



The Disability Support Gap:

Community support systems for persons with disabilities in low- and middle-income countries

Advanced unedited version

Discussion paper

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Introduction

Disability inclusion requires community support for persons with disabilities. Supporting one another is an intrinsic element of community life. The human condition is one of interdependency: everyone needs help from others in many areas of life. Some forms of support are taken for granted and naturally embedded in society. Still, the additional support that many persons with disabilities require to participate in community and live with dignity is often not available, creating significant inequalities in participation and the exercise of rights.

Across the life cycle and diversity of identities, persons with disabilities have different support requirements in various life domains, such as communication, decision making, self-care, mobility, and housing, which are often poorly met or unmet. Globally, families and close communities are the primary providers of support, with significant issues regarding lack of choice for persons with disabilities and substantial opportunity costs for those providing support, especially women and girls.

The situation is particularly dire in low- and middle-income countries (LMICs), where formal support services for persons with disabilities are under-developed or simply non-existent. As a result, persons with disabilities rely primarily or solely on their families and communities to get the support they need, facing high disability-related costs and barriers to true inclusion. Often, the few existing support services are provided by non-governmental organizations (NGOs), with little to no government engagement and no overarching policy framework. Since the adoption of

the Convention of the Rights of Persons with Disabilities (CRPD), there has been an increase in investments in accessibility, disability mainstreaming, and, more recently, assistive technologies and social protection. Still, less so on how persons with disabilities can access the support they need for participation and inclusion, especially in LMICs.

The lack of publicly funded community support in LMICs is a significant source of direct and indirect disability-related costs for persons with disabilities and their families; they must pay for such support or family members either stop working, work less or take less remunerative work that provides them the flexibility to provide support.¹ This situation increases the likelihood of persons with disabilities living in poverty, experiencing violence and neglect, being institutionalised, and being denied legal capacity. It also raises significant gender inequality implications as most unpaid support is provided by women and girls, with significant impacts on their education, health, income, and life opportunities. While families and communities will undoubtedly remain a critical source of support, formal mechanisms and services should be developed to provide equal participation, choice, and opportunities for persons with disabilities while fostering gender equality.

The global crisis caused by COVID-19 has painfully exposed many countries' inability to provide adequate support to persons with disabilities. When schools closed, many children with disabilities were left without any form of support, including therapists and one-to-one supporters. The high death rate in institutions and the dramatic disruption of family and community supports underscored the limited capacity of countries to provide support to children, working-age adults and older persons with disabilities to live and participate equally in their communities with dignity, autonomy, safety, and choice.

This discussion paper aims to provide a conceptual framework for understanding disability-related support requirements across the life cycle and an overview of the issues related to developing support systems and services for persons with disabilities in LMICs to foster inclusion, choice and gender equality, in line with human rights standards.

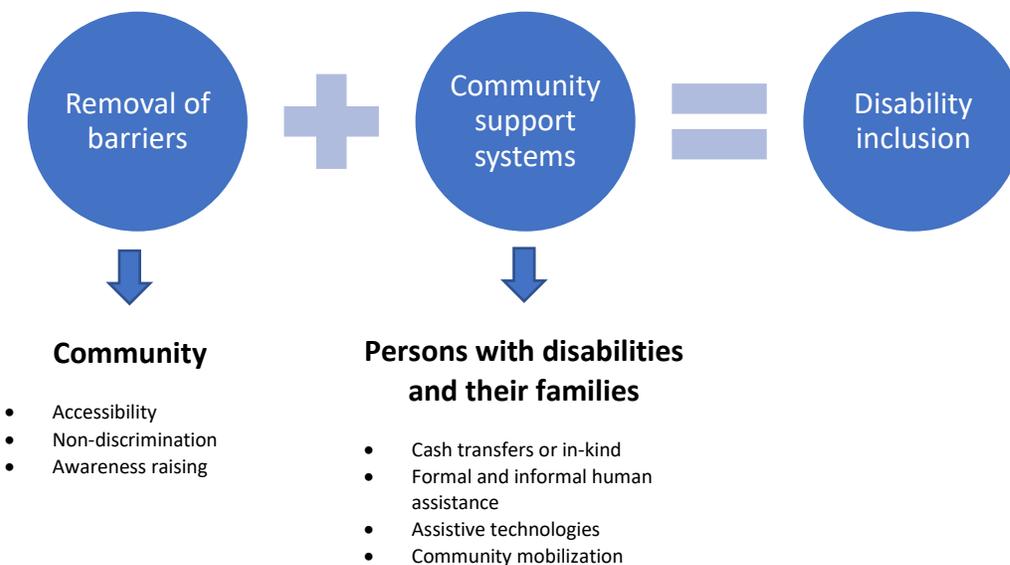
1. Community support systems for persons with disabilities

Community support systems refer to the combination of services, products, organisations and people (e.g., friends, family, peers, NGOs, religious and civic organizations, local authorities, social services), that assist persons with disabilities to carry out daily life activities and participate in their communities. These include human assistance and assistive technology to support communication, decision-making, personal assistance, mobility, housing, and other life activities.² It can be delivered as one to one support (personal assistance for instance) and by community organising (circle of support, peer support group..).

Community support systems provided formally or informally. Formal community support services are those directly provided or funded by governments or the private sector, whereas informal community support refer to those provided directly by people in the community without state or private support, such as unpaid assistance and peer-support.

Community support systems is a critical component for disability inclusion, together with the removal of barriers for participation (see **Figure 1**). They enable, connect, and leverage accessibility and inclusion efforts by filling the gap between general services and facilities and people’s individual requirements. In doing so, community support systems ensure the most marginalised are not left behind, increasing their opportunities and enabling them to have better control over their own lives.

Figure 1. Community support as a critical component for disability inclusion



Support requirements vary according to the circumstances and characteristics of each individual, including age, sex, gender, type and degree of impairment, individual preferences and culture. A person with disabilities may require support in one or more areas of life. The following table describes, in a non-exhaustive way, key domains of community support (see **Table 1**).

Table 1: Key domains of community support systems

Formal or informal interventions - Services or products			
Domains	Description	Examples	Mostly used by
Communication CRPD, arts. 19, 21	Support to overcome barriers that limit the ability to communicate and be understood.	e.g., sign language interpretation, tactile interpretation, assistive technology and software, easy-to-read and plain language, , captioning, augmentative and alternative communication, among others. Speech and language therapy or often useful as well	Deaf and hard of hearing persons, blind and persons with low vision, deafblind persons, persons with speech impairments, persons with physical or intellectual disabilities.
Decision-making CRPD, arts. 12, 19	Support to make decisions and exercise legal capacity. This includes assistance to: (a) obtain and understand information, (b) evaluate the possible alternatives and consequences of a decision, (c) express and communicate a decision, and/or (d) implement a decision.	e.g., support agreements, peer support, self-advocacy support, advance directives, crisis support, financial management assistance, among others.	Persons with intellectual disabilities; persons with psychosocial disabilities; persons with high support needs; older persons with cognitive disabilities.
Mobility CRPD, arts. 9, 19, 20	Support for personal mobility and access to affordable and available quality mobility assistance. This includes training in mobility skills to persons with disabilities and staff working with them. They help overcome lack of or limited accessibility of existing public transport	e.g., mobility aids, , assistive technologies and devices (prostheses, orthotics, wheelchairs), interpreter-guide, personal assistant assistance animals, point-to-point transport, among others.	Persons with mobility impairments, blind persons and persons with low vision, persons with intellectual disabilities, persons with psychosocial disabilities, persons with deafblindness.
Assistance with daily life CRPD, arts. 12, 19	Support to assist persons with disabilities in a one-to-one relationship to perform daily life activities like getting up, bathing, dressing, grooming, going out, cooking, cleaning, guiding, shopping, or laundry.	e.g., full or part time professional personal assistance, paid friends or family members, informal personal assistance, household cleaner, equipment for independence, among others. Assistive technology and home adaptation	Persons with disabilities with high support needs, across the life cycle.
Housing and accommodation CRPD, arts. 19, 28	Support in relation to housing and living arrangements, including home modifications.	e.g., housing information and assistance, home support, supported living services, respite services, among others.	Persons with disabilities with high support needs, across the life cycle.
Family support CRPD, art. 8, 16, 19, 23, 28 UNCRC art. 18, 23	Training and support to families providing informal support for persons with disabilities.	e.g., awareness-raising, peer support groups, support on parenting strategies, surrounding support services (such as day care), early childhood support, respite care, advocacy and legal support, among others.	Families of all persons with disabilities, especially of children with disabilities

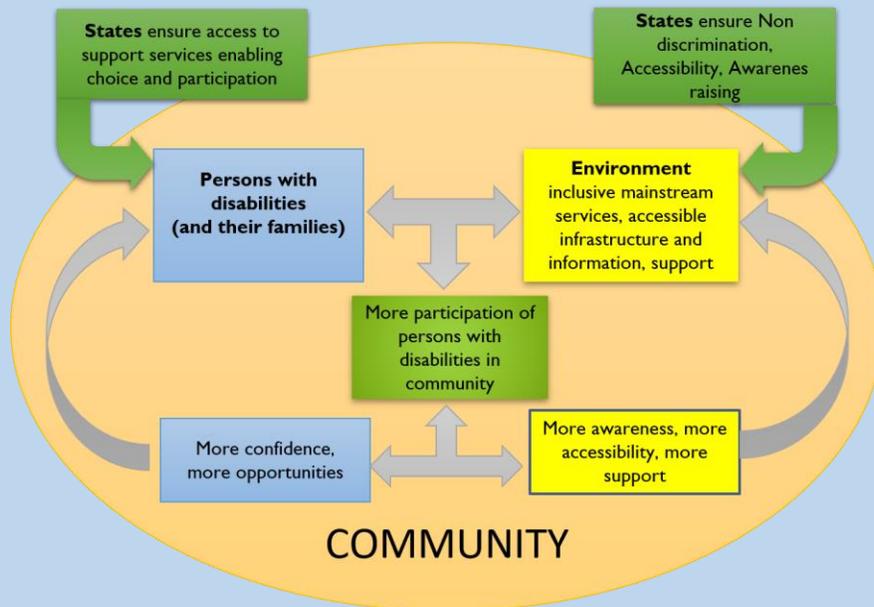
The lack of formal support services negatively impacts both persons with disabilities and their families. It can make persons with disabilities overly dependent on family members, affecting the social and economic opportunities of both individuals with disabilities and their families.³ For example, when people do not get the support they need to go to school or work, family members, often women and girls, may have to stop working or going to school to provide the support required. This situation, in turn, can lead households into poverty and prevent their sustainable escape from it. It can also contribute to burnout of family members providing support with significant consequences on their health and increased risk of neglect and abuse towards persons with disabilities.

Community support is a crucial precondition for the realisation of human rights and inclusive development. Community support systems help persons with disabilities to be fully included and live independently in their communities with enhanced self-determination and independence and with equal choices to others. For many persons with disabilities, access to such support is a precondition for participating in society and living with dignity.⁴ For children with disabilities, such support systems are key to live with family and to develop greater personal autonomy and independence as they grow up. Without community support, many persons with disabilities would not communicate, get out of bed, bathe, eat, leave the house, go to school or work, or participate in community activities and public life. In addition, support services can enable many persons with disabilities who would otherwise be considered unable to work to engage in employment. Parents of children with disabilities need support and guidance on how to encourage their children to have greater self-determination; with practice, support, refinement of the skills early in life children with disabilities are more prepared for transitioning to adulthood and greater independence. Community support can also help overcome remaining barriers in the environment and make health, education, justice, and other mainstream services inclusive. Further, access to formal support services provides employment prospects for family members who provide support.⁵

Access to community support is a prerequisite to ensure that persons with disabilities are not left behind in realising the Sustainable Development Goals (SDGs). It is integral to target 10.2 (empower and promote the social, economic and political inclusion of all) and key to achieve Goal 1 on poverty reduction, Goal 2 on health and wellbeing, Goal 4 on quality education, Goal 5 on gender equality, Goal 8 on decent work and inclusive growth, among others.

Box 1. The virtuous circle of disability inclusion

Disability inclusion requires both the removal of barriers for inclusion and the provision of support for participation, which reinforce each other in a virtuous circle.



While removing barriers may be a long-term endeavour, the provision of community support services can increase participation immediately. For example, adjusting the public infrastructure and transportation system as well as community facilities to meet accessibility standards is a long-term goal in many contexts. Providing assistive devices, personal assistance or guide interpreter and implementing point-to-point transport can partially offset the lack of accessibility and enhances immediately participation. This increase in participation despite existing barriers allows better visibility of persons with disabilities and the need to eliminate barriers and raise awareness of stakeholders in the community to provide more support and remove barriers.

As barriers are removed the need for some community support services will ultimately decrease but many persons with disabilities will continuously require some level of support. For example, some persons with disabilities need the support of a personal assistant to perform daily life activities such as bathing or eating. Similarly, some persons with disabilities need supported decision-making services or an interpreter for effective communication. Furthermore, progress in removing barriers is likely to increase the demand for community support as persons with disabilities will have more awareness and opportunities to study, work, or participate in public life.

Under the CRPD state have the duty to simultaneously invest in systematic removal of barriers in community through awareness raising, non-discrimination and accessibility as well as providing individual support to facilitate immediate participation. In many contexts considering public resources' limitation, community resources mobilisation will always be needed to make needed support available. Policies and services need to be developed to optimise to make the best use of both public and community resources in ways that foster both autonomy of persons with disabilities as well as gender equality.

From segregation to community inclusion

The CRPD, ratified by 182 States Parties, represents a shift from institutional and segregated care provision to community-based support. Traditionally, lower or no expectations for children and adults with disabilities led to the view that they were not capable of participating in everyday social and economic activities and the additional support required by persons with disabilities was viewed as a 'dependency' and a 'burden' disqualifying them from participation and inclusion. Services, where they existed, were conceived under a medical or charity model, emphasising protection and the need for being taken care of rather than the promotion of autonomy and independence. This approach led to the institutionalisation of millions of children, adults, and older persons with disabilities worldwide. For this reason, the notions of care and caregiving often bear a heavy historical connotation for many persons with disabilities associated with oppression and segregation.⁶

The CRPD recognises the right of persons with disabilities to live independently in the community and considers access to community support integral to it. Under the CRPD, ensuring access to support is a cross-cutting obligation, and the provision of specific forms of support is referred to in many of its articles.⁷ For example, article 19 on living independently and being included in the community stresses the obligation of State Parties to ensure that persons with disabilities have control over the support they receive; this necessarily implies 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. Article 28 on an adequate standard of living and social protection also emphasises states' obligation to ensure access to quality and affordable disability services and devices and to support coverage of disability-related costs.

The CRPD does not prescribe any specific system for the provision of community support. It acknowledges that countries may respond differently to designing community support systems and delivering support services based on their political systems, economic development, cultural traditions, and social norms. However, the Committee on the Rights of Persons with Disabilities – the body of independent experts which monitors implementation of the CRPD – has provided in its General Comment No 5 (2017)⁸ a set of guiding principles for the provision of community support:

- Respect for the inherent dignity and autonomy of persons with disabilities.
- Be available, universally accessible, affordable, acceptable, and adaptable for all persons with disabilities within the community.
- Be individualised according to their requirements and personal preferences
- Be flexible to adapt to the needs of the service user and not the other way round.
- Enable choice and control over the way support is provided.
- Enhance community inclusion and combat segregation or isolation.

- Have a holistic approach to provide services within all domains of life, including employment, education, and political and cultural participation.

Gender considerations are critical for the design of community support systems. On the one hand, women and girls with disabilities regularly experience non-responsiveness of services, encounter a heightened risk of abuse, neglect, and violence⁹, and face cultural norms and values that adversely restrict their autonomy and choices¹⁰. In addition, family members other than their primary supporters may not see merit in spending any resources to support them.¹¹ On the other hand, most of the unpaid support is provided by women and girls with a significant impact on their life opportunities and health. Therefore, when designing and implementing support systems, the multiple and intersectional discrimination experienced by them must be taken into account.

Box 2. Reasonable accommodation and community support

The requirement to provide reasonable accommodation is distinct from, although complementary to, the obligation to provide support.

To promote equality and eliminate discrimination, as per the CRPD, States are required to ensure that reasonable accommodation is provided by a wide range of duty bearers (employers, public and private services and facilities open or for the use of the public...). Reasonable accommodation refers to all necessary and appropriate modifications and adjustments that ensure that a person with a disability can enjoy and exercise their human rights and fundamental freedoms on an equal basis with others. In this sense, reasonable accommodations can be implemented in different settings such as the labour market, education and health services, or public events. A reasonable accommodation is an immediate obligation, and it should not impose a disproportionate or undue burden on the duty-bearer. Denial of reasonable accommodation is considered a form of discrimination.

Reasonable accommodation can be used to ensure support for a person with disabilities in a particular situation, such as ensuring access to supported decision-making in using banking services or getting additional assistance in a health care service, a restaurant or a shop. However, supports provided through reasonable accommodation are bound to the entities legally obliged to provide such accommodation and are limited by the concept of disproportionate or undue burden, and may not cover activities carried out outside public settings, such assistance at home or in the private sphere.. Therefore, there is always a need to develop community support systems and services.

Example: a deaf person using sign language may access sign language interpretation from their employer in the formal sector, or the public hospital or public administration as it is their legal obligation to ensure non-discrimination, but there would be a need for other financing arrangement with regards to access sign language interpretation in informal work or community gathering, family life...

A lifecycle approach to community support

While some support requirements are present throughout the lifecycle, such as mobility and communication support, some requirements change or are more relevant in certain lifecycle stages, from childhood to old age. Therefore, a lifecycle approach to community support that underscores the support requirements throughout a person's life is required to implement effective policy responses based on people's actual requirements.

Children with disabilities and their families require community support systems that enable them to reach their full potential and participate equally. While also related to health care and rehabilitation, early childhood interventions designed to meet the needs of children between birth and five years who are physically, cognitively, communicative, socially, and/or emotionally developmentally delayed or have a diagnosed condition are critical as they can prevent aggravation of initial impairment, increase functioning and address possible risk of neglect and abuse resulting from lack of awareness and support to parents. A continuum of individualised support services has to be available and adapted to the changing needs of children and families as they develop and mature. The support provided needs to build the skills and competencies of children with disabilities to enable them to successfully navigate and participate in school, social interactions, and recreation and leisure activities. Supports may include assistive technology suitable for them, including paediatric devices; support in communication such as having sign language interpreters and teaching hearing parents of deaf children sign; physical, occupational speech therapy; parenting guidance. As children grow older they may require personal assistance or sign language interpreters to take part in activities with their peers. Moreover, their families may need assistance to understand disability in a positive frame and have adequate knowledge to support their child with disabilities to become autonomous and independent.¹² They may also need support on advocating for their children's rights, including legal support. Some may also need respite service options that offer short-term breaks and avoid burn-out of the family. The lack of support increases dramatically the risk of abandonment and institutionalisation.

Youth with disabilities require support for completing basic education or pursuing higher education. This age group can also benefit from support for social interaction with peers and participation in leisure activities, which are crucial to prevent isolation and feelings of loneliness. Youth with disabilities may also need assistance in accessing and understanding sexual and reproductive health information and services. Furthermore, many youths with disabilities need support to transition into adulthood. This includes the provision of community support that helps youth move out of their family homes into independent or assisted living arrangements, access to vocational training, and supports that facilitate entering the labour market.

Adults with disabilities require support for participating in the job market. This can entail job-seeking support, job coaches, return-to-work programmes, personal assistance in the workplace, among other support services. They may also need assistance to live independently in the community, including in-home support, personal assistance, and support for housing and accommodation. Adults with disabilities may also need help for fulfilling their family responsibilities and participating in the community. Appropriate parenting supports, including help with supervising, lifting and carrying, bathing and grooming, recreational activities are

essential to the lives of parents with disabilities and their children. Lack of proper supports can result in family separation. This includes support for parents with disabilities, communication support, mobility and travel assistance, advocacy support services, supported decision-making, and financial management assistance.

Older persons with disabilities represent a significant percentage of the overall population aged 60 years and above—46 per cent – whose support needs are often invisible.¹³ Indeed, while many older persons acquiring functional difficulties as they age may not self-identify or be considered persons with disabilities, they may also require in-home support, assistive technologies, assisted living arrangements and companionship to maintain autonomy and live in their own homes and communities. Older persons with disabilities may also need additional support to participate in community activities, including mobility, communication, self-care, and decision-making. As the share of older persons increases, greater attention is needed to the support requirements of older persons with disabilities and its framing under the CRPD paradigm.

The role of social protection

Social protection is critical to ensure income security, cover health care and disability-related costs, including community support for persons with disabilities. Even if social protection systems – combining both mainstream schemes and those targeting persons with disabilities only – may not always have the responsibility to provide community support services directly, they are critical in identifying, planning, gatekeeping, and financing such assistance. In most high-income countries (HICs), social protection systems, , cover the costs of the support required by persons with disabilities with a combination of cash transfer, health or long-term care insurance and direct service provision (see **Box 3**). In LMICs, only a few countries such as Costa Rica¹⁴, Tunisia¹⁵ and Thailand¹⁶ have attempted to implement personal assistance services, albeit with low coverage. Other countries such as Kenya¹⁷, Indonesia¹⁸ and Peru¹⁹ provide cash transfers to low-income families with a member with high support needs, but it is unclear if the value of these transfers is sufficient to address disability costs; they are also delivered in ways that do not foster choice and control for individuals with disabilities themselves, for instance, by requiring that another household member receive and manage the transfer. South Africa has a ‘grant-in-aid’ for beneficiaries of the disability grant and old age pension that helps to cover a small part of the third person’s support. Health insurance coverage of disability related services is low in many LMICs; but countries such as Turkey, Kazakhstan and Montenegro include a variety of rehabilitation services in their healthcare packages for both children and adults with disabilities (UNICEF, 2019). Assistive devices for children and adults can be covered by health insurance (Turkey, Serbia, Montenegro, Philippines, Thailand), provided in-kind (Tajikistan, Kyrgyzstan, Kenya) or by social assistance, either cash or voucher (Georgia, Bulgaria) (UNICEF, 2019)

Eligibility criteria design plays a vital role in facilitating access to community support services. Governments must decide who is eligible for accessing support services and receiving government aid either through social protection mechanisms or through their universal health care system (e.g., assistive devices). This determination of eligibility may include disability certification and means-tested thresholds. In some LMICs, access to community support services

is limited to persons with disabilities who are eligible for means-tested social protection programmes, whose thresholds may not consider disability-related costs. These eligibility criteria exclude persons with disabilities who live in households not regarded as poor but still cannot afford the support services they need. In addition, eligibility criteria based on incapacity to work undermines the development and access to community support services by lowering expectations on the potential of participation of persons with disabilities.

Disability assessments and certification mechanisms are central for designing community support systems. Despite the adoption of the CRPD, disability assessment and certification processes remain mainly medical (assessing impairment, medical diagnoses) or, if functionally based, rarely consider support requirements²⁰ and are often cumbersome and not easy to access. Countries need to ensure disability assessments are easily accessible by all persons with disabilities and incorporate a human rights-based approach to disability, emphasising support requirements and societal barriers. Disability assessments should be flexible and periodic to account for changing support needs, especially as children and adults with disabilities age or living situations change. Disability assessments need to be age appropriate; and take into consideration children’s developing capacities. Disability assessments should not merely be used to deliver disability certificates or determine eligibility to few benefits but also to collect information relevant for case management and policy planning to provide community support for full participation. The interoperability of information systems is critical for ensuring shared access to information on support requirements across programs.

The growing investment in the development of social protection systems in LMICs, in part as a response to COVID-19 and the renewed mobilisation for deinstitutionalisation, offers a window of opportunity for mobilising and leveraging significant resources for community support. However, seizing this opportunity requires collaborative work at the global and national levels from governments, development agencies, service providers and organisations of persons with disabilities.

Box 3

Case Study: National Disability Insurance Scheme, Australia

The Australian National Disability Insurance Scheme (NDIS), launched in July 2013,²¹ represents a major reform on how disability services and support can be delivered. The NDIS was born out of an inquiry into disability care and support, which found the existing system was underfunded, fragmented and unfair,²² and established a new system for individualized support for persons with disabilities, their families, and carers.

The NDIS provides all Australians with a ‘permanent and significant disability’, aged under 65, with the ‘reasonable and necessary’ supports they need to live an ordinary life.²³ Eligible persons are given a plan of supports that is developed and tailored to their individual requirements. For example, a plan could include informal supports that a person receives through family, friends, mainstream, or other community services. If required, the NDIS will also fund reasonable and necessary supports that help participants achieve their goals.

The NDIS takes an insurance-based approach and moves away from the previous ‘block funding’ system to agencies or organizations to deliver services. Instead, it relies on a fee-for-service, market-based system, which provides funding to persons with disabilities to access the supports they need. It aims to provide individualized funding based on support requirements and give back people’s choice and control over the supports they receive.

The NDIS may fund three types of support budgets:

- **Core supports:** They support everyday activities, which include consumables (e.g., continence products or low-cost assistive technology), support for daily activities (e.g., self-care), assistance with engaging in social and recreational activities, and transport costs.
- **Capacity building supports:** They help persons with disabilities to build their independence and skills. These include support to access services, employment, or lifelong learning; to obtain and retain appropriate accommodation; and to develop skills for social and community participation.
- **Capital supports:** They support access to higher-cost pieces of assistive technology, equipment and home or vehicle modifications, and funding for one-off purchases.

The amount of funding for each category varies from plan to plan, and it is based on people’s individual requirements. The funding can either be flexible or fixed, but most funding for core support is flexible. There are three options to manage the NDIS funding: **self-managed**, in which the National Disability Insurance Agency (NDIA) provides funding to the individual so they can access the supports that will best help them; **plan-managed**, in which the NDIA will provide funding to pay for a Plan Manager who pays the providers; and **NDIA-managed**, in which the NDIA pays providers on people’s behalf. Persons with disabilities can choose a combination of these options.

Although many persons have benefited from the NDIS, challenges remain, and the NDIS continues to undergo review and change. Concerns include inconsistent and inequitable access related to the determination of people’s functional capacity; thin markets, in which participants have funding but are unable to access supports due to a lack of service providers, especially in rural and remote areas; complexities for many participants and service providers in navigating the administrative requirements of the NDIS; and inconsistencies and inequities in levels of funding received. These challenges, all of which impact the central tenet of giving ‘choice and control’ to persons with disabilities, must be carefully navigated by governments and policymakers seeking to introduce similar individualized, needs-based funding schemes.

2. Community support in low- and middle-income countries

While the CRPD requires all persons with disabilities to have access to adequate, appropriate, and affordable community support services, persons with disabilities experience significant unmet support needs throughout the world.²⁴ For example, only 1 in 10 persons in need has access to assistive technology.²⁵ The situation is even direr in relation to other forms of support, such as personal assistance, communication support, or living arrangements. Even in high-income countries where such services are available,²⁶ they are commonly underfunded, have limited portability, lack user involvement, are dependent on the individual's family situation, provided in segregated settings, or are not fully covered by social protection schemes.²⁷ This situation has led to an uneven quality of support, high out-of-pocket payments, and overreliance on informal support provided by family and friends.

In most LMICs, community support systems and services are underdeveloped or just non-existent. Families are expected to be the main, if not only, source of support, with no or little support from governments. This has a significant negative impact on persons with disabilities and their families. On the one hand, individuals lose choice and control over the support they receive, and disputes related to overprotection, privacy, and conflict of interests are usual.²⁸ On the other hand, informal, unpaid support can lead to long-term social and economic disadvantages, including forgone education and employment opportunities, added household expenses, burnout, family breakdown and even violence.²⁹ There is a further gender implication to this, as girls and women of the family provide the support and bear the costs of foregone opportunities. As a result of the overreliance on family support, in several LMICs, caregiver organizations are demanding greater rights and benefits, although not always referring to the need to develop better support systems for persons with disabilities.³⁰

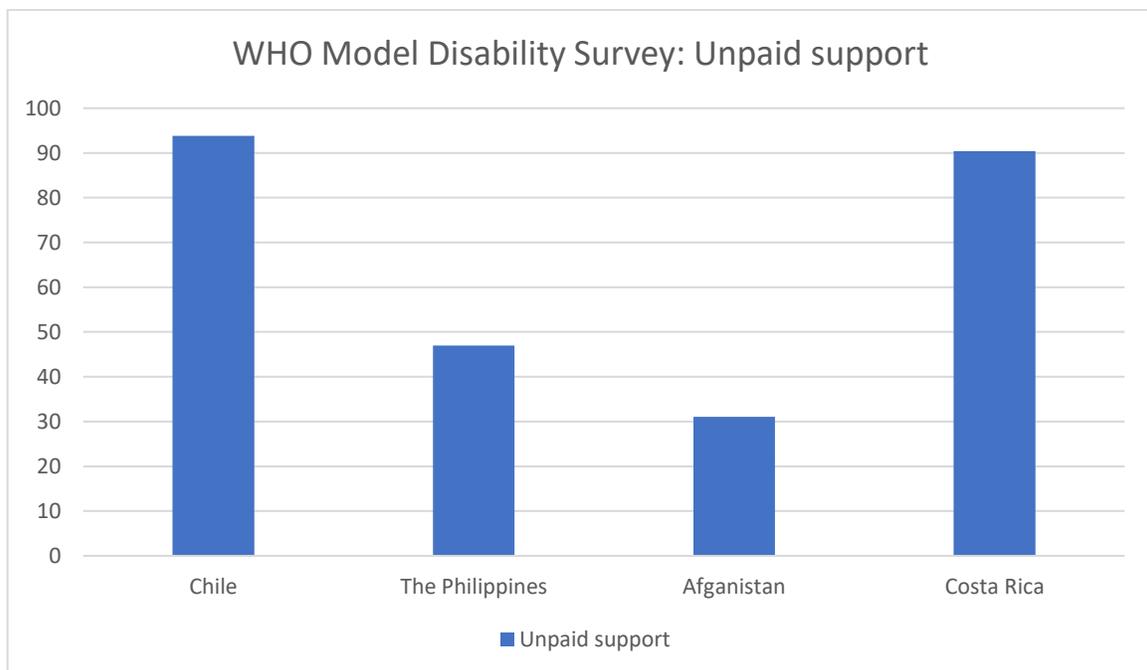
There is at the same time a growing risk that the lack of services will push the creation of institutions. In former socialist Central and Eastern Europe countries, which historically have had high institutionalisation rates, deinstitutionalisation reform has progressed, but with uneven and re-institutionalising results.³¹ In many of these countries, community support services outside residential settings, such as personal assistance, are scarce.³² In other middle-income countries, institutionalisation is at its initial stages. This is the case of China, which has experienced significant growth of formal residential long-term care services for older persons, many of them older persons with disabilities.³³ This process is driven by many factors, including population ageing, social stigma, scarce specialist resources, and lack of community alternatives.³⁴ Some of these new institutional settings are run by NGOs and private organisations, which often operate unregulated and unmonitored.

The disability support gap

Although there are no extensive nor comprehensive data on gaps in access to community support in LMICs, different surveys and studies have noted important gaps in service provision. For example, in Chile, where 40.4% of persons with disabilities require some form of human support, 93.6% of the support provided is unpaid, 93.8% of assistants are family members, and 73.9% are

women.³⁵ Similarly, in the Philippines, persons with high support requirements rely mostly on unpaid assistants (i.e., family members, friends or volunteers) or a combination of unpaid and paid assistants, including from charity organizations.³⁶ In Afghanistan, 81.7% of persons with disabilities report they do not have someone assisting them with their day-to-day activities, while only 18.3% reported that they do. Among those with existing assistance, 60.6% believe they require additional help and among those without, 20.2% think they need someone to assist them. Approximately one-third of the support received is unpaid support from family, friends, or volunteers.³⁷ Further, it is likely that this discrepancy in availability of formal supports is even wider in rural and remote regions where poverty rates are often higher. WHO estimates that one billion people need assistive devices, but only 1 in 10 have access ([WHO, 2018](#)).

Figure 2. Unpaid support in LMICs



Sources: National surveys from Afghanistan (2019), Chile (2015), Costa Rica (2018), and the Philippines (2016).

Different challenges limit access to community support in LMICs. On the demand side, there is a lack of awareness at all levels on the need for and importance of support services. Due to the systemic and structural discrimination experienced, persons with disabilities and their families do not often advocate for community support services. Support services are not considered a human rights obligation, and family members are expected to provide this support. There is also invisibility of disability-related support requirements due to limited capacity and incomplete information of population needs for support services. On the supply side, there is limited capacity to provide quality support services due to low investments and shortages in service providers and trained workforce (i.e., professional sign language interpreters, trained personal assistants, etc.). Services, particularly (re)habilitation services for children require specialized training on working with children and using play-based approaches to build and support skills development.

Where services exist, they are typically fragmented, unsustainable, and of low quality. This is particularly challenging in rural areas where shortages in service providers are even starker.

In response to the need to improve access to assistive technology, the World Health Organization (WHO) launched in 2014 the Global Cooperation on Assistive Technology (GATE) initiative to assist States to improve access to assistive technology as a part of Universal Health Coverage. As part of this initiative, WHO has developed various tools to support countries in developing national policy and programmes, including a list of priority assistive products, a system-level capacity assessment tool (ATA-C), two population-based household surveys, and a global guide on assistive product specifications.³⁸ UNICEF is also working on new assistive technologies for children with disabilities and disability-inclusive supplies.³⁹ However, unlike these advancements in assistive technology, no United Nations entity is actively working on a system-wide approach to improving access to disability-related support services.

Box 4

Providing Assistive Technology to Children in Humanitarian Settings

Humanitarian emergencies, including natural disasters and armed conflicts, overwhelmingly occur in LMIC countries where there is a higher “existing prevalence of child disability and further increase the rate of child disability” directly, through injury, or indirectly through poor health of child or parent. These countries also shoulder the burden of displaced populations. Evidence indicates that children present with different injuries from adults and have unique AT needs.

Children are physiologically different from adults, they have different functional needs, their bodies are still growing and developing, and may have different psychological needs associated with the disability, all of which impact on AT and how it is provided. Humanitarian action needs to systematically assess and respond to the needs of all children with disabilities – both those who had pre-crisis disabilities and those with direct and in-direct crisis related disabilities. However, provision of AT remains low and uneven.

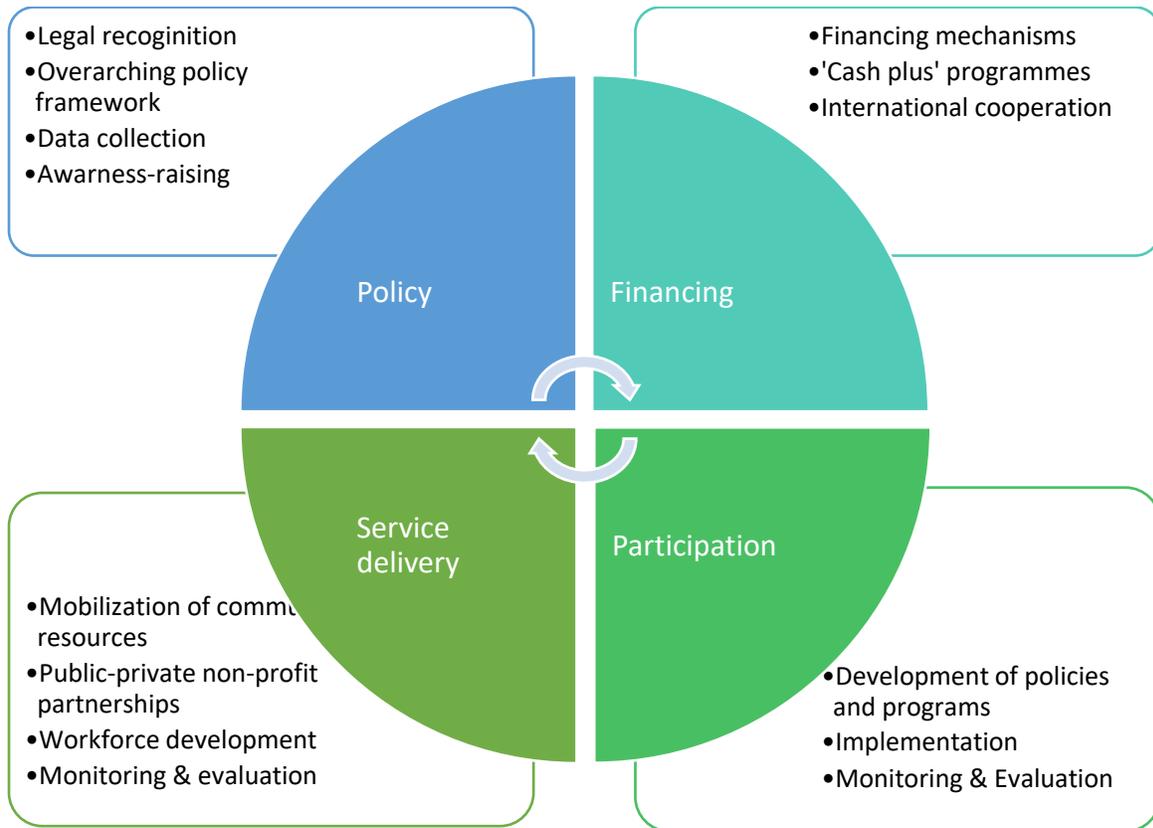
Research by UNICEF in Afghanistan and South Sudan found that non-governmental organizations were the primary providers of assistive devices, most commonly for mobility and more limited provision of AT for visual, hearing, communication, and cognitive impairments. In addition to standard barriers to provisions of AT, such as stigma against children with disabilities and lack of demand, humanitarian settings are further constrained by issues around access, coordination, government leadership, and information on new and existing needs.

[Pathways for improving access to community support for persons with disabilities in LMICs](#)

To advance the right of persons with disabilities to live independently in the community in LMICs, a high-level commitment to support systems and services on political, financial, and service provision levels is needed. While there cannot be a unique approach to the diversity of

institutional, social, political, and economic contexts in LMICs, improving access to disability-related support requires system-level interventions that consider at least four major components: policy, financing, service provision, and participation.

Figure 3. Components for improving community support systems



a) Policy

Legal recognition of support services as an integral part of the right to live independently in the community. The provision of support is a human rights obligation recognized in international human rights law as part of the right to live independently in the community. Whatever the form of provision of community support, States have the primary responsibility to ensure that persons with disabilities, regardless of age or gender, have access to and receive quality support services.⁴⁰ Recognizing community support services as an integral part of the right to live independently in the community is key to ensuring enforcement and compliance. It can help increase the demand and supply for such services, contributing to their availability and affordability.

Comprehensive data collection of support requirements. More and better information is needed on the diversity of support requirements of the population with disabilities. Few specialized surveys and studies collect information on these requirements, which prevents

greater awareness and understanding of unmet needs' scope, scale, and impact. Surveys should consider limitations to basic and instrumental activities of daily living as well as parenting and social barriers. In addition, individual disability assessments, which remain primarily medical in most countries, do not systematically collect information on support requirements.⁴¹ They deprive social protection systems and policymakers of administrative data critical for policy planning.

Development of an overarching policy on community support. An overarching, comprehensive policy framework covering different support requirements across the life cycle and multiple identities is crucial. This policy should facilitate coordination across sectors and levels of government and include deinstitutionalization actions when necessary. Poor coordination between numerous programmes can produce opposite incentives, limit flexibility and portability, create access barriers, and result in service gaps. Also, different programs may target different sub-populations (e.g., communication support v. personal assistance), so a unifying framework can help to efficiently target the various support needs of the diversity of the disability community, including their families. Like accessibility and non-discrimination, community support is also essential to make mainstream services inclusive; hence they should be included in policies across sectors. Effective leadership and governance through a comprehensive policy framework can ensure a good use and supply of formal and informal community support and appropriate standards and monitoring in place.

Improving awareness-raising at all levels on community support services. The need, importance and potential of support services remain unrealized. Although the need for disability support is high, the demand in LMICs is low. The experience on assistive technology shows that if it is not known, it is not needed. Self-stigma and public stigma associated with disability, help-seeking and assistive devices, and gender stereotypes and roles also need to be addressed. Improving awareness can help change attitudes, better identify support needs, increase demand, and mobilize political will and action.

b) Participation

Participation in program and policy development, implementation, monitoring and evaluation. Persons with disabilities and their representative organizations should be consulted and actively involved in the agenda-setting, formulation, implementation, delivery, monitoring and evaluation of community support systems and services. Persons with disabilities know best their support requirements and what can be done to meet those. Further, this could include hiring people with disabilities for the delivery of services. Their participation across the policy cycle will ensure support systems and services respond effectively to their individual needs and respect their rights. Particular attention should be paid to groups traditionally excluded from decision-making processes. Efforts should be made to include the voices and experiences of children with disabilities, where possible by themselves or through their parents/caregivers.

c) Service delivery mechanisms

Mobilisation of community resources. While some HICs countries are transitioning to community-based support models based on increasingly personalised schemes, including individualised budget,⁴² there is little chance of developing community support systems for persons with disabilities in LMICs without mobilising community and family resources. Social networks and solidarity play an essential role in developing countries, and community mobilisation provides an avenue to maximise resources. Community structures, including organisations of persons with disabilities and community-based organisations and volunteers, could potentially be leveraged and strengthened, including through sustainable government funding, to deliver community support for persons with disabilities. Families should also be supported through information, training, respite, and funding to assist their family members with disabilities. Community involvement can further help to develop models that are both economically viable and culturally acceptable. However, it is critical to ensure that development of community support takes into account gender inequalities in unpaid care provision. Developing mechanisms that enable gender-responsive community support and that foster agency and choice for persons with disabilities should be a priority.

Exploring public-private non-profit partnerships. Historically, HICs have relied on non-profit and voluntary organisations to provide community support to persons with disabilities, financed and regulated by governments. However, a market-based approach reliant on value-driven private service providers is increasingly used, raising concerns about the commodification of care and its impact on its quality.⁴³ In LMICs, governments could support non-profit organisations through an adequate regulatory and financing framework to provide disability support. This includes organisations of persons with disabilities, non-governmental organisations, and community-based inclusive development (CBID) and community-based rehabilitation (CBR) initiatives. These services and programs might, at times, be partially financed by the Ministry of Social Affairs or Health or local governments. However, there are often challenges related to system building, sustainability, and scalability of the interventions. Sectors with experience fostering public-private non-profit partnerships, such as HIV/AIDS and child protection, could provide valuable insights.

Implementing ‘cash plus’ programmes. ‘Cash plus’ interventions, also called ‘integrated social protection’ programmes, combine cash transfers with one or more complementary interventions or services. This can be done by linking cash transfer programme recipients to externally provided services or by providing multiple interventions within a cash transfer programme (or combinations of both).⁴⁴ Integrating cash transfer programmes with disability support services will enhance the impact of cash transfer on the autonomy and participation of persons with disabilities and can create streams of public funding for the development of community support services.

Workforce development. There is a shortage of service providers and trained workforce (i.e., sign language interpreters, personal assistants, etc.) throughout LMICs.⁴⁵ This requires the development of human resources, especially in areas where specialisation is necessary. It also involves the training of informal caregivers and other supporters. Recognising and developing their skills and competencies is a good investment since these are crucial to secure disability

support within low-resource settings. In addition, training developed by organisations of persons with disabilities can help to ensure a rights-based approach in the provision of community support while including people with disabilities within that workforce.

Strengthening monitoring and evaluation. Sound monitoring and evaluation systems can help identify shortcomings, capture emerging challenges, and systematically measure the quality of support services. Problems with data harmonisation and data quality are expected in LMICs, and building disability management information systems can improve planning and provision of support services to persons with disabilities.

d) Financing

Need for increased investment in community support. While HICs spend on average 1.4% of their GDP on disability benefits and support, most LMICs spend less than 0.1% of their GDP.⁴⁶ While numerous studies have proven the greater cost-effectiveness of community-based support services over institutional care, available evidence from HICs shows that the cost impact of providing good quality disability support is usually high and transitional costs related to deinstitutionalisation (e.g., double running costs) could be significant.⁴⁷ As a result, LMICs will have to invest substantial public resources to develop basic quality support services and commit to investing in community responses rather than institutional care, which will also require international support in some countries. The growing investment in disability-inclusive protection systems in LMICs and the renewed mobilisation for deinstitutionalisation offer a window of opportunity for mobilising and leveraging significant resources. The COVID-19 crisis may reinforce this interest as it has exacerbated and exposed many of the current failings of institutional settings.⁴⁸ Further, with limited fiscal space in the context of the economic recovery from the COVID-19 pandemic, countries will look to implement cost-efficient programs with high impact.

International cooperation on community support. Considering the fiscal space of many LMICs, especially during and in the aftermath of the COVID-19 crisis, international financing support will be required to enable countries to develop community support systems and services. International cooperation can also add significant value by investing in innovative support services, practices and evidence, which could be integrated into social protection reform and anchored in the Sustainable Development Agenda. In addition, it is critical to develop knowledge and technical capacities to help policymakers, development agencies, the disability community, and services providers in developing models that make the most of public and community resources, foster choice and control, and promote gender equality in the provision of support. Finally, greater efforts should be made so that international discussions on the care economy incorporate and combine gender equality and disability inclusion perspective.

Conclusion

Access to community support systems is critical for facilitating the participation of persons with disabilities in social and economic life. Yet, in most LMICs, there are little to no established formal support systems, forcing children and adults with disabilities to rely on their families and other informal forms of support.

Improving access to community support in LMICs must involve changes concerning policy, participation, service delivery mechanisms, and financing. First, countries must legally recognize community supports as an inherent component of independent living and establish an overarching policy framework to implement community support. This also requires a sound evidence base and data on the actual support needs. Second, efficient and sustainable financing must be secured to build comprehensive systems, which may include cash plus programs. Third, service delivery mechanisms must leverage informal community support systems, public-private non-profit partnerships and workforce development programs to increase the supply of formal support services, in addition to supporting family members providing support. Finally, civil society organizations must participate in the decision-making and monitoring of community support systems and services.

To advance the development of community support in LMICs, further research is needed with regards to estimating support gaps, costs of support services, and how to incentivize the creation of formal services while considering limited fiscal space. Further, the difference in urban-rural challenges for implementing support systems should be explored. Additionally, the lack of formal services and programs supporting families impacts the quality of supports for persons with disabilities and the earnings potential of women and girls; this notion requires further evaluation. Finally, in the context of the COVID-19 crisis or future crises, it is crucial to measure the impacts on support systems and ensure community services are able to adapt in times of emergencies.

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