in cases in which functional limitations evolve, and provide affordable maintenance services.

4. Transport

Mobility cannot be ensured only through assistive products. Also, a combination of human support and transportation is required to ensure this right in certain contexts, particularly in rural areas or in inaccessible environments that will remain



inaccessible due to topological characteristics. Accessible transport is developed according to the demand, starting with point-to-point transport and scaling up into paratransit (collective transport for persons with reduced mobility) and flexi-lines (flexibility to get on and off public transport flexibly e.g. close to home), mass transport as well as inter-urban and international transport. For instance, transport is essential for facilitating access to education, to employment etc. In addition, good transport will reduce time required for human care.

5. Housing

Accessible and affordable housing is a precondition to living independently in the community. Working towards housing support is also key to preventing institutionalization. Rental subsidies, social housing, supported housing, home adaptation, among other policy solutions need to be integrated into support and care systems to ensure community living.

To ensure a broad consensus, the initiative is built on a collaborative partnership between the disability movement and civil society organizations, in particular women's, older person's and children's organizations, disability specific and mainstream service providers, UN agencies, donors and States. These partners will work together to:

- Define the demand of support structures and contribute community- and experience-based solutions
- Collect and highlight the support needs of persons with different impairments and across different types of identities
- Influence the 2030 negotiations on new UN development goals, including by developing standards and guidelines for good practice in inclusive community development that will be implemented by UN country teams and other stakeholders.

This document has been developed by the "Community 2030" core group to ensure consistent and aligned communication to stakeholders about the global "Community 2030"partnership.

June 2023

Cover Image: Six-year-old Esther, who has cerebral palsy, with her mother Edda, brother Mike, and grandparents Tobias and Mary, at home in Lilongwe, Malawi. Esther normally uses her wheelchair to get to school, but recent rains damaged the road and made the journey impossible.