The Care Economy and Disability Inclusion in Low and Middle-Income Countries

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Abbreviations and Acronyms

CarerQol Care-Related Quality of Life Instrument

CAVIs Centros de Apoio à Vida Independente (Brazil)

CRPD Convention on the Rights of Persons with Disabilities

DHS Demographic Health Survey

EBSCOhost

HICs High-Income Countries

LMICs Low and Middle-Income Countries

MDS Model Disability Survey

MICs Middle-Income Countries

MICS Multi Indicator Cluster Survey

NDIA National Disability Insurance Agency (Australia)

NDIS Australian National Disability Inclusion Scheme

OECD Organisation for Economic Co-operation and Development

PPP Public-Private Partnership

QUALY Quality-Adjusted Life Years

RCPCD Care Network for Persons with Disabilities (Brazil)

SUS National Health System (Brazil)

TUS Time Use Survey

UNSTATS- United Nations Statistical Databases

WG-SS Washington Group Short Set Survey

WOS Web of Science

WTP Willingness-to-Pay

Introduction

In recent years, the care economy has emerged as a pivotal element in the global discourse on development, especially in low and middle-income countries (LMICs) (UN General Assembly 2023; Ikkaracan 2018; Ahmed et al. 2023). This sector holds immense potential not only for reducing gender inequalities and creating employment opportunities, but also for bolstering overall economic growth (Addati et al. 2018).

Investment in the care economy can affect the overall economy in multiple ways. For example:

- Compensating unpaid caregivers for the work they are already doing would improve their household's economic well-being.
- Substituting paid professional support for unpaid work that is currently being provided by household members could increase income for those who must currently either work less than they would like, or choose flexible, but less remunerative work.
- Providing reliable care and support can enable improved access to education and employment, both for the people receiving care and support and for those who are giving it, thereby increasing their potential for generating a livelihood, and reducing household poverty.

The intersection between the objectives of the care agenda and those of disability inclusion presents a unique opportunity to further these economic objectives. Appropriate care policies can catalyze disability inclusion and bridge gaps in access to support and services for persons with disabilities; this can then result in reducing gaps in education and the labor market among persons with disabilities, raising human capital, and increasing the potential for increased household income (Riobóo-Lois et al. 2024). Simultaneously, investments in disability inclusion directly impact the care economy; improving accessibility to and encouraging inclusion in education, employment, health, transportation, and housing increases the possibility that persons with disabilities will be able to live independently and actively participate in their communities. This in turn has the potential of reducing their need to rely on unpaid care and support, and encourages the redistribution of care and support responsibilities away from households.

Yet historically, tensions and misunderstanding have characterized the interface between the care economy and the disability sector (Marker 2022). Often care policy undermines the agency of individuals with disabilities and risks perpetuating models of care that are at odds with the principles of autonomy, independence, and inclusion. Furthermore, care policies are often centered exclusively on the needs of caregivers, overlooking the needs of persons with disabilities. As a result, the design and implementation of these policies often fails to meet the diverse needs of both persons with disabilities and their caregivers.

In LMICs, the dearth of formal care and support services, compounded by limited resources and rapid aging in many regions, makes the need for focused investment in improving the care

economy particularly pressing. However, transforming care systems necessitates a paradigm shift toward care and support models that are responsive to gender, age, disability, and human rights considerations (OHCHR 2023; Barrantes & Cretney 2024). By aligning care and disability frameworks, LMICs can make significant strides in advancing the care agenda while also promoting disability inclusion.

Against this background, **this report explores the interdependent relationship between the care economy and disability inclusion, and emphasizes the mutual benefits of a holistic approach to care and support systems.** The audience for this report includes policy makers, researchers, and practitioners involved in international development, disability inclusion, and care economy strategies, particularly those working within or in collaboration with the World Bank and other multilateral organizations. **The report aims to offer a comprehensive overview of disability inclusion in the care economy, as well as the barriers to and strategies for advancing disability-inclusive care investments.** This includes:

- **Conducting analyses of the demand** for the care and support of persons with disabilities;
- **Identifying policy options** that are responsive to persons with disabilities through a scoping review; and
- **Highlighting key entry points** to inform the World Bank's LMIC initiatives.

Part 1: Conceptual Framework

Understanding the conceptual frameworks that inform disability inclusion and the care agenda is crucial for promoting disability inclusion within care policies, especially in LMICs.

This report adopts the definition of disability from the Convention on the Rights of Persons with Disabilities (CRPD), which sees it **as the result of the interaction between impairments, and the attitudinal and environmental barriers that can hinder a person's full and effective participation in society on an equal basis with others**. This definition presents disability as a social construct and acknowledges the role of societal barriers in preventing the full participation of persons with disabilities. Consequently, **inclusive policy focuses on removing such barriers, and providing appropriate support** to persons with disabilities in order **to enhance their inclusion in all areas of life, including education, health care, employment, and civil spaces**.

On the other hand, in this report the terms "care" and "support" are used with a degree of conceptual fluidity, acknowledging that the meanings of these terms can vary widely across regions, cultures, and policy contexts. **Care is a broad concept with various meanings**, referring to everything from a type of work or activity to an emotional state, a moral value, or a social relationship (Rummery & Fine 2012). From a policy perspective, **care work refers to the activities undertaken to ensure the well-being and development of individuals throughout the life cycle,** including direct, personal, and relational care activities--such as feeding a baby or providing assistance to an ill person or a person with disabilities--as well as indirect care activities such as cooking and cleaning (Addati Et Al. 2018). The types of care are often defined by the social identity of those receiving care—for example in the case of childcare or elder care—or by the employment status of those providing care, distinguishing between paid and unpaid care work (Marker 2022). The **care economy** refers to the sector of economic activities related to providing care (Peng 2019).

Although the notion of care encompasses the support that individuals with disabilities may require in order to perform their daily living activities and participate in their communities, **the disability sector favors the term support when referring to adults with disabilities** (Special Rapporteur on the Rights of Persons with Disabilities 2017). In the disability sector support is widely seen as representing the paradigm shift promoted by CRPD. **This term emphasizes personal autonomy, independence, and inclusion** in the community. In contrast, **within the disability sector, care is often associated with outdated models that portray persons with disabilities as "dependent"** or as a "burden" (ENIL 2023)—models that have historically promoted their segregation and institutionalization (Knapp et al. 2021; Šiška & Beadle-Brown 2020). **Due to these tensions, international stakeholders are increasingly referring to "care and support"** in order to acknowledge the critical perspective of disability rights activists (General Assembly 2023).

Another significant issue is the care agenda's focus on caregivers' rights and needs, which often overlook the rights and interests of those receiving care, such as children, older persons, and persons with disabilities. Frequently, persons with disabilities are sidelined in policy debates despite being both providers and recipients of care and support. This bias can result in policies that unintentionally compromise the rights and self-determination[1] of these groups. This necessitates a transformative approach to caregiving infrastructure, one that actively incorporates the diverse needs of persons with disabilities. While it was developed with a focus on caregivers, **the 5R Framework for Decent Care Work**—which encompasses recognizing, reducing, and redistributing unpaid work, as well as rewarding and representing paid care work—**offers a valuable perspective for disability-inclusive care and support policies** (Addati Et Al. 2018; OHCHR 2023).

Additionally, a lifecycle approach to care and support is important in recognizing that needs evolve across different stages of life. From early childhood through old age, individuals require varying levels of care and support, influenced by factors such as age, gender, disability, cultural context, and available resources. Framing care and support across the lifespan—encompassing childhood, adolescence, working age, and old age—helps to identify how tailored interventions can enhance autonomy and independence at each stage of life, and the specific resources needed to increase participation for all individuals (**Table 1**).

1 In the context of this report, self-determination refers to persons with disabilities having the freedom to exercise control and make decisions for their own lives, including managing required services and supports.

Table 1: Care and Support for Persons with Disabilities Across the Lifespan

Life Stage	Key Goals	Care and Support Interventions	Additional Resources/Interventions
Childhood	Developing cognitive, social, and physical skills	Parental support and guidance, parental leave and workplace accommodations, assistive technologies, communication support, cash transfers.	Early intervention programs; physical, occupational, and speech therapy; psychosocial support; inclusive childcare; inclusive education; habilitation services; accessible play spaces; accessible transport
Adolescence	Preparing for independence, employment readiness, social skills	Educational support, supported decision-making, peer support, assistive technologies, communication support, point-to-point transportation, cash transfers.	Vocational training; inclusive education; comprehensive sexuality education; sexual and reproductive health services; rehabilitation services; psychosocial support; inclusive sport and leisure activities; accessible transport
Working Age	Sustaining employment, independent living, financial stability, parental responsibilities	Cash transfers, personal assistance, supported decision-making, home modifications, communication support, assistive technologies, independent living support, supported housing, advocacy support, parental support and guidance, point-to-point transportation	Vocational rehabilitation, workplace accommodations, rehabilitation services, inclusive housing programs, legal services, disability-specific services, accessible transport
Old Age	Maintaining independence, managing health conditions, social engagement	Cash transfers, in-home support, financial and legal planning support, assistive technologies, home modifications, assisted living programs, point-to-point transportation	Comprehensive health care, accessible transport, companionship, psychosocial support, accessible social activities, palliative care

Source: Authors' elaboration

Creating an inclusive and equitable care economy is crucial to harnessing the full potential of every individual in society. **Investing in disability-inclusive care and support systems not only promotes equality but can also yield substantial economic returns**. For example, a more inclusive care economy can facilitate girls' education and women's employment. Since women often shoulder the majority of unpaid care responsibilities, this enhances their economic empowerment and also contributes to broader economic growth (Addati et al . 2018). At the same time, it can spur economic growth through job creation in the care sector. Furthermore, providing care and support options that accommodate individuals with disabilities can expand their access to education and employment, and increase their opportunities for participation in the community. Various studies have shown that closing such gaps may lead to significant GDP gains (Buckup 2009; Banks & Polack 2014). Recognizing and addressing these links is a pivotal step toward a more equitable and sustainable global economy.

Part 2: Methodology

The main research questions in this report are:

1. **What is the estimated demand for care and support services among persons with disabilities in LMICs?** What are the specific care and support needs of persons with disabilities, and how do these needs change throughout the lifespan?
2. **What is the extent of unmet care and support needs among persons with disabilities in LMICs,** and what factors are contributing to these unmet needs?
3. **What are the demographic characteristics of individuals providing care and support in LMICs**, and how do these characteristics correlate with those receiving care?
4. **What models and interventions currently exist to provide care and support to persons with disabilities?**
5. **What are the drivers for and barriers to disability-inclusive care policies?**
6. **What approaches and methodologies can be used to value the costs and benefits related to disability inclusion** in the care economy?
7. **What strategies are needed to address current gaps, and guide future investments** in disability-inclusive care?

Guided by these questions, this report employs a methodology consisting of a scoping review, and secondary data analysis.

Scoping Review

This review involved a search of peer-reviewed literature across databases.[2] Publications in English and Spanish from 2015 to 2023 were included, based on the research team's linguistic proficiency and the predominance of these languages in regions where care policies are most concentrated. The review covered quantitative, qualitative, and mixed-method studies, as well as conceptual papers. Gray literature—for example, publications from multilateral organizations, governments, and World Bank documents--were also considered. A total of 191 publications were reviewed.

The review was complemented by key informant interviews with researchers and policy practitioners working on the intersection of disability and care policy in international development.

Secondary Data Analysis

For this component, we identified existing datasets from LMICs that could be used to estimate the demand for care and support services for persons with disabilities for the period of 2013 to 2023. This involved searching for surveys that collected data on disability and care from sources such as the World Bank, the Disability Data Initiative, Demographic Health Survey programs, Multi Indicator Cluster Survey (MICS), the OECD Time Use database, the Multinational Time Use Survey, UNSTATS, and National Statistics Offices. We considered surveys that use the Washington Group Short Set (WG-SS) or similar questions, and

[2] Medline, Scopus, and the databases Academic Search Complete, CINAHL®, EconLit, Psychology & Behavioral Sciences Collection, and Library, Information Science & Technology Abstracts through the EBSCO platform and Web of Science (WoS).

focused on those that specifically addressed the provision of care and support. We selected only data sources where microdata was available.

After identifying 25 relevant surveys (14 disability-specific surveys; 3 time-use surveys; 6 care surveys; and 2 support service surveys),[3] we conducted a descriptive analysis of variables related to disability, care provision, and the sociodemographic characteristics of caregivers.

[3] Disability-specific surveys: Afghanistan, Model Disability Survey (2019); Cameroon, Model Disability Survey (2016); Chile, Disability National Survey (2015); Costa Rica, Disability National Survey (2018); Georgia, Model Disability Survey (2021); India, Laos, and Tajikistan, Brief Model Disability Survey (2018); Mexico, National Survey on the Perception of Disability (2010); Nicaragua, National Household Disability Survey (2003); Pakistan, Model Disability Survey (2015); Peru, National Disability Survey (2012); the Philippines, National Disability Prevalence Survey (2016); and Sri Lanka, Model Disability Survey (2015). Time-use surveys: Chile, National Survey on Time Use (2015); Colombia, National Survey on Time Use (2020-2021); Mexico, National Survey on Time Use (2019). Care surveys: Mexico, National Survey for the Care System (2022); Oxfam, Household Care Surveys in the Philippines, Uganda, and Zimbabwe (2017); Peru, IEP, Survey on Representations of Care Work (2023); Rwanda, Baseline Survey on Unpaid Care Work Status among Women and Men (2022). Support service surveys: Kenya, Support Needs Assessment (2022); The Philippines, Support Needs Pilot Survey (2022-2023).

Part 3: Estimating Demand for the Care and Support of Persons with Disabilities in LMICs

This analysis aims to assess the care and support needs of persons with disabilities; the extent to which these needs are being met; and the role of family members in providing such support. Accurately measuring this demand requires comprehensive data on individuals with disabilities, including their care and support needs; the care and support they are receiving; and information about their caregivers or assistants. To provide evidence on this topic, various data sources were examined, and available information was analyzed (**Box 1**). The findings revealed that a significant proportion of persons with disabilities require care and support, yet many of these needs remain unmet.

Box 1. Types of Data Sources Used to Estimate the Demand for Care and Support

Four primary sources of data contain information that can be used to help estimate the demand for the care and support of persons with disabilities: (1) disability-specific surveys; (2) time-use surveys (TUS); (3) care surveys; and (4) support service surveys.

Disability-specific surveys, such as the Model Disability Survey (MDS), typically include questions that ask whether the person is receiving any human support; if that support is sufficient; and if additional support is needed.

Time-use surveys (TUS) collect information on how people allocate their time. Countries such as Mexico and Colombia incorporate questions aimed at identifying care-related activities and specifically aimed at the persons with disabilities. When these surveys allow for the identification of individuals with disabilities, it is possible to determine whether they are also providing care, and how many hours a day they spend on care duties.

Care surveys collect information regarding the care activities that men and women perform in their everyday lives. These surveys have been implemented in LMICs such as Mexico, Peru, the Philippines, Rwanda, and Uganda. The advantage of this type of survey is that it includes questions on the type of care activities that people provide for persons with disabilities; perceptions about care; and the use of public care facilities.

Support service surveys conducted in countries such as Kenya and the Philippines have focused on the care and support needs of persons with disabilities, or the beneficiaries of disability social programs. They also assess how support services can alleviate the effects of functional difficulties in the lives of persons with disabilities.

According to data gathered from 14 countries that use the MDS or national disability surveys, on average over 40 percent of adults with disabilities receive some form of human support. However, in most of these countries, more than one-third of those receiving support report need additional assistance. The highest percentages of persons with disabilities needing more support are in Laos

(73.6 percent), India (65.7 percent), Sri Lanka (64.1 percent), and Afghanistan (63.2 percent). Additionally, a significant share of persons with disabilities who are not receiving any care report that they need it. In countries like Cameroon, Laos, and the Philippines, this proportion exceeds 50 percent of all persons with disabilities. **(Table 2)**

Table 2. Demand for the Care and Support of Persons with Disabilities

		Percentage of persons with disabilities receiving care/support	Percentage of people receiving care/support that report needing more care/support	Percentage of people that do not receive care/support that need it
Latin America & the Caribbean	Chile	28.1	29.3	NA
	Costa Rica	48.1	16.3	NA
	Mexico	36.9	26.0	NA
	Nicaragua	53.4	NA	NA
	Peru	40.7	NA	NA
Central & South Asia	Afghanistan	31.6	63.2	44.2
	India	36.8	65.7	31.9
	Pakistan	43.4	37.1	16.1
	Sri Lanka	23.6	64.1	11.1
Europe & Central Asia	Georgia	33.8	40.5	31.8
	Tajikistan	71.8	50.1	25.6
Sub-Saharan Africa	Cameroon	51.3	33.3	44.6
East Asia & Pacific	Laos	75.4	73.6	59.5
	Philippines	29.5	29.5	80.7

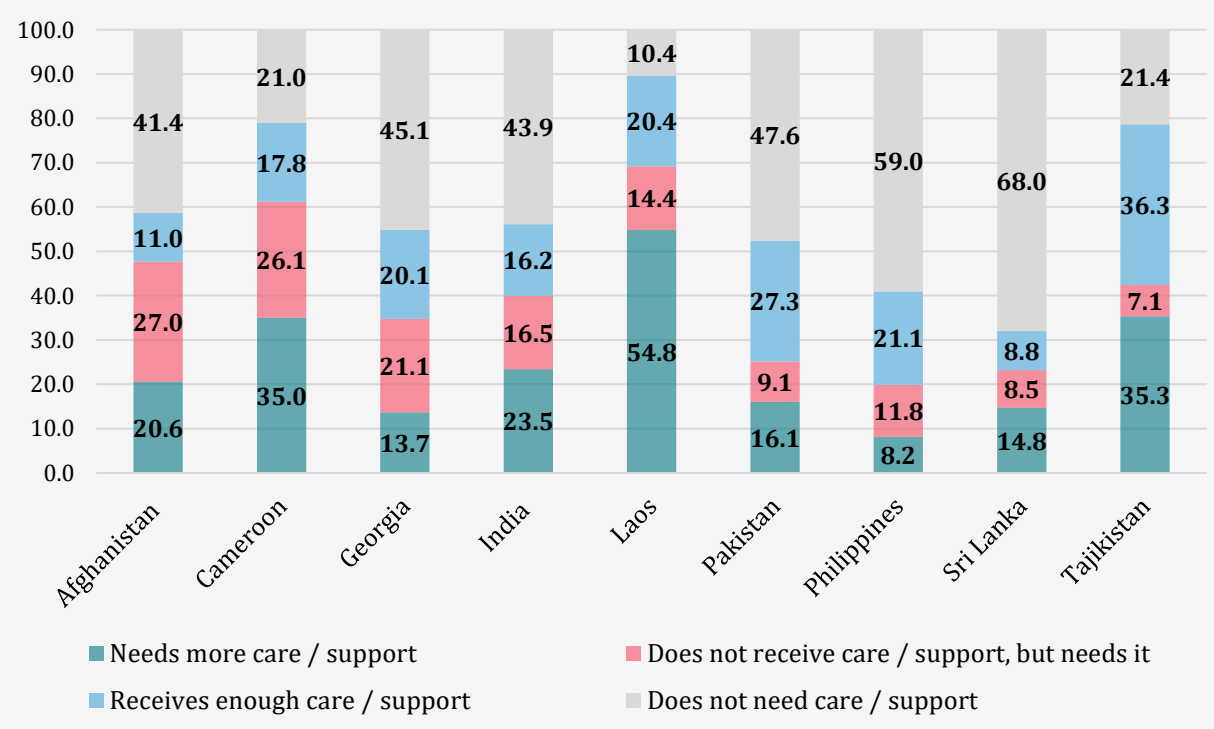
Note: The results from Cameroon and Pakistan should be interpreted with caution, given that the surveys do not employ population weights, and the sample size is less than 500 observations.
Sources: Afghanistan, Model Disability Survey (2019); Cameroon, Model Disability Survey (2016); Chile, Disability National Survey (2015); Costa Rica, Disability National Survey (2018); Georgia, Model Disability Survey (2021); India, Laos, and Tajikistan, Brief Model Disability Survey (2018); Mexico, National Survey on the Perception of Disability (2010); Nicaragua, National Household Disability Survey (2003); Pakistan, Model Disability Survey (2015); Peru, National Disability Survey (2012); the Philippines, National Disability Prevalence Survey (2016); and Sri Lanka, Model Disability Survey (2015).

Gender-based results differ by region. In general, in Latin America and the Caribbean men with disabilities are more likely to report that they require more care/support than women with disabilities (Appendix A). However, with the exception of India, in Asian countries women are more likely to report that they require more support (see **Appendix A**).

In most countries, working-age adults are more likely to report that they require additional care and support: the exceptions are Afghanistan, Chile, India, Mexico, and Tajikistan, where persons with disabilities aged 60 or older are more likely to report they need additional support (**Appendix A**). In most countries, persons with disabilities in rural areas are more likely to report that they need more care and support relative to people in urban areas, with the exception of in Laos and Sri Lanka (Appendix A). Additionally, while not all disability surveys collect this information, where data is available analysis reveals that there is a significant share of persons with disabilities without care or support that report needing it. In countries such as the Philippines and Laos, more than 50 percent of all persons with disabilities are without care/support **(Table 2)**. In other words, in most countries there is a large proportion of persons with disabilities that either need more care/support than they receive, or need care/support but don't receive any.

This suggests that the proportion of people with unmet care and support needs is large. Across nine countries, over 20 percent of persons with disabilities have unmet care and support needs, either because they require more care and support than they receive or because they don't receive needed care/support. In five of these countries, 40 percent or more of persons with disabilities have unmet care and support needs (**Figure 1**). These results suggest that in general, many persons with disabilities have unmet care and support needs. However, these results do not show which types and degrees of disability are more likely to experience unmet care and support needs.

Figure 1. Percentage of Persons with Disabilities by Support Need Status



Note: The results from Cameroon and Pakistan should be interpreted with caution, given that the surveys do not employ population weights, and the sample size is less than 500 observations.

Source: Afghanistan, Model Disability Survey (2019); Cameroon, Model Disability Survey (2016); Georgia, Model Disability Survey (2021); India, Laos, and Tajikistan, Brief Model Disability Survey (2018); Pakistan, Model Disability

Survey (2015); the Philippines, National Disability Prevalence Survey (2016); and Sri Lanka, Model Disability Survey (2015).

Based on analysis of support services surveys, we can infer that the need for human support among persons with disabilities varies based on the type of disability they have. Support services surveys in Kenya and the Philippines showed that around 50 percent of respondents reported needing human assistance. Many also indicated that receiving care and support helped to alleviate the negative impacts related to their disabilities. **In addition, the severity of a disability is likely related to both the demand for care and support and the number of hours of care required**. However, due to data limitations and small sample sizes in support services surveys, it is not possible to analyze the association between type and severity of disability with support needs. For example, we were unable to determine whether persons with severe visual difficulties require more support than those with mild visual difficulties, since the sample sizes in each group are too small for analysis in support services surveys. The available data from support services surveys also does not allow for assessment of the specific types of activities that persons with disabilities need assistance with, nor does it provide information on the number of hours of support needed. These limitations constrain our understanding of the services required, and how formal or informal providers could help meet those needs and should be studied in future research.

Despite these limitations, **the data from support services surveys reveals that the demand for care and support encompasses all persons with disabilities, regardless of the type or severity of their disability,** indicating that care and support services are needed for more than just those with severe or multiple disabilities. Moreover, the support needs vary not just with the type and degree of disability, but also with the environment, and the life choices of any given person, all of which can change over time. Therefore, **policies should consider a spectrum of programs that can offer varying levels of care and support depending on the type and severity of the disability, as well as the personal characteristics of the individuals concerned.**

Moreover, Time Use Surveys (TUS) allow for the analysis of how much care and support persons with disabilities provide compared to other caregivers, as well as the characteristics of caregivers who support persons with disabilities. In countries where data on disability is available in TUS, such as Chile, Colombia, and Mexico, a lower percentage of persons with disabilities provide care compared to those without disabilities, and they spend fewer hours on such activities. This contrasts with findings from a US study, which found that persons with disabilities provided more care and dedicated more time to caregiving compared to people without disabilities (University of Pittsburgh 2023). These differences may stem from household structures: nuclear families, which are more common in the United States and other high-income countries, have fewer options for who provides care and support, and therefore may turn to persons with disabilities to fulfil unpaid caregiver roles. Additionally, these responsibilities often depend on age. For instance, among elderly couples, the partner with fewer functional limitations may take on a support role for their spouse despite having their own functional limitations. **More research is needed in LMICS to**

analyze the relationship between disability and caregiving, and the role that people with disability play in the provision of unpaid care in families.

The analysis of care and support is fundamental in order to reduce the extra costs associated with living with a disability. Studies that have attempted to measure these costs – both those estimating the amount needed to have an equivalent standard of living as their non-disabled peers and those estimating the extra costs required for full participation—back the finding that a large proportion of persons with disabilities have care and support needs, and that the severity of unmet needs, and their associated costs, varies greatly based on type and degree of disability. Human support is frequently among the main categories of disability-related extra costs, as was found in studies in Georgia and India (Bagrationi 2023; Balasubramanian 2024). Thus, persons with disabilities would need to spend significantly more than people without disabilities on human support to achieve the same standard of living or level of participation in society.

Findings from MDS, disability-specific surveys, care surveys, and TUS all suggest similar profiles across countries when analyzing the characteristics of caregivers. From analysis of disability surveys, we can conclude that **most people providing care and support to persons with disabilities are women, typically their mothers or sisters, with an average age of 50**. Given the association between age and disability, **it is very likely that those providing care and support are women older than retirement age, who may also have unmet care and support needs of their own due to age and disability.** Additionally, since they perform unpaid work, these women are vulnerable to socioeconomic inequalities. For example, in Costa Rica, Chile, Nicaragua, and Peru, between 76.1 and 94.4 percent of persons with disabilities who receive support are primarily supported by a family member—usually a woman--while between 89.7 and 95.6 percent receive unpaid support or care (Pereira et al. 2023). This is not surprising, since in Latin America and the Caribbean, nearly 80 percent of all domestic tasks are performed by women, a responsibility that is reinforced by entrenched gender roles and stereotypes (Garcia Mora et al. 2021). As a result, women experience income loss due to unpaid caregiving responsibilities of persons with disabilities. In countries such as Bolivia and Costa Rica, this effect reduces household income by around 10 percent. Additionally, between 5 and 7 out of 10 female heads of households with a person with a disability are unemployed, further exacerbating the long-term reduction in women's earnings (Garcia Mora et al. 2021).

According to TUS data, caregivers in Colombia and Mexico spend at least seven hours per day providing care and support to persons with disabilities. The actual time spent varies based on the type of disability and the availability of other forms of support, whether within or outside of the household, or through formal care institutions. Caregivers in Chile reported fewer hours of care, averaging only two to three hours per week. However, this disparity may be linked to differences in survey design, since the TUS in Colombia and Mexico included specific questions on "general" care for persons with disabilities, questions that were not included in the Chilean TUS.

In conclusion, a large share persons with disabilities in LMIC need care and support, yet many have unmet care and support needs. Among those who do receive support, most receive unpaid care and support from female family members, many of whom are older women and therefore

likely have care and support needs of their own. Moreover, human care and support are among the main drivers of disability-related extra costs. Hence, addressing these extra costs has the potential of improving the quality of life of persons with disabilities, the women who primarily provide support, and their households at large. Public policies and programs should respond to these needs in ways that promotes dignity and autonomy and therefore garners the trust of persons with disabilities and their families.

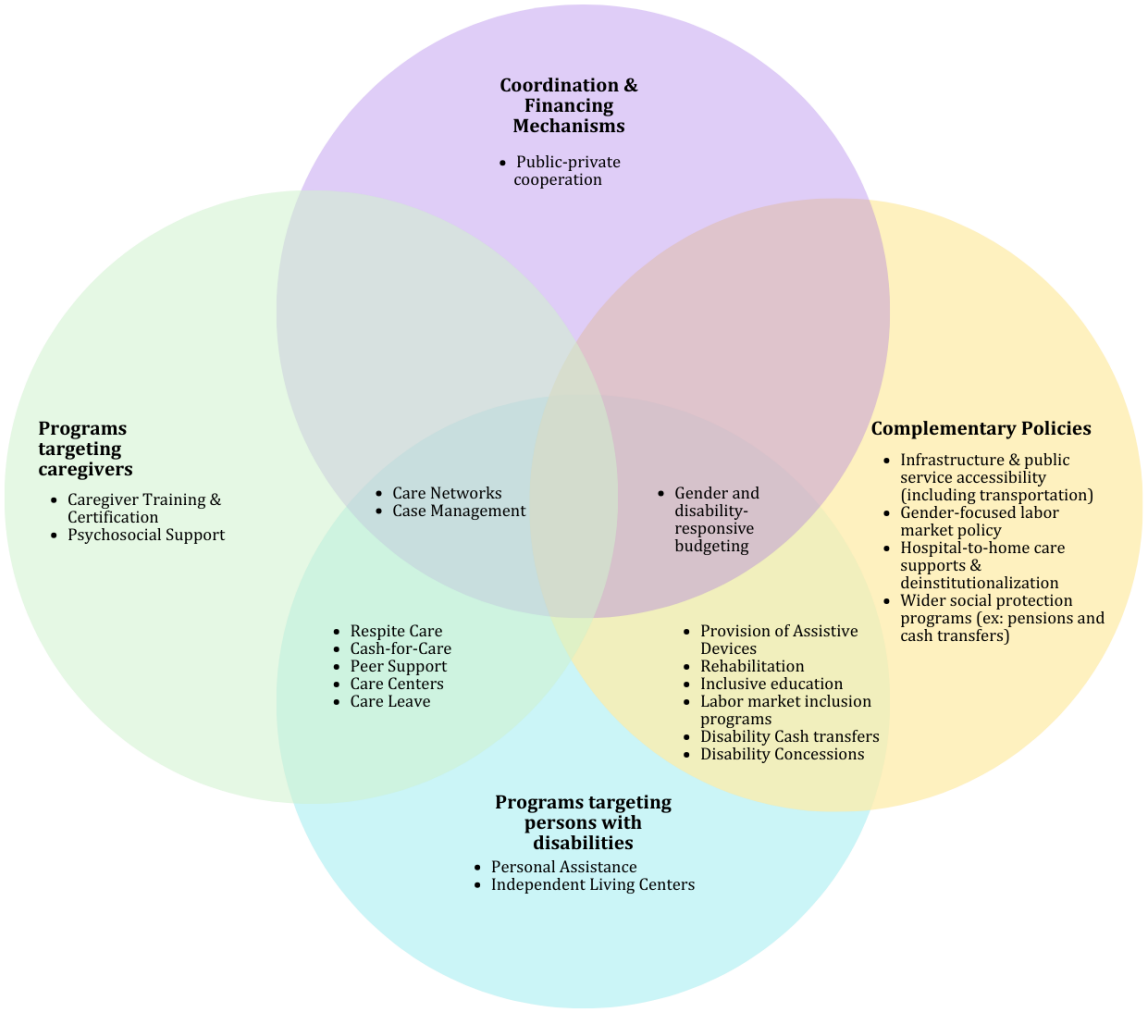
Part 4: Discussing Disability-Inclusive Care Policy Models

While extensive research has been conducted on the care economy, especially in high-income countries, most of it has focused on the adverse effects of caregiving, which predominantly affects women; but the situation of those **receiving** care and support has been much less considered. Notably, rigorous studies have primarily evaluated interventions that are aimed at reducing care work. Consequently, the impact of care policies on recipients, including persons with disabilities, remains significantly understudied, resulting in limited evidence about their effects.

Despite the lack of rigorous evidence, multiple disability-specific care policy models and practices are being implemented in high-income countries and LMICs. The figure below provides a framework for understanding various disability-inclusive care policy models. This taxonomy is based on this scoping review and key informant interviews with care and disability policy specialists in international development. The framework identifies the main policies and programs that support caregivers, and those receiving care and support.[4]

[4] In Figure 2, each circle encompasses a different category of policies and programs. However, some policies and programs may fall under one or more of these categories. For example, Personal Assistance and Independent Living Programs were created for, and primarily target, persons with disabilities. Similarly, caregiver training and psychosocial support to caregivers focuses primarily on caregivers. However, respite care, cash-for-care, peer support, care centers, and care leave programs usually are designed to target both caregivers and persons with disabilities. Because of this, they fall into the intersection of the green and blue circles. Care Networks and Case Management also occur at the intersection of these two circles, but since they are also coordination and financing mechanisms, they fall into the intersection of two different circles.

Figure 2. Taxonomy of Disability-Inclusive Care and Support Policy Models



Source: Authors' elaboration

In this section of the report, these policy models are discussed in more depth. Here we examine any significant evidence concerning these models, and explore how they can integrate essential disability considerations.

Programs Targeting Persons with Disabilities and Caregivers

Cash-for-Care

Cash-for-care programs provide monetary transfers to persons with disabilities or their caregivers, to pay for care and support. Traditionally, these programs have focused on

compensating informal caregivers for unpaid work.[5] Therefore, in most situations, the transfer goes directly to the caregiver to increase their economic agency while also improving the quality of care. While most of the countries offering such benefits to informal caregivers are high-income nations, similar schemes have also been adopted in some LMICs, including the Cook Islands, Egypt, Mauritius, Mongolia, and South Africa (OHCHR 2024).

However, disability rights advocates have been concerned that giving the transfer to the caregiver can limit the agency of persons with disabilities (Vásquez Encalada et al., 2023). Consequently, it has been suggested that programs consider transitioning to direct payments to the persons with disabilities, enabling them to make their own decisions about the care and support they receive.

Although the literature on cash-for-care programs for persons with disabilities is limited, preliminary evidence suggests that different programs have different effects on caregiving relations, depending on their design. For instance, according to a study in the Czech Republic, caregivers of older adults receiving a cash-for-care transfer typically view the funds as their parents' money and thus use them directly for their parents' needs. In contrast, when mothers of children with disabilities receive the transfer, they often see it as compensation for their care work and may not necessarily spend it on their children's needs (Dudová 2022). **Thus the recipient of the funds can be a critical aspect of program design that influences outcomes.** It is imperative to advance this research to better understand how to design cash-for-care programs that support the agency of both persons with disabilities and their caregivers.

Personal Assistance

Personal assistance is an alternative to traditional caregiving for persons with disabilities. **Personal assistance schemes provide direct one-on-one support, enabling individuals with disabilities to exercise choice and control over their lives, and to participate actively in society** (ILO 2024). They also facilitate their inclusion in the workforce and improve the quality of life both for them and for their families (Riobóo-Lois et al. 2024). Governments have implemented a variety of strategies to design and deliver personal assistance, leading to a wide range of models, from provider-led to user-led (Nally et al. 2022). Under the latter model, personal assistants are directed and managed by the persons with disabilities themselves, allowing them to hire, manage, and train assistants according to their preferences and support needs (OHCHR 2023). However, inadequate working conditions for personal assistants have contributed to workforce shortages in many countries. These conditions vary, and may involve either employment-based or service-based contracts, with the latter offering fewer benefits and protections. Low salaries also reduce job appeal, which worsens workforce shortages (ILO 2024).

[5] It is important to note that while some cash-for-care programs specifically target individuals with disabilities and can, therefore, be considered disability cash transfers, not all disability cash transfers are cash-for-care programs. Indeed, most disability cash transfers aim to ensure **some** basic income security for persons with disabilities, rather than covering all disability-related costs, or facilitating access to needed support services. As such, they are typically of relatively low value. Some of these programs focus on providing some monetary support to the families of children with disabilities, but they seldom cover the true costs of care. In contrast, cash-for-care programs, which may or may not be disability-specific, usually offer a much larger sum to cover the costs of care. Given the high programmatic costs, these programs often exclusively target persons with high support needs, even though other persons with disabilities may also require care and support.

Due to their emphasis on autonomy and support**, personal assistance programs have become increasingly prevalent in high-income countries (HICs),** including Germany, Sweden, Switzerland, the United Kingdom, and the United States (Nally et al. 2022). But state-funded personal assistance schemes in LMICs remain limited in number and scope: Albania, Armenia, Costa Rica, Moldova, Serbia, Thailand, and Uruguay (OHCHR 2024). Our scoping review could not identify any experimental or quasi-experimental evaluations of these programs. Furthermore, the cultural appropriateness of these schemes remains uncertain, particularly in indigenous and rural contexts. A qualitative study of Thailand's personal assistance scheme highlighted several implementation challenges related to power dynamics among stakeholders, provider-driven models, and misunderstandings of the principles of independent living (Yokoyama & Punpuing 2023). For instance, many users of personal assistance didn't understand that their assistants were volunteers rather than paid workers, which led to a lack of awareness about the assistants' rights and choices. Moreover, the dominance of charity-based and medical models distorted the independent living philosophy, reinforcing some caregiver-dependent dynamics.

Peer Support

Peer support programs connect people with shared experiences of disability or caregiving, enabling them to exchange knowledge and provide mutual assistance. They facilitate access to psychosocial, social, and practical support by creating supportive communities that are grounded in lived experience and shared understanding. The academic literature evaluating the impact of peer support programs is growing but still limited outside high-income countries (Price et al. 2022). The benefits include emotional support, reduced social isolation, improved self-care skills, better navigation of health and social systems, connections to community-based resources, and an enhanced sense of purpose (Joo et al. 2022). When effective, they may also help reduce the demand for health and social care services (Price et al. 2022). However, more comprehensive and rigorous research is needed in order to optimize the design and funding of these programs in LMICs.

Respite Care

Respite care programs provide short-term relief from care responsibilities, allowing family caregivers to engage in other activities and self-care, while also catering to the needs of the care recipients. **The duration of respite can last anywhere from a couple of hours to several days**. The main types of respite are in-home respite, daycare centers, overnight respite, and vacation/emergency respite. Respite care can be seen as an essential component of a comprehensive support system, and a complement to psychosocial support programs for caregivers. However, these services are more common in HICs than in LMICs, where they are limited and often underdeveloped (Abrahams & Kleintjes 2023).

While respite care can potentially improve outcomes for caregivers, the evidence suggests mixed effects (Whitmore 2016). For instance, while some studies find that respite care reduces stress, others find that it does *not* affect stress, or even that it increases stress. In some instances, family

members distrust the idea of outsiders providing care to their family members with disabilities (Whitmore 2016). Furthermore, the effects of respite care on persons with disabilities have not been sufficiently studied. Respite care may allow access to skills development for independent living and professional specialist services (Abrahams & Kleintjes 2023). However, concerns have been raised about the institutional nature of some forms of respite care (OHCHR 2023). The preliminary evidence also suggests that respite care as a component of a care package should be determined by need, considering the needs of both those providing care and those receiving care (Abrahams & Kleintjes 2023).

Care Centers

Care centers provide a range of care and support services to individuals who need assistance due to age, disability, or illness. There are various types of centers, including **daycare centers,** which offer daytime care and activities for persons with disabilities or older people; **long-term residential centers,** where individuals live and receive ongoing care; and **occupational centers**, which focus on skills development and vocational training. These facilities offer care, support, and rehabilitation in a structured environment. Intergenerational colocated care centers, where services for children, adults, and older persons are offered in the same space, are gaining popularity in terms of fostering community integration. For example, in Japan, the Wakabadai Housing Complex successfully integrates intergenerational services through a multigenerational community center that offers childcare support, and resident organizations that foster a strong sense of community and reduce long-term care needs for older residents (Yamashita et al. 2021).

However, many care centers, especially long-term or residential ones, raise human rights concerns due to their reliance on institutionalized care models, which can undermine the autonomy and community inclusion of persons with disabilities (Committee on the Rights of Persons with Disabilities 2017). Such institutionalization contradicts Article 19 of the CRPD, which guarantees the right of persons with disabilities to live independently and to be included in the community. Furthermore, institutions often facilitate abuse, neglect, or exploitation, especially in environments where oversight is insufficient, or where residents have limited control over their support. In contrast, assisted living arrangements and supported housing models offer individuals more choice and control over their living situations for persons with disabilities, while still providing the support they need within the community.

Independent Living Centers

As an alternative to traditional care models, **centers for independent living offer a progressive model that emphasizes autonomy, participation in the community, and self-determination**. They enable persons with disabilities to live independently by providing advocacy, peer counselling, independent living skills training, and information services. These centers also create employment opportunities for individuals with disabilities, particularly jobs that involve running the centers, or offering peer support. They can also play a crucial role in supporting youth and young adults with disabilities, particularly during the transition to adulthood (Plotner et al. 2022). In Brazil, Centros de Apoio à Vida Independente (CAVIs) provide personalized assistance,

allowing individuals to live independently rather than in institutional settings by focusing on personal assistance, daily living support, and community-based care, all tailored to each person's needs (Nogueira & Brauna 2021). We did not identify any evaluations of independent living centers in LMICs.

Care Leave

The care agenda has led to significant progress in establishing leave policies and workplace accommodations to assist families in supporting persons with disabilities. Recognizing the additional support that is required when a child is born with a disability, some countries have introduced extended maternity leave to address this need (Vásquez & Pereira 2023). Other countries have acknowledged the right of workers to take leave and to receive workplace adjustments, including flexible work schedules, to better support their family members with disabilities. A number of Latin American countries have also implemented measures to ensure job stability for the family members of persons with disabilities, helping to secure their roles as caregivers while also allowing them to maintain employment (Vásquez & Pereira 2023).

Programs Mainly Targeting Caregivers

Caregiver Training & Certification

Caregiver training programs aim to support formal and informal caregivers in developing caregiving skills. Those providing the care and support for persons with disabilities may need specific, specialized skills. While there is no causal evidence on the impacts of caregiver training programs**, there is ample evidence that improving caregiver competence and their sense of self-efficacy can significantly affect care outcomes** (Eterovic Díaz et al. 2015; Parra-Aguirre et al. 2020). Caregiver competence has been associated with increased care quality (Huang et al. 2020), reduced stress (Eterovic Díaz et al. 2015), and a reduced sense of caregiver "overburden" (Eterovic Díaz et al. 2015; Parra-Aguirre et al. 2020). Therefore, it is not surprising that caregiver training programs have been widely adopted in high-income countries such as the United States (Palesy et al. 2018) and Australia (Goh et al. 2018). While these types of programs are less developed in low-income countries, some governments have developed caregiver training and certification programs. For instance, the Sahayogi Scheme in India is a government-funded training program for caregivers of persons with disabilities (OHCHR 2024). This type of training, for caregivers both with and without disabilities, should be further evaluated, especially in LMICs, to ascertain whether it improves outcomes such as health, psychological well-being, and the ability to participate in economic and social activities. Further study may even determine whether the quantity of care needed may be reduced by improving its quality.

Psychosocial Support

The psychosocial impact of caregiving on mental health is well-documented (Del-Pino-Casado et al. 2019; Thrush & Hyder 2014). As a result, **high-income countries have emphasized the**

importance of developing programs that provide psychosocial support to caregivers, including caregivers providing care and support to persons with disabilities. Such programs include psychoeducation, professional support, support groups, online forums, and training in psychological strategies. However, the evidence suggests that these programs have only small to moderate positive effects on reducing caregiver distress and depression, benefits which tend to diminish over the long term (Etxeberria et al. 2021; Yesufu-Udechuku et al. 2015). Furthermore, **current research on psychosocial support interventions largely overlooks the effects on care recipients, presenting a critical area for future study.**

Coordination & Financing Mechanisms

Case Management

In some high-income countries, such as Australia and the United States, **case managers help persons with disabilities develop their own support plans** (Wong et al. 2022). As a result, they coordinate care and support at the individual level, and also advocate for persons with disabilities when provided services do not meet their needs. In this sense, **they act as intermediaries between persons with disabilities, caregivers, healthcare professionals, and official government programs**. Given the difficulties in transitioning to or remaining in independent living, case management has been adopted as part of deinstitutionalization efforts in some high-income countries (Reilly et al. 2015).

Successful case management systems depend on robust disability management information systems that allow case managers to access and store information regarding each client. In some cases, such as in Rwanda, these information systems are connected to survey data and data on available services, facilitating public policy planning and case-by-case management (CBM 2022).

The limited experimental or quasi-experimental evidence available on case management interventions suggests that there are moderate positive effects on decreasing institutionalization and care costs in the medium term, particularly among people living with dementia (Reilly et al. 2015). Nevertheless, it remains uncertain whether case management effectively contributes to deinstitutionalization in the long term, or if individuals who are deinstitutionalized and receive case management support fare significantly better than those who do not. However, case management may also reduce caregivers' responsibilities and modestly improve their quality of life in the short term (Reilly et al. 2015). **Given the short- and medium-term effects of case management, these interventions may need to be complemented with other care policies to achieve a sustained long-term impact.**

Care Networks

Given the diverse needs of individuals providing and receiving care, **some countries have created structures to facilitate interoperability among multiple programs** (OHCHR 2024). These care networks coordinate a variety of services for persons with disabilities, older adults,

children, and caregivers. These may include cash-for-care programs, personal assistance schemes, respite care and training programs, and daycare centers. **Centralized administration within these networks facilitates beneficiary identification and prevents duplication of services**, thereby reducing operational costs. While this model is still developing in LMICs, it is rapidly emerging in some Latin American countries, such as Chile, Colombia, and Uruguay (Vásquez & Pereira 2023). For example, Bogotá's Manzanas de Cuidado offers a local, community-based, participatory system that supports caregivers, primarily women, through services like training, respite care, and community laundries. Its participatory design involves local communities in identifying needs, and tailoring services to match local realities.

Evidence from a now-defunct program in Brazil —the Care Network for Persons with Disabilities (RCPCD)— suggests that governance and inadequate monitoring and evaluation mechanisms can be significant obstacles; in this particular case such problems led to the program's termination (Ribeiro et al. 2023; Ferreira et al. 2023). In Brazil, the RCPCD was implemented by the Brazilian National Health System (SUS) as a way to increase access to care and support services for persons with disabilities. However, from its inception the program faced several obstacles. First, there were significant challenges in coordinating robust cooperation between the states to ensure access to appropriate services, especially in rural and vulnerable areas such as the Amazonas. Additionally, the program did not implement robust contracting mechanisms, and had unclear certification criteria for care providers. As a result, the success of the program in increasing formal caregiving and support was low, especially in rural areas[6]. This case study highlights the importance of focusing on increasing the supply of care and support services, as well as acknowledging the challenges associated with service provision in vast rural areas. Further research is needed to assess the effectiveness of integrated care networks, particularly regarding the sustainability of governance structures and the long-term impacts of combined interventions.

[6] A study that assessed the level of implementation of the RCPCD in 8 of the 26 states in Brazil found that implementation was moderate in 7 states and low in the Amazonas (Ribeiro et al. 2023

Box 2. Examples of Coordinating Care Networks: Australia and Uruguay

Australia and Uruguay have comprehensive care networks to enhance support for persons with disabilities. The Australian National Disability Inclusion Scheme (NDIS) pioneered care networks around the world, and continues to be seen as a reference point for the development of other systems. Launched in 2013, NDIS provides individualized funding for support and services, emphasizing individual autonomy and choice. The NDIS takes an insurance-based approach, relying on a fee-for-service, market-based system that provides funding to persons with disabilities to access the support they need. The funding allocated to each beneficiary varies based on their support plan. Given the diversity of the kinds of support covered, cross-sectoral coordination is critical for its success.

Despite the overall success of NDIS, challenges remain with its implementation. Concerns include inconsistent and inequitable access related to the determination of people's functional capacity; complexities for many participants and service providers in navigating the administrative requirements; and inconsistencies and inequities in the levels of funding received. Additionally, thin markets limit the participants' access to support due to a lack of service providers, especially in remote rural areas.

Other countries have opted instead to fund, develop, and coordinate a series of public care services that beneficiaries can access free of cost. This approach is particularly relevant in LMICs, where a lack of private service providers and high-priced services pose significant challenges to accessing care and support. This is exemplified by the National Integrated Care System of Uruguay, launched in 2015, which coordinates care services for caregivers, children, older adults, and persons with disabilities. Uruguay has one of the most comprehensive care networks in Latin America and the Caribbean. Its services include daycare, remote assistance for older adults, and caregiver training and certification. A key component of this system, particularly for persons with disabilities, is its personal assistance program.

This program provides subsidies to households with individuals classified as having "severe dependency," aged 0 to 30, or over 80, allowing them to hire a personal assistant from a database of registered, qualified professionals. All assistants must meet minimum training standards, with most receiving their training through the National Integrated Care System. As of 2023, this is the largest program of its kind in Latin America and the Caribbean; it supports 6,048 beneficiaries across Uruguay's 19 provinces. Notably, 75.3 percent of households receive the full subsidy, benefiting predominantly low-income families (Sistema Nacional Integrado de Cuidados 2024).

Despite the strengths of Uruguay's care system, several areas for improvement remain. Eligibility for personal assistance is based on an evaluation of dependency, which does not capture specific support needs. Additionally, the required training for personal assistants lacks disability-specific components, such as support for decision-making, or sign language interpretation. Funding limitations have also led to age and hour restrictions. The program also excludes those aged 30 to 79, leaving out adults with disabilities who may need support in order to work or study.

Moreover, it finances only a maximum of four hours of assistance per workday, with no coverage for weekends or vacation time, which many persons with disabilities need. Finally, both beneficiaries and assistants face challenges in safeguarding their rights, since the care system provides only limited oversight once assistants are hired. And while complaints can be filed, systematic oversight is lacking (Ríos-Espinosa 2024).

It is important to note that Uruguay's National Integrated Care System uses block funding rather than individualized funding, which can lead to underestimating or overestimating the demand for certain services. A closer evaluation of both fee-for-service and block funding models is needed in order to assess their cost-effectiveness and suitability for organizing care networks.

Sources: Vásquez Encalada et al., 2023; OHCHR 2024.

Gender and Disability-Responsive Budgeting

Gender-responsive budgeting calls for making budgetary allocations to government programs based on gender considerations. It has been used widely across LMICs, especially for policies that are more likely to affect women and girls, such as care policies. **This concept has been widely promoted for the last two decades as an important way to promote the well-being of women and girls, and to uphold the legal commitments made by countries to promote gender equality.**

Some countries have used gender-inclusive budgeting as a guide to conducting disability, race, and/or ethnicity-responsive budgeting. For example, in Uganda the 2023/2024 Budget Call Circular references a mandate that the Ministry of Finance, Planning and Economic Management reviews all budget framework papers to assess their gender and equity responsiveness, including in relation to disability; any budget framework paper that does not meet a threshold of gender and equity integration will be rejected and must be revised (Combaz et al. 2023). Despite these initiatives, the sum budgeted for disability inclusion in LMICs is often very low. For instance, available data indicate that LMICs often spend less than 0.5 per cent of their GDP on disability inclusion, although some countries spend significantly more (Combaz et al. 2023).

While gender and disability-responsive budgeting are tools that are not specific to the care agenda, care policy will affect both persons with disabilities and their caregivers, who are mostly women. As a result, it is crucial to implement disability and gender-inclusive budgeting in care policy. This analyzes not only the extent of funds targeted at these groups but also the manner in which the funds are being used. For example, money spent building institutions is going towards disability, but not in a way that is consistent with the CRPD.

Public-Private Cooperation

Care and support systems require the joint responsibility of states, markets, social and community organizations, families, and individuals. Collaboration between public and private-

sector actors holds significant potential for mobilizing the operational capacity, technology, and financial resources needed to meet the growing demand for care and support services, particularly in LMICs. In HICs, the private sector—both for-profit and nonprofit—has grown to meet the rising demand for care and support services as more women enter the labor market. Nonprofits in particular play a key role in fostering social innovation and creating community-based care services. However, concerns remain that relying too heavily on for-profit providers may lead to lower-quality care, higher costs, and unequal access, exacerbating existing inequalities (Barrantes & Cretney 2024). Private employers can also contribute by improving employee welfare through care and support initiatives such as lactation rooms, childcare, flexible working arrangements, family care leave, disability support services, and care- and disability-related subsidies (Vásquez & Pereira 2023; Laplonge et al. 2024).

There is limited evidence of lessons learned from public-private partnerships (PPPs) in the care economy in LMICs. **Evidence from PPPs in health care indicates that these collaborations can increase service accessibility, enhance care quality, and drive innovation, especially in resource-limited settings** (Srivarathan et al. 2024; Joudyian et al. 2021; Fanelli et al. 2020; Parker et al. 2019). However, there are remaining challenges such as poor governance, inadequate coordination, lack of accountability, unequal resource distribution, sustainability issues, and difficulty aligning public and private interests.

Complementary Policies

Care outcomes for persons with disabilities and their caregivers can be enhanced both directly through care policies, and indirectly by supporting programs from other sectors. **Inclusive policies in education, employment, health care, and transportation have the potential to reduce the need for support, leading to time savings, greater independence, and less unpaid care.** For example, inclusive education allows children with disabilities to attend school, decreasing the likelihood of their needing constant home care. Access to quality education also fosters skills development, facilitating their transition to employment, and reducing their future support needs. Evidence also suggests that children with disabilities may experience greater returns from education than their peers (Lamichhane 2013).

Similarly, access to vocational rehabilitation and employment opportunities enables persons with disabilities to afford the care and support services they need, lessening their reliance on unpaid family support. Inclusive health care is also critical to prevent functional decline and illness, which would otherwise increase care needs. Early childhood screening and timely interventions further enhance a child's long-term independence, reducing the need for future support.

Beyond care-specific policies, broader initiatives can complement disability care and support programs. Infrastructure improvements and the creation of accessible public services can reduce the need for human assistance. For example, universally designed public

transportation systems can allow persons with disabilities to navigate their environments independently. Other complementary initiatives include hospital-to-home transition programs, gender and disability-inclusive labor market policies, and broader social protection measures such as cash transfers and pensions. Traditional cash transfer programs target low-income households; receipt of the transfer is conditional on having met certain requirements such as vaccination status for children, and school attendance rates. In addition to this, some countries have disability cash transfers intended to support low-income households that include persons with disabilities, which may face greater costs than their counterparts who do not have members with disabilities. Some of these programs focus specifically on children, while others focus on adults with disabilities. While these programs are not designed to facilitate access to care and support services, they do provide monetary supports that can alleviate the extra cost burden.

Concessions such **as tax exemptions, discounts, fee waivers, and subsidies can also play a vital role in lowering the cost of everyday goods and services for persons with disabilities, helping to offset disability-related expenses.** These measures complement cash transfers, which often fall short of covering both household and disability-specific costs. Many LMICs, including Argentina, India, and South Africa, offer concessions within their social protection frameworks (Cote et al. 2023; Vásquez & Huertas 2021). Concessions are especially important for those who do not qualify for cash benefits but still face significant disability-related costs, particularly in health care, transportation, utilities, and education (Permatasari et al. 2022). However, these benefits tend to favor those in formal employment, and often exclude persons with disabilities who live in rural areas, or whose care is in the informal sector. Public transport concessions, for example, may not be available in rural areas, and women with disabilities may face additional barriers due to restrictive social norms. And while tax exemptions and subsidies on disability-specific items offer financial relief, they often benefit households that can already afford such goods.

Addressing these structural elements is key to improving inclusion and targeting the root causes of inequality in the care economy; a multisectoral approach to disability inclusion is essential for truly transformative care policies.

Part 5: Drivers and Barriers for Disability-Inclusive Care Policy

Implementing a disability-inclusive care policy in low and middle-income countries (LMICs) is complex. Practitioners must balance implementing comprehensive programs with tight fiscal budgets and competing priorities. **Several papers and case studies have identified common enablers for and barriers to designing and implementing disability-inclusive care policies. These barriers and enablers are summarized in the following points:**

Developing robust legal frameworks. The development of local legislation that supports disability rights, which is often influenced by ratification of the Convention on the Rights of Persons with Disabilities (CRPD), can play a crucial role in shaping inclusive care and support policies. For example, in Costa Rica the adoption of Act No. 9379/2016, the Law for the Promotion of Personal Autonomy of Persons with Disabilities, was key for the development of a new personal assistance scheme. In Australia, the National Disability Insurance Scheme Act 2013 established the National Disability Insurance Agency (NDIA) and gave birth to the Australian National Disability Insurance Scheme (NDIS), a national government-funded program that provides funding to persons with disabilities to help them gain access to support and services.

Fostering synergies between civil society groups. The differing perspectives of the disability movement and the women's rights movement have led to challenges in integrating disability and gender considerations within a unified care policy agenda, resulting in the inefficient and siloed implementation of care and support programs (Whitmore 2016). Moreover, it has often resulted in caregivers with disabilities, particularly women, being overlooked. **To strengthen the effectiveness of care and support models, it is essential to acknowledge that women and persons with disabilities share a common goal of autonomy; to embrace an intersectional approach; and to involve local organizations in policy discussions about how the care and support agendas can be more effectively integrated.** Transitioning from a singular focus on a "care agenda" to focusing on inclusive "care and support systems" could foster a more comprehensive approach that respects the needs and demands of all participants.

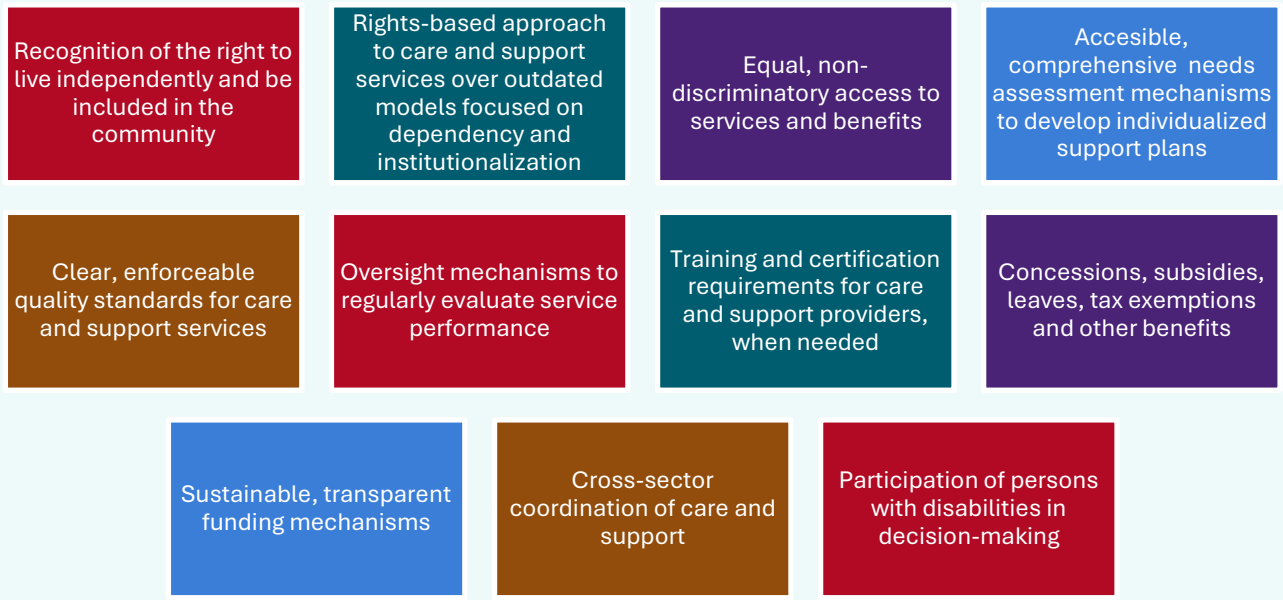
Understanding care and support paradigms and preferences. Diverse cultural paradigms shape care norms; some communities emphasize familial obligations; others adopt a communal approach; and some display paternalistic views that may limit the agency of persons with disabilities. For instance, **in small rural communities, persons with disabilities and those who provide them with support may be concerned about social pressure and privacy issues that can arise when non-family members enter their households** (Gupta 2021). Recognizing these differences is crucial for developing culturally sensitive care and support policies that confront stigma and discrimination, and make accommodations for local values and expectations, thus ensuring the effective implementation of programs.

Facilitating the supply of formal care and support while also supporting informal caregiving. In LMICs where informal care is predominant, those who provide care and support, as well as those who receive it, face unmet needs. To bridge this gap, **developing formal care and support services can present an opportunity to complement and strengthen the informal care economy**. The scarcity of formal care and support professionals outside the health care sector (case managers, personal assistants, sign language interpreters, etc.) highlights the need for investment in the professionalization and skills development of caregivers in order to ensure the provision of adequate disability-inclusive care. However, it is equally important to acknowledge the challenges associated with the feasibility of building comprehensive professional networks, particularly in remote rural areas. Supporting informal care and support through measures such as caregiver training programs for family members and cash-for-care programs is also crucial.

Increasing knowledge of the care and support needs of persons with disabilities. Accurate measuring of care and support needs is crucial in order to develop effective policy responses that consider the extent of support required, whether for the recipients or the providers of care and support. In countries that lack such data, policies may be imprecise, and may result in persons with disabilities being incorporated into broad care policies that don't address their specific needs; or in the creation of small-scale, disability-specific programs that are too narrowly targeted. **Disability certification based on individualized assessments is key in ensuring that support is tailored to each person's unique needs, providing a more accurate basis for policy and service provision.** Understanding how disability impacts care relations and outcomes is essential in order to inform comprehensive and effective care and support policies. Research can highlight the associations between care hours, household income, caregiver well-being, and unmet care and support needs, which may vary based on the country context. It is therefore imperative to invest in research furthering the care and support needs of persons with disabilities.

Box 3. Key Elements for a Comprehensive Legal Framework for Disability-Inclusive Care and Support Systems

Good laws do not necessarily imply good outcomes. The impact of legislation on care and support necessarily depends on the degree of implementation and the existence of conditions that facilitate or hinder inclusion. In this box we mention some of these key elements.



Part 6: Methodologies to Value Disability Inclusion in Care Policy

The literature on the monetary valuation of disability policy interventions is minimal. This review did not find studies that evaluate the cost-effectiveness of disability care policies and programs, or of disability-specific components in larger care policy initiatives. This underscores the need to advance the literature on conducting cost-effectiveness evaluations of disability care policies and programs.

This review could only identify methodologies associated with valuing the costs to caregivers who provide unpaid informal care and domestic work. Two main types of studies that estimate the costs of informal care stand out in the literature: **cost-of-illness studies** and **care prevalence studies**. These studies only focus on valuing informal care based on the costs and benefits to caregivers, while ignoring the potentially significant benefits to persons with disabilities. Nonetheless, they do make essential contributions to the implementation of methods for estimating the value of informal care. **They mainly leverage micro-costing; human capital or opportunity cost methods; willingness-to-pay methods; substitution cost methods; and quality-of-life methods.** While this is not the focus of this report, **Appendix B** provides a short description of how each of these methods has been used to estimate the value of care to caregivers. Furthermore, even though these methods have traditionally focused on the caregiver's perspective, the same methods can be adapted to measure the costs and benefits of care for persons with disabilities.

Nonetheless, **several additional costs and benefits should be considered in order to effectively evaluate disability-inclusive care policies and programs**. In Table 3, we have summarized the key factors that should be considered, and potential methodologies that could be used to value such effects. Different cost-benefit evaluations may consider different factors and methods to avoid double counting.

Table 3. Potential Individual and Societal Costs and Benefits of Disability Care Policy

Cost or Benefit	Method
Persons with Disabilities	
Payment for care services	• Micro-costing
Changes in employment *(gaining or losing a job)*	• Opportunity Cost
Changes to well-being *(gaining or losing well-being)*	• Willingness-to-pay methods • Quality-of-life methods
Caregivers	
Payment for care services	• Micro-costing
Changes in employment *(gaining or losing a job)*	• Opportunity Cost
Changes to well-being *(gaining or losing well-being)*	• Willingness-to-pay methods • Quality-of-life methods
Government	
Direct costs of program operations	• Micro-costing • Substitution method

Source: Author's elaboration.

Two issues must be considered when undertaking cost-benefit studies. The first is the difficulty in placing a monetary value on subjective well-being. Most commonly, this is accomplished using willingness-to-pay (WTP) methods, which essentially measure the amount a person is willing to pay for a certain outcome, for instance the cost of keeping a personal assistant (in the case of persons with disabilities); or the cost of reducing the amount of time spent providing care and support (in the case of caregivers). For this reason, WTP methods provide closer approximations to the intrinsic value of goods and services, regardless of what the market price is. However, these methods may struggle to capture the full range of benefits associated with support services, such as improved quality of life, autonomy, dignity, and social inclusion. Moreover, they may not account for income disparities among individuals with disabilities. For example, those with lower incomes might be less willing to pay for a service even if they would benefit greatly from it, because paying more would mean foregoing some other important necessity, like food or shelter. This can skew the results and underestimate the true value of the service to certain demographics.

Secondly, the estimated economic benefits in any cost-benefit study (regardless of the method used) are calculated based on recent historical conditions. If improvements in the care economy occur simultaneously with improvements in the labor market or public infrastructure, then using historical data to estimate the returns to the employment of persons with disabilities will be underestimated going forward. This is particularly when evaluating the benefits of education. Also, inclusion cuts across all sectors, so the return to reform in one sector will depend greatly on what occurs in other sectors.

Part 7: Conclusions

The existing evidence on incorporating a disability perspective within care policy is limited. The vast majority of studies are concentrated in high-income countries, and they primarily explore the adverse effects of caregiving, especially on women. This approach has concentrated predominantly on evaluating interventions aimed at alleviating the caregiving "burden" for women. As a result, there is a significant gap in our understanding of the impact of care policies on individuals receiving care, particularly those with disabilities.

Despite this gap in the literature, this review has identified various disability-specific care policy models and practices. The evidence on **case management** suggests that it has small to moderate effects on deinstitutionalization in the medium term**. Caregiver training** and **psychosocial support** programs exhibit moderate positive effects on caregiver well-being, mainly by reducing stress and depression. **Peer support** programs may also have similar effects. The evidence on **respite care** shows mixed results on caregiver stress. **Personal assistance**, a model that emphasizes autonomy and control by persons with disabilities, has gained traction in high-income countries but remains limited in LMICs; experimental and quasi-experimental evidence on this approach is nonexistent. While the impact of **care centers** has not been rigorously evaluated, there are human rights concerns associated with these care models, particularly for long-term care and residential centers which may rely on institutionalization models that undermine autonomy and inclusion. Providing care and support services through **independent living centers** are an alternative to these models; yet there are no experimental evaluations of these programs. The impacts of **cash-for-care** appear to vary depending on program design, but evidence on these programs is still emerging. Similarly, evaluations of **care networks** and **multisectoral approaches to care policy** are scarce despite these programs being common in many LMICs. While many of these care policy models show promise in addressing the needs of persons with disabilities, further research is needed to better understand their long-term effects, and to ensure cultural appropriateness.

This review of academic and gray literature has identified common enablers and barriers to the development of disability-inclusive care policies that are prevalent across many LMICs. **Robust legal frameworks, influenced by the CRPD, are crucial. Fostering collaboration between civil society groups, understanding cultural norms, ensuring the availability of formal services, and enhancing knowledge about the needs of persons with disabilities are also pivotal enablers. These factors are vital for the success of effective disability-inclusive care policies in LMICs.**

The literature on the monetary valuation of disability policy interventions is notably limited. **There is a lack of studies on the cost-effectiveness of disability care policies and programs, which underscores the urgent need to advance research in this domain.** There is a relatively large literature focused on valuing informal care; but these valuation methods are all done from the caregiver's perspective, using methodologies such as micro-costing, human capital methods, willingness to pay, substitution cost, and quality-of-life approaches. **It is crucial to broaden the**

scope of valuations of informal care and other aspects of care policy by considering the costs and benefits accrued directly by persons with disabilities. While this has not yet been done, this document provides guidance on how various methodologies could be used to comprehensively evaluate the costs and benefits of disability-inclusive care policies and programs.

Data on disability and care are scarce. Only a few surveys have included questions on disability, or have inquired about specific care activities for persons with disabilities. This scarcity has significantly limited analysis of the demand for the care and support of persons with disabilities in LMICs, since most surveys lack a disability perspective and fail to facilitate an analysis of care specific to this group. **Therefore, it is imperative that new data sources not only incorporate questions on disability, such as those found in the Washington Group Short Set of Questions (WG-SS), but also include the Washington Group's extended set, and, for children, the UNICEF/WG Child Functioning Module**. Moreover, information on care exclusively for persons with disabilities should be included in time use surveys (TUS), with questions that cover general support for individuals with disabilities, not just information on specific daily activities. Care surveys and TUS's should also acknowledge that persons with disabilities can be both recipients and providers of care and support. Consequently, this group must be represented in data collection efforts, with specific questions about their time use and caregiving activities.

The results of this analysis reveal that the demand for care and support extends beyond persons with severe functional difficulties. In fact, individuals with a variety of levels of functional difficulties and severities require care and support, and the extent of their needs depends on the type of support they receive. For example, in countries where a significant proportion of persons with disabilities receive care, a lower percentage report having unmet support needs. In addition, in LMICs that have available data (Colombia and Mexico), caregivers spend, on average, seven hours per day, with most of the caregivers providing general care—not specific to any activity. These caregivers are usually women, often the mothers, daughters, or sisters of persons with disabilities. Moreover, in LMICs where information is available, persons with disabilities who provide care spend on average fewer hours in these activities compared to persons without disabilities, a finding that contradicts what happens in countries such as the United States, where women with disabilities are more likely to be caregivers and to spend more time providing care (National Association of Chronic Disease Directors 2018). Therefore, policies and programs that aim to expand the variety and availability of care services must take into account the needs of persons with different types of disabilities, and assess whether those needs have been met by informal care.

Appendix A. Demand for the Care and Support of Persons with Disabilities: An Extended Table

	CHI	CRI	MEX	NIC	PER	AGH	IND	PAK	SRI	GEO	TAJ	CAM	LAO	PHI
Percentage of persons with disabilities receiving care/support	**28.1**	**48.1**	**36.9**	**53.4**	**40.7**	**31.6**	**36.8**	**43.4**	**23.6**	**33.8**	**71.8**	**51.3**	**75.4**	**29.5**
Male	26.7	41.8	39.2	51.7	39.2	32.9	35.0	25.6	25.1	38.4	68.9	48.9	74.1	27.3
Female	29.0	52.9	34.7	54.7	42.1	30.6	38.1	50.0	19.5	31.0	73.5	54.2	76.7	30.9
18-30	14.8	31.7	30.2	50.7	45.5	29.3	32.0	38.5	27.2	37.2	66.8	50.0	78.6	11.4
31-59	17.2	35.3	30.5	40.0	34.9	28.9	31.0	30.0	18.0	31.3	67.5	48.2	72.3	21.9
60 o older	43.3	64.6	40.6	59.5	38.8	46.5	51.1	67.3	29.6	34.5	83.9	61.0	78.9	42.3
Rural	27.0	46.4	36.5	56.6	43.1		38.9		25.6	33.9	72.8	51.5	73.2	
Urban	36.2	48.8	36.9	49.0	40.0		36.1		17.1	33.7	68.5	50.0	76.7	
Percentage of people receiving care/support that report needing more care/support	**29.3**	**16.3**	**26.0**			**63.2**	**65.7**	**37.1**	**64.1**	**40.5**	**50.1**	**33.3**	**73.6**	**29.5**
Male	23.7	13.1	23.4			70.6	62.7	70.0	63.7	38.5	52.2	33.3	76.0	34.7
Female	32.5	18.3	28.3			67.4	67.8	30.8	59.0	42.0	49.0	33.3	71.4	26.4
18-30	15.8	9.8	22.3			69.7	52.9	80.0	82.6	71.3	51.2	18.2	75.9	47.1
31-59	25.6	17.8	21.5			65.4	64.5	29.2	54.1	55.4	45.7	43.6	72.3	29.5
60 o older	32.1	16.3	31.0			75.4	72.7	36.4	66.1	30.4	57.0	28.0	72.1	27.9
Rural	41.2	16.7	33.6			NA	73.2		61.4	41.3	50.5	38.5	64.7	
Urban	27.1	16.2	18.7			NA	63.3		67.9	39.6	48.8	32.3	78.1	
Percentage of people that do not receive care/support that need it						**44.2**	**31.9**	**16.1**	**11.1**	**31.8**	**25.6**	**44.6**	**59.5**	**80.7**
Male						49.1	30.4	24.1	10.6	25.2	21.2	48.8	61.7	86.7
Female						40.3	33.1	11.5	12.2	35.5	28.7	38.7	57.3	76.6
18-30						41.6	27.3	25.0	8.6	23.9	14.5	50.0	64.0	96.8
31-59						44.1	28.2	14.3	7.5	23.6	28.7	44.2	58.9	86.8
60 o older						52.4	46.6	18.7	16.2	36.5	27.0	50.0	51.1	68.9
Rural							31.7		11.9	32.6	29.7	47.5	69.1	
Urban							32.0		8.6	31.0	15.2	30.8	44.3	

Note: The results from Cameroon and Pakistan should be interpreted with caution, given that the surveys do not employ population weights and the sample size is lower than 500 observations.

Source: Afghanistan, Model Disability Survey (2019); Cameroon, Model Disability Survey (2016); Chile, Disability National Survey (2015); Costa Rica, Disability National Survey (2018); Georgia, Model Disability Survey (2021); India, Laos, and Tajikistan, Brief Model Disability Survey (2018); Mexico, National Survey on the Perception of Disability (2010); Nicaragua, National Household Disability Survey (2003); Pakistan, Model Disability Survey (2015); Peru, National Disability Survey (2012); the Philippines, National Disability Prevalence Survey (2016); and Sri Lanka, Model Disability Survey (2015).

Appendix B. Informal Care Valuation: Methods from the Caregiver Perspective

Micro-Costing

Micro-costing is a methodology employed in cost-of-illness studies that looks at consumption expenditures in detail to estimate unit cost data; in this case, the cost of expenditures associated with informal care. In other words, **this technique focuses on the direct costs of care**: for example, how much a caregiver spends on **transportation** to reach the person they care for, and on **medications or hygiene items** for the person they care for.

While micro-costing is easy to implement and yields interesting results regarding direct spending, this method has several limitations. First, for this methodology to accurately measure direct care costs, respondents must have a very clear and precise knowledge of how much they spend; furthermore, asking respondents to recollect the exact prices of an exhaustive list of goods and services is not either easy or reliably accurate. Therefore, results using micro-costing are likely to be biased—either overestimated or underestimated. Furthermore, micro-costing techniques do not consider the indirect costs of care, or the intrinsic value of care to the persons with disabilities, or to their caregivers. For this reason, studies often use micro-costing along with other valuation methods.

Human Capital Method

The human capital method, also known as the **opportunity-cost method**, estimates the value of human capital as the value of future earnings had the person who is providing care continued to engage in formal employment. It is often described as **foregone income** and therefore is considered an indirect cost. The human capital method is widely applied in the literature and yields important estimations of the costs of informal care. But it is important to acknowledge the limitations of this methodology, which can be problematic; for one thing, it assumes that a person's productivity remains unchanged over time. Furthermore, it can be a complicated methodology to implement in low-income settings that have high rates of informal labor, since wages in the informal sector may be highly variable. Therefore, estimates of foregone income may not be very accurate.

Willingness-to-Pay Methods

Willingness-to-pay (WTP) methods are an important alternative to the micro-costing or human capital valuation methods. These methods attempt to measure the amount a person would be willing to pay for a certain outcome, in this case, in order to reduce the amount of time spent providing care. For this reason, willingness-to-pay methods provide closer approximations to the intrinsic value of the time spent on care by an individual person. This value may or may not

coincide with the market price of professional caregiving. Rather, it reflects the value to an individual person of their time.

Most studies that estimate willingness-to-pay use either contingent valuation or discrete choice experiments. **Contingent valuation** asks people what they would be willing to pay for a hypothetical scenario in which substitution care is offered. **Discrete choice experiments** ask people to choose between two or more options over various choice sets.

The main criticism of willingness-to-pay methods is that they are **stated preference** methods: that is, they rely on what people *say* they would do instead of what they actually do. In other words, people may say they are willing to pay a given amount for care, but in a real situation, they might pay a much lower or higher amount. Furthermore, none of the studies that use willingness-to-pay methods consider the preferences of the persons with disabilities; they consider only the person providing informal care. So it is unclear if the persons with disabilities value the care provided by their family members more or less than they would value care provided by others. Also, since these studies have occurred thus far only in high-income countries, it is unclear whether replication in low-income countries would yield similar results.

Estimating Substitution Costs

Much of the literature considers what it would cost to substitute unpaid informal care with formal care services. These studies leverage **large-scale surveys** to measure the prevalence of persons with disabilities receiving informal care and the number of informal care hours provided. Then the average cost of care per hour is estimated based on the direct costs of existing services. This allows calculation of the total substitution cost of informal care.

While the substitution cost method is practical, it too has limitations. First of all, most low and middle-income countries (LMICs) do not have comprehensive private or public care programs. Given the reliance on informal care, it would be impossible to estimate the average cost of care per hour based on existing services. Secondly, even in contexts that have developed publicly funded care programs, this method assumes that there is an infinite number of trained care providers ready to be paid to substitute informal caregivers. This is especially problematic in LMICs, where there is a shortage of professionalization opportunities for care workers. Furthermore, mere substitution does not reflect the true intrinsic value of care to those receiving or providing care.

Quality-of-Life Method

Over the last 20 years, the knowledge generated on the effects of caregiving has been used to create valuation methods for informal care based on caregiver perceptions of their quality of life. Perhaps the most notable example is the development of the Care-Related Quality of Life instrument (CarerQol), which was designed to measure and value the impacts of caregiving on the

quality of life for those providing informal care. This method has been widely used in Europe and is also beginning to be adapted and used in LMICs. Understanding and implementing quality-of-life methods are the gold standard valuation method for the value of care work to caregivers.

This methodology is relatively straightforward. First, respondents are asked to provide information on the amount of time they have spent on care, in order to estimate the total number of years spent caregiving. Then they rate their own quality of life across various domains: physical and mental health, social relationships, financial stability, and overall quality of life. Then they are asked to rate how important each of these domains are to their own quality of life, which allows the researchers to create weights that reflect the relative importance of each domain to each caregiver. Finally the weighted sum of each domain score is summed and normalized to create an overall quality of life score that reflects the relative importance of specific domains in each country. These normalized scores are then multiplied by the number of years spent caregiving to calculate Quality-Adjusted Life Years (QALY). Researchers can then use the human capital or willingness-to-pay method to assign a monetary value associated with gaining or losing one QALY. This represents the monetary value of one year of caregiving based on respondents' sense of how caregiving has affected multiple dimensions of the quality of life.

However, quality-of-life methods have several limitations. First, these methods rely on subjective assessments; respondents may over- or underestimate these effects. Furthermore, as in the other valuation methods described in this section, the value of care and support to those receiving care has not been considered.

Glossary

5R Framework: The 5R Framework for Decent Care Work is a policy framework focused on recognizing, reducing, and redistributing unpaid care work, along with rewarding and representing paid care work.

Care: A concept with various meanings; it can denote a type of work or activity, an emotional state, a moral value, or a social relationship. Within development debates, the term "care" often refers to **care work**.

Care economy: The sector of economic activities related to providing care, including both paid and unpaid care work.

Care work: Activities undertaken to ensure the well-being and development of individuals throughout the life cycle, including both direct and indirect forms of care.

Caregivers: Individuals who provide care and support to others; this includes both unpaid and paid care workers.

Disability inclusion: Ensuring that persons with disabilities are fully included and able to participate meaningfully in society, and that they have access to opportunities equal to those of others, through the removal of environmental and social barriers, and the provision of individualized support as needed.

Micro-costing: A method used in economic evaluations that calculates the costs directly associated with each component of care or service delivery.

Human capital or opportunity-cost methods: Methods used in economic evaluation that estimate the value of human capital as the value of future earnings had the person who is providing care continued to engage in formal employment.

Willingness-to-pay (WTP) methods: Methods used in economic evaluation that seek to measure the amount a person is willing to pay for a certain outcome, in this case, in order to reduce the amount of time spent providing care.

Substitution cost methods: Methods used in analysis of large-scale surveys to estimate what it would cost to substitute unpaid informal care with formal care services based on the prevalence of people receiving informal care, the number of informal care hours provided, and the direct costs of existing care services.

Quality-of-life methods: Valuation methods for informal care based on caregiver perceptions of their quality of life.

Personal assistance: Services provided to individuals with disabilities through which they receive one-on-one support that respects their autonomy and supports their independent living.

Respite care: Services that provide short-term relief for family caregivers from their care responsibilities in order to facilitate their ability to engage in various activities and self-care, while also continuing to support the needs of care recipients.

Support: Term used to describe assistance provided to individuals with disabilities that helps them to carry out their daily activities and participate in their communities, while respecting their autonomy and supporting their independent living. This term (rather than "care") is preferred by the disability inclusion community.

Time Use Survey (TUS): A survey that collects detailed information on how individuals allocate their time daily, including time spent on care activities.

Washington Group Short Set (WG-SS): A set of questions designed by the Washington Group on Disability Statistics for the purpose of identifying persons with disabilities based on their functional limitations. It is used globally for data collection.

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