

AUTONOMY: A REGIONAL CHALLENGE

**Building systems of support for
community living for people with
disabilities in Latin America
and the Caribbean**

Center for Inclusive Policy
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INTRODUCTION

The socio-economic crisis caused by the COVID-19 pandemic and its effects has underscored the centrality of support and care systems that enable people with disabilities to live in community. Several studies indicate that people with disabilities, particularly those with intellectual disabilities and those in institutions, died from COVID-19 at a higher rate than people without disabilities (Knapp et al., 2021). Also, during the pandemic and periods of quarantine and isolation, people with disabilities faced serious challenges when trying to get access to basic services such as health and education for a variety of reasons including health services discriminating on the basis of disability, lack of accessible virtual educational platforms, and lack of support systems and services that help people with disabilities and their families in their daily living activities including overcoming the barriers listed above (COVID-19 Disability Rights Monitor, 2020). In fact, contagion and isolation measures significantly affected both formal services and informal support networks including the assistance provided by family and close relatives or friends, most of whom are women.

Although Latin America and the Caribbean are gradually making progress in building a caregiving agenda, people with disabilities and their organizations are, for the most part, on the fringes of such efforts. On one hand, there is a historical resistance on the part of the disability movement against addressing the rights of people with disabilities from a caregiving perspective. This is because traditional care narratives position people with disabilities as a "burden" or "dependent," and caregiving policies and approaches have left a negative legacy of medicating, segregating, and disempowering them. On the other, although feminist movements and caregivers, who are leading the advocacy and debates, are beginning to make the need for a systemic view of care that incorporates the demands for autonomy and participation of people with disabilities visible, this is not yet reflected in all national agendas and many of the proposals still maintain a paternalistic and medical approach to disability (Bango & Cossani, 2021). Building comprehensive caregiving systems must not become a missed opportunity to advance the rights and inclusion of people with disabilities.

In this respect, this report is an attempt to identify the gaps in support and care for people with disabilities in Latin America and the Caribbean. It is also an effort to explore opportunities and recognize best practices for the development of comprehensive care and support systems that promote independent and community living for this group of people. Therefore, this document could serve as a framework for not only those seeking to further the rights and inclusion of people with disabilities but also those working on developing integrated caregiving systems.

In this report, the term "support and care" is used to refer to the assistance that people with disabilities may need in order to do everyday activities and to participate actively in their communities. "Support" is a term widely accepted by the disability movement to represent the paradigm shift promoted by the Convention on the Rights of People with Disabilities (CRPD), which emphasizes personal autonomy, independence, and community inclusion. The use of the term "care," in turn, is intended to highlight assistance throughout the life cycle of people with disabilities, especially during childhood, and to reflect the changes in the way this term is understood within feminist movements. It also seeks to show that the debate on

services and support networks for people with disabilities is inextricably linked to the care agenda.

The document is divided into five chapters. The first one explains what support and caregiving systems for people with disabilities consist of and their importance in the framework of the disability and caregiving agenda. The second addresses the gaps in access to support and care for people with disabilities. The status of legislation, policies, and programs regarding support and care for people with disabilities is analyzed in the third section. The investment with respect to support and care for people with disabilities in the region is estimated in the fourth section. Finally, in the fifth chapter, the main components needed for developing support and caregiving systems for people with disabilities are analyzed. Throughout these chapters, the challenges and opportunities for developing support and caregiving systems for people with disabilities are analyzed.

While preparing the report, the situation with regard to support and care responses in 18 countries in the region was analyzed: Argentina, Barbados, Bolivia, Brazil, Chile, Colombia, Costa Rica, Dominican Republic, Ecuador, El Salvador, Jamaica, Mexico, Panama, Paraguay, Peru, Trinidad and Tobago, Uruguay, and Venezuela; all members of CAF - Development Bank of Latin America. The relevant regulations and policies of the countries in question including their disability laws and their caregiving systems and policies were reviewed. National reports on compliance with the CRPD and the Inter-American Convention on the Elimination of All Forms of Discrimination against People with Disabilities (CIADDIS) were also consulted as were the conclusions of monitoring bodies and contributions from civil society. In addition, requests for information were sent to various ministries and secretariats in the 18 countries to gather information on programs, services, and budgets. Last of all, experts and academics from several countries were consulted.

Chapter 1

SUPPORT AND CAREGIVING SYSTEMS FOR PEOPLE WITH DISABILITIES

Talking about support and caregiving systems for people with disabilities requires an understanding of the conceptual frameworks underlying the disability rights agenda and its relationship to comprehensive care systems. To do this, it is important to understand who people with disabilities are, what their demands for support and care are, why they are important to people with disabilities, their families, and society at large, and what international regulatory framework underpins these demands.

1.1. Who are the people with disabilities?

People with disabilities represent 15 percent of the world's population, that is, approximately 70 million people with disabilities in Latin America and the Caribbean (World Disability Report, 2011; Disability and Rights COVID-19, 2021). They are a diverse and heterogeneous population, with multiple intersecting characteristics and identities, such as age, gender, sexual orientation, race, skin color, ethnic and social origin, culture, religion, and migratory status. It is estimated that at least 20% have intense support needs (World Report on Disability, 2011).

Disability" is a constantly evolving concept that results from the interaction between people with impairments and attitudinal and environmental barriers (CRPD, 2006). According to the United Nations Convention on the Rights of People with Disabilities (CRPD), ratified by all countries in Latin America, people with disabilities include "those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (CRPD, Art.1, 2006).

The CRPD definition is not a closed definition but an inclusive one, which seeks, on one hand, to recognize the diversity of the group of people with disabilities and the social barriers they face, and, on the other, to emphasize that disability is not the result of "impairments" or functional diversity of people, but of the interaction with attitudinal and environmental barriers that limit their participation. Indeed, for a long time, and still in many contexts, disability was understood from charitable and medical approaches, which emphasized "changing" the person rather than transforming the environment. This led to disability being approached mainly through paternalistic, rehabilitative, and segregated models.

Although each country has its own definition of disability and people with disabilities for the purposes of its legal and, in particular, social protection systems, a broad conception of disability should be used in the implementation of support and caregiving systems including traditionally invisible groups such as people with intellectual disabilities, people with psychosocial disabilities, autistic and neurodivergent people, deaf and blind people, people with dementia, people with rare and infrequent diseases, and people with chronic diseases that may require support and care.

1.2. What are the support and care needs of people with disabilities?

Over the course of their lives, people with disabilities have a variety of support and caregiving needs. These vary based on the characteristics of each individual, such as age, gender, type and degree of disability, and individual preferences as well as the circumstances and context in which they live.

An inaccessible environment is likely to demand greater assistance because support will be essential in order to overcome accessibility barriers such as lack of information in accessible formats or lack of accessible public transportation. Also, access to technical aids and support devices can reduce the need for human support. However, as some authors have noted, the elimination of accessibility barriers and inclusion practices may, at the same time, increase the demand for support and care systems in the medium term since people with disabilities will tend to participate in a greater number of areas (Vásquez et al., 2021).

Support and caregiving needs have traditionally been classified as follows:

- **Basic daily living activities (BDLA):** Are those personal care activities that are essential for life, such as eating, personal hygiene, clothing, and personal mobility.
- **Instrumental activities of daily living (IADL):** are those necessary for independent living, but which are more complex than BDLA such as managing money, using communication devices (e.g., telephone), preparing meals, shopping, moving around their surroundings, and maintaining a home.
- **Advanced daily living activities (ADLA):** are those needed to participate in the community and to develop a socially satisfactory life such as education, work, recreation, and social participation. They are linked to the values, interests, skills, and social context of each person.

Although these classifications can be useful for making the different support and caregiving needs visible, there is a risk that one may be favored over another. In addition, they can lead to making other support needs invisible such as the support in decision making that is intrinsic to all categories. The demands that people with disabilities be included require that all support and care needs be met to ensure independent living and active participation in the community.

1.3. What are support and caregiving systems for people with disabilities?

Support and care systems refer to the combination of services, networks, people, and products that assist an individual with a disability in making decisions or carrying out daily living activities to enable the person to exercise the right to live independently in the community (OHCHR, 2023). Thus, they include the relationships that an individual develops with family, friends, neighbors or other trusted people who provide support (Deinstitutionalization Guidelines, 2021).

Support and care systems encompass a wide range of formal and informal services and assistance, including support for decision-making and the exercise of legal capacity; human support to carry out daily living activities; supportive and mobility technologies to

compensate for functional limitations and to address environmental barriers; transportation and housing assistance to address accessibility barriers in these areas; financial assistance to cover additional costs related to support and care needs; counseling and support programs for families; and other community services needed to prevent institutionalization and ensure independent living in the community for people with disabilities.

To this end, support and care systems connect and enhance disability inclusion efforts in various sectors such as education, labor, health, or social protection and thus facilitate the inclusion and full participation of people with disabilities and their families through the coordination of a variety of plans, services, and networks that involve the State, communities, and families.

1.4. How do support and caregiving systems for people with disabilities relate to the Agenda for Care?

In recent decades, the care agenda has gained prominence in Latin America and the Caribbean, especially after the socioeconomic crisis triggered by COVID-19. This is due to the momentum of feminist movements that have succeeded in positioning the centrality of care for the advancement of gender equality. This agenda has placed particular emphasis on recognizing, revaluing, and redistributing caregiving work between men and women as well as between the State, communities, families, and the market.

Within this agenda, caregiving has been defined broadly and encompasses a wide set of activities that include health care, home maintenance, assistance for people considered "dependents" and caregivers as well as self-care (Bango & Cossani, 2021, p. 11-12). The target populations of care systems and policies include children; people who require assistance, support, or care due to aging, illness or disability; and caregivers (paid and unpaid). Thus, the support and care required by people with disabilities are part of the caregiving agenda. These two agendas have an impact on and influence each other's development and progress.

However, people with disabilities and their organizations are not getting meaningful participation in discussions related to the construction of care systems and policies. In addition to the lack of visibility and participation of people with disabilities in decision-making processes, this omission, is partly explained by the historical criticism of the movements of people with disabilities to the notion of "care" and the traditional models of "care" organizations (OHCHR, 2023).

For example, the independent living movement, which emerged in the 1970s, questions and rejects the description of disability as a "burden" and the view of people with disabilities as "dependents" (Shakespeare, T., 2000; Maker, 2022). This perspective of care has perpetuated charitable and medical models of disability that undermine the autonomy and independence of people with disabilities. Moreover, it has caused traditional care services to result in the infantilization, discrimination, exclusion, and segregation of these people, even within families and institutions. There is also a palpable concern that an agenda focused on the needs of caregivers will reduce people with disabilities to the passive role of mere recipients of "care." Hence, within the disability movement, there is a preference to speak of "support" for independent living rather than "care."

In response to this concern, new developments in the care agenda seek to ensure that care policies respond to the diversity of demands of all the target populations. An agenda based on the recognition of care as a right, the universality of care, co-responsibility, the promotion of autonomy, solidarity, and participation in decision-making processes is proposed (OHCHR, 2023). Rethinking the care agenda to make it inclusive of people with disabilities requires recognizing people with disabilities as subjects with agency who receive and provide care. It also demands the application of the model of human rights for people with disabilities and the abandonment of welfare models that reproduce oppression such as the creation and maintenance of institutions for people with disabilities and the development of measures that reinforce the economic dependence of this group.

1.5. Why are support and caregiving systems important for people with disabilities?

Systems of support and care for people with disabilities are important for their inclusion and for the exercise of their rights, gender equality, and sustainable development.

First, they are a central obligation within the right of people with disabilities to live independently in the community. For most people with disabilities, access to support and care systems is a necessary condition for living and participating fully in their communities with equal opportunities as other people (Devandas, 2016). Moreover, for those with high support needs, support and care systems are indispensable for living with dignity, autonomy, and independence. Without them, many people are at risk of becoming poor, socially excluded, abandoned, and institutionalized. In addition, support and caregiving systems are instrumental to the exercise of rights: they facilitate decision-making, communication, mobility, employment, participation in public and political life as well as providing access to and enjoyment of services such as education, health, and justice.

Secondly, the development of comprehensive support and care systems for people with disabilities that include the integration of services and support for families and caregivers is key to ensuring the redistribution and reduction of unpaid care that, due to the lack of services and the traditional division of roles by gender, is mostly provided in families by women; mothers, daughters, wives and sisters with and without disabilities. This overburdening of women with unpaid caregiving work has a negative impact on gender equality in not only the labor market, but also in education, social, and political participation, and the enjoyment of leisure time. In Latin America and the Caribbean, women have spent three times as much time as men on unpaid care work since before the pandemic (Bango & Cossani, 2021). This reality was aggravated during the pandemic by the increase in the demand for care and the reduction in the availability of services caused by lockdown and social distancing measures. Hence, investing in support and caregiving systems for people with disabilities will help to reverse this situation.

Third, investment in support and care systems for people with disabilities represents a commitment to sustainable development. Access to support and care is not only a prerequisite for ensuring that people with disabilities are not left behind in achieving the Sustainable Development Goals but can also contribute to the development of countries and generate wealth. The lack of comprehensive support and care systems is one of the reasons why many people with disabilities do not attend school or find employment and thus limits

the prosperity of individuals, their families, and societies. In fact, access to support services can enable many people with disabilities, who would otherwise be considered unable to work, to obtain employment and bring an income into their households. In addition, sustained investment in support and care systems has the potential to create millions of jobs in the region that would benefit mainly women and youth (Addati et al., 2022).

1.6. What are the obligations of the States in terms of support and caregiving?

As we have shown, access to support and care systems for people with disabilities is a human rights issue. Hence, international human rights law requires States to ensure that people with disabilities have access to the support they may need to exercise their rights and to ensure their inclusion and full participation in the community (Devandas, 2016). This is an obligation that arises from several rights recognized in international and regional human rights instruments and is definitively expressed in the United Nations Convention on the Rights of People with Disabilities (CRPD), in force since May 3, 2008.

The provision of support is an obligation that runs throughout the text of the CRPD, from general obligations to specific obligations related to various substantive rights. For example, Article 12 on equal recognition before the law requires member states to provide people with disabilities access to the support they may need to exercise their legal capacity. Article 19, in turn, recognizes the right of people with disabilities to live independently and be included in the community and, in its subparagraph b), requires member states to ensure that they have access to a range of home, residential, and other community support services including personal assistance. Article 28 on an adequate standard of living and social protection also emphasizes the obligation of member states to ensure access to affordable, quality services, devices and other forms of assistance to meet disability-related needs as well as the assistance necessary to meet disability-related expenses including training, counseling, financial assistance, and respite services.

Note that the CRPD has been ratified by 186 States including all the countries of Latin America and the Caribbean. In this respect, all the countries in the region have the obligation to respect, protect, and fulfill the right of people with disabilities to live independently and to be included in the community as well as to implement comprehensive systems of support and care for people with disabilities.

Table No. 1. Ratification of the CRPD by CAF member countries

Country	Signed	Ratification/Adherence
Argentina	30 Mar 2007	2 Sept 2008
Barbados	19 Jul 2007	27 Feb 2013
Bolivia (Plurinational State of)	13 Aug 2007	16 Nov 2009
Brazil	30 Mar 2007	1 Aug 2008
Chile	30 Mar 2007	29 Jul 2008
Colombia	30 Mar 2007	10 May 2011
Costa Rica	30 Mar 2007	1 Oct 2008
Dominican Republic	30 Mar 2007	18 Aug 2009
Ecuador	30 Mar 2007	3 April 2008
El Salvador	30 Mar 2007	14 Dec 2007
Jamaica	30 Mar 2007	30 Mar 2007
Mexico	30 Mar 2007	17 Dec 2007
Panama	30 Mar 2007	7 Aug 2007
Paraguay	30 Mar 2007	3 Sept 2008
Peru	30 Mar 2007	30 Jan 2008
Trinidad and Tobago	27 Sept 2007	25 June 2015
Uruguay	3 April 2007	11 Feb 2009
Venezuela (Bolivarian Republic of)		24 Sept 2013

Source: United Nations Treaty Collection

Based on the work of the Committee on the Rights of People with Disabilities and the former Special Rapporteur on the rights of people with disabilities, Catalina Devandas, it is possible to identify some parameters for the development of support and care systems including:

- Support should be considered a right;
- Support encompasses formal and informal arrangements of different types and intensities;
- The support must respect the rights, will, and preferences of the person with a disability;
- Support should allow for personal choice and control by the person with a disability;
- The support must be personalized and flexible enough to adapt to the requirements of the person with a disability and not the other way around;
- Support should always be based on individual needs, not on the interests of the service provider;
- Support must be available, accessible, acceptable, affordable, and adaptable;
- Support must take cultural and geographic (urban/rural), age, and gender differences into account;
- Peer support, self-advocacy groups, circles of support and centers for independent living, etc., are forms of support that should be fostered and recognized;
- The purpose of support is to achieve full inclusion in the community and any institutional form of support services that segregates and limits personal autonomy is not permissible and is contrary to human rights; and
- Caregivers must, in turn, have access to the support they may need to assist their children or family members to live independently in the community.

The CRPD also imposes an obligation on member states to consult closely and collaborate actively with people with disabilities, including children with disabilities, through their representative organizations in the development and implementation of legislation and policies relating to people with disabilities including the design, implementation, and monitoring of support and care policies.

Finally, the member states have made a commitment to adopt measures to the maximum of their available resources and within the framework of international cooperation to progressively achieve the full exercise of the economic, social, and cultural rights of people with disabilities. These steps should be taken immediately or within a reasonably short period of time and should be deliberate, concrete, targeted, and should use all appropriate means (Equality and non-discrimination observation, 2018). Member States have an immediate obligation to eliminate any discrimination against people with disabilities in the enjoyment of their right to live independently in the community; They must also initiate strategic planning, with adequate time frames and sufficient resources, in close consultation with organizations of people with disabilities, to replace all institutionalized settings with community-based care and support systems.

Chapter 2

GAPS IN ACCESS TO SUPPORT AND CARE FOR PEOPLE WITH DISABILITIES

Given the obligation and growing interest of several countries in the region in providing support and caregiving for people with disabilities, it is important to quantify the magnitude of the problem. This involves identifying who the people with disabilities are in Latin America, the percentage of people with disabilities who have support or care needs, the extent to which these needs are unmet, and the extent to which the care and support economy for people with disabilities creates inequalities within the household and in the community. These points are discussed below.

2.1. People with disabilities in Latin America and the Caribbean

In Latin America and the Caribbean, approximately 14.7% of the population has a disability and one in three households has at least one person with a disability (García Mora et al., 2021). In addition, among people with disabilities, 29% have severe ones (García Mora et al., 2021). The following table presents estimates of the prevalence of disability for several countries in the region projected to 2020 using census data (Table 2).

Table No. 2 Disability Prevalence Projected to 2020

Country	Year of the data	% of total population with disabilities	% of total population with severe disabilities	% of households with disabled person
Argentina	2010	12.7	NA	30.5
Bolivia	2012	5.2	NA	10.3
Brazil	2010	23.9	6.7	49.3
Chile	2017	19.9	NA	NA
Colombia	2018	7.1	4	16.6
Costa Rica	2011	10.4	NA	26.5
Ecuador	2014	25.1	5.8	51.8
El Salvador	2007	4.1	NA	13.7
Mexico	2018	7.5	NA	16.3
Panama	2010	7.7	NA	22.7
Paraguay	2012	11	NA	29.5
Peru	2017	10.4	NA	26.3
Dominican Republic	2010	11.9	NA	30.6
Trinidad and Tobago	2011	4	NA	NA
Uruguay	2011	15.7	4.6	34.4
Venezuela	2011	5.3	NA	15.7

Source: García Mora et al., 2021

Moreover, the prevalence of disability is projected to increase in the coming decades: **the total number of people with disabilities in the region is expected to rise to approximately 145.5 million people by 2050.** As a result of accelerated aging in the region, **it is estimated that the prevalence of disability will rise to percentages that are between 15.4% and 25.0% depending on the country** (Berlinski et al., 2021). These estimates could be even higher if we

consider the impact of conflict and violence in the region, the severe and long-term effects for some people infected with COVID-19, and the increase in chronic diseases in the region (Garcia Mora et al., 2021).

Despite representing a significant segment of the population and the increasing prevalence of disability, people with disabilities face greater exclusion gaps than their non-disabled peers. People with disabilities are more likely to be poor and have less access to education, health services, or employment (García Mora et al., 2021).

2.2. Gaps in support and caregiving in Latin America and the Caribbean

Despite the fact that people with disabilities are a particularly marginalized segment of the population, there is a severe lack of data on the magnitude of gaps in support needs. The limited information comes mostly from surveys that specialize in disability or the economics of caregiving. Specifically, the results of the analysis of specialized disability surveys done by the statistics institutes of Costa Rica, Chile, Nicaragua, Peru, and Mexico reveal huge gaps (Apoyos vida en comunidad/Community living support, 2023).

It is clear that people with disabilities have high human support needs and often these needs are not met. For example, 40.70% of adults with disabilities in Peru receive support or care compared to 53.36% in Nicaragua and 36.85% in Mexico. In Chile, 80.56% of adults with disabilities require permanent support or care but only 28.10% of adults with disabilities receive support or care from a person. In addition, 29.30% of adults with disabilities who do receive support need more support than they get. In other words, in Chile, 60.69% of adults with disabilities do not have their support or care needs met. In Costa Rica the data are similar: 67.93% of adults with disabilities require permanent support or care but only 48.13% receive support and 16.3% of adults with disabilities who do receive support need more than they get. In other words, in Costa Rica, 27.66% of adults with disabilities do not have their support or care needs met (Community living support, 2023). Although it is not possible to estimate dissatisfaction gaps for other countries or for children, the gaps are probably large throughout the region.

Moreover, the gaps are greater in the rural context and among younger adults. In Costa Rica and Chile, the percentage of people with unmet support needs in urban areas is 25.81% and 53.87% respectively. In rural areas, the gap rises to 32.73% and 66.31% respectively. In both Costa Rica and Chile, in turn, the percentage of people with unmet human support needs is higher among adults with disabilities between 18 and 30 years of age (31.89% in Costa Rica and 67.64% in Chile) than among adults with disabilities in any other age group (Community living support, 2023). These observations may suggest that there is a greater lack of support and care services in rural areas and for adults entering the labor market or higher education.

In terms of gender, the gaps are not as clear. In Costa Rica, Chile, Mexico, Nicaragua, and Peru, women with disabilities are more likely to receive support than men with disabilities, but they are also more likely to need more support than they receive. It is possible that this is associated with the fact that, in general, women are more likely to live longer. Hence, there are more elderly women with disabilities than men (Berlinski et al., 2021). Thus, these gaps may be due to differences in the age breakdown between men and women. Moreover, these gaps appear to vary from country to country. In Costa Rica, the percentage of men with

disabilities with unmet support needs is higher than the percentage of women with unmet support needs by 13.04 percentage points. In contrast, in Chile, women have higher levels of unmet needs than men, by 3.70 percentage points (Community living support/Apoyos vida en comunidad, 2023). There is insufficient information available to establish the percentage of women with disabilities who do caregiving compared to men, or to determine how this relates to meeting their support needs.

The estimates of support gaps presented in this section are limited for several reasons. First, these estimates are based on questions that focus on human support and may not capture all the support needs people with disabilities have. People with disabilities may not consider point-to-point transportation, housing adaptations, or other types of assistance to be human support or care. For example, among households surveyed as part of the 2018 National Study of Disability in Argentina, approximately 13.20% of households with people with disabilities felt that their homes needed adaptations but had not been able to make them (National Institute of Statistics, 2018). In addition, given the gaps in access to technical aids, the need for support is likely to be even greater. The WHO estimates that 31.30% of the world's population needs one or more support technologies; 36.10% of this population without access to support technologies needs, with the exception of glasses, such technologies (Global Report on Support Technology, 2022). In addition, WHO estimates that the gaps are larger in low- and middle-income countries. Given the gaps in other aspects of support and the lack of access to technical aids, the support needs of people with disabilities in Latin America and the Caribbean are likely to be even greater.

2.3. Impact on households

In addition to the direct impact of the gaps in support and care needs of people with disabilities, these gaps have direct consequences for their households. This is because most support and care services are provided by the families of people with disabilities. In Costa Rica, Chile, Nicaragua, and Peru, **between 76.08% and 94.42% of people with disabilities who receive support get it mainly from a family member. In addition, between 89.68% and 95.64% of adults with disabilities receive unpaid care or support** (Community living support, 2023).

Based on this, it is possible that family members who are providing support or care may have to stop working or studying to help their relatives and that this could have a major impact on household income. There is no explicit data on the percentage of family members who stop working or studying to provide support or caregiving for their family members with disabilities. However, levels of inactivity and unemployment rates are higher among adults living in households where one member has a disability than among adults in households without a member with a disability regardless of gender (García Mora et al., 2021). Since they do not receive compensation for their work within the household, this is likely to result in large differences in income between households. Although we do not know the explicit differences in household income directly related to support or care for people with disabilities, data from Bolivia, Chile, Costa Rica, and Mexico suggest that the income of adults living with people with disabilities is lower than the income of adults not living with people with disabilities by as much as 10.1 percentage points (García Mora et al, 2021).

Furthermore, the concentration of care and support within the household has important gender implications. The majority of unpaid work in Latin America and the Caribbean is done by women and girls. This includes care and support work for people with disabilities. In Costa Rica, Chile, Mexico, and Nicaragua, the majority of people who provide support/care for people with disabilities are women. **The difference between the percentage of support providers who are women versus men varies between 39.20 percentage points in Costa Rica and 66.82 pp in Nicaragua** (Community living support, 2023). These gender differences in care and support within the household could result in a negative impact on the education, income, employment, and decision-making power of women and girls inside and outside the home.

In Chile, for example, it is estimated that adult women living in households with people with disabilities earn less than women living in households without people with disabilities by 5.8 percentage points (García Mora et al., 2021). Furthermore, in Bolivia, Costa Rica, Panama, and Peru, inactivity rates are higher among adult women who live with a person with a disability than those who do not live with a person with a disability (García Mora et al., 2021). Only in Mexico and Bolivia are inactivity rates higher for women who do not live with people with disabilities. However, in all countries, inactivity and unemployment rates are higher for women living with family members with disabilities than for men living in the same households (García Mora et al., 2021). In addition, it should be emphasized that estimates of inactivity as a direct result of providing support or caregiving would likely be higher.

Finally, note that the average age of the people providing support varies between 43 in Nicaragua and 64 in Costa Rica. Clearly, although most of the people providing support are of working age, there are more and more older people providing support. Given the accelerated aging in the region, this trend is likely to intensify and implies that many of these people will also need support.

It is possible that the impact on income and employment would be lower in households of people with disabilities if there were qualified caregivers and support professionals offering services at affordable prices. Data on this subject are virtually non-existent in Latin America and the Caribbean. However, given that most support and care is provided by family members, these professional services are expected to be in short supply. It is imperative that the countries in the region collect data on support and care and encourage the professionalization of these services. This has the potential to increase the quality of the services and help people by providing support and care within the home, especially for those who are also in need of support and care.

Disability and human mobility

In Latin America and the Caribbean there are two large-scale movements of refugees and migrants: the movement of refugees and migrants from Venezuela and the migratory movement from Central American countries such as El Salvador, Guatemala, Honduras, and in recent years Nicaragua to Mexico and the United States.

According to a study published by the Latin American Network of Non-Governmental Organizations of People with Disabilities and their Families (RIADIS in Spanish) with the support of the United Nations High Commissioner for Refugees, refugees, displaced people, and migrants with disabilities face barriers of different types (attitudinal, environmental, and institutional) and in different areas (political, economic, social, cultural, civil) that have an impact on the exercise of their rights (RIADIS, 2021). This study reveals the limitations faced by these individuals in getting access to support services and technologies at each point along the route they are traveling as well as the role of caregivers in this regard. This also exposes them to risky situations since there is little real chance that people with disabilities, who require the help of a support person, will disclose the violence they are experiencing.

Chapter 3

COMPARATIVE ANALYSIS OF LEGISLATION AND POLICIES ON SUPPORT AND CARE FOR PEOPLE WITH DISABILITIES

The implementation of support and caregiving systems for people with disabilities requires a regulatory and policy framework that facilitates action by the State to guarantee the right of people with disabilities to live independently and in community. The study of legislation and public policies in 18 countries in Latin America and the Caribbean shows that the progress governments are making in building support and care systems for people with disabilities is unequal since they prioritize certain needs and demands for support and care over others.

3.1. Support and caregiving as rights

Regarding both support and care as rights is central to ensuring a rights-based approach in the design, implementation, and evaluation of support and caregiving systems for people with disabilities as well as to reaffirm the co-responsibility between government and communities (Bango & Cossani, 2021).

Although all legal systems in the region have laws that regulate, in one way or another, support and care (Inter-American Commission of Women, 2022), few countries have comprehensive regulatory frameworks that formalize the international obligations of the governments in terms of support and caregiving and, therefore, guarantee their application, enforceability, and justifiability. For instance, of the 18 countries analyzed, only **El Salvador**¹ and **Peru**² explicitly recognize the right of people with disabilities to live independently and to be included in the community in their national law. None of these countries, however, establishes specific obligations or responsibilities to make this right effective.

With respect to the caregiving agenda, **Costa Rica**, **Uruguay**, and **Venezuela** have recognized care as a right, and the first two have established caregiving systems to make this recognition effective.

In **Costa Rica**, Act 10192/2022 created the National Care and Support System for Adults and Elderly People in Condition of Dependency (Sinca in Spanish) in order to coordinate care and support services to guarantee the quality of life of people who both receive and provide care including those with disabilities. The system's main principles include comprehensive care and support services, non-discrimination, progressive implementation and access to services and benefits, accessibility and universal design, solidarity, and personal autonomy (art. 6). The National Council for People with Disabilities (Conapdis in Spanish) is part of the Interinstitutional Technical Commission created to strengthen Sinca's mission.

In **Uruguay**, Act 19353/2015 created the National Comprehensive Care System (SNIC in Spanish) as a set of actions and measures intended to design and implement public policies that establish a model of solidarity and co-responsibility between families, the government, the community, and the market. Care is defined as both a right and "a social function that implies encouraging the development of personal autonomy and providing dependent people

¹ Decree 672/2020, Special Act on Inclusion of People with Disabilities, art. 7, sub. h).

² Act 29973/2012, General People with Disabilities Act, art. 11.

with care and assistance" (art. 3, sub. a)). People with disabilities are the SNIC's target population and this law created a National Bureau for Care and Disability along with a Disability Office.

Although Chile does not have care and support regulations or a comprehensive care system, a National Support and Care Subsystem (SNAC in Spanish), also known as "Chile Cuida (Chile Cares)," is being developed. Its goal is to provide people who require assistance and caregivers as well as their households and their support network with guidance and support (National Subsystem of Support and Care, n.d.). This program facilitates access to different services offered by the municipalities.

Note that **Argentina, Chile, Colombia,**³ **Mexico,**⁴ **Panama, Paraguay,** and **Peru**⁵ are discussing proposals to set up national care systems (SINCA, 2022; Chile Care System, 2022; Panama Comprehensive Care System, 2019; Paraguay Care Policy Design, 2019). It is crucial to ensure that those proposals incorporate an all-encompassing disability focus and clearly recognize the need to adopt measures that guarantee that people with disabilities have access to the support they may require in their decision-making or independent life within the community including the exercise of their role as caregivers.

3.2. Legal capability and supported decision-making

Legal capacity is a precondition for the exercise of rights. It is a person's ability to be the holder of rights and be able to exercise them on his own. For a long time, based on an enabling approach to legal capacity, this was denied to certain groups of people, specifically those who were wrongly considered "incapable" of making decisions, such as people with intellectual disabilities and people with psychosocial disabilities. However, since the adoption of the CRPD, international human rights law recognizes that all people with disabilities should enjoy legal capacity on an equal basis with all other people and that intellectual or psychosocial disability should not be a limiting factor for exercising it. Furthermore, recognizing the need for support that some people may have in their decision-making, the CRPD establishes that the governments must guarantee access to the support people with disabilities may need in order to exercise their legal capability as well as safeguards to ensure that their rights, will, and preferences are respected (art. 12).

In Latin America and the Caribbean, several countries have made progress in recognizing the legal capacity of people with disabilities and establishing mechanisms for supported decision-making. **Costa Rica, Peru, Colombia,** and **Mexico** are globally at the forefront of legislation on legal capability since they have adopted reforms that eliminate interdiction on the basis of disability and have replaced it with various forms of support.

In **Costa Rica**, Act 9379/2016, the Advancement of Personal Autonomy of People with Disabilities Act, establishes the figure of safeguarding the legal equality of people with disabilities in order to guarantee full respect for their legal equality and provide them with a

³ Decree 1228/2022, whereby the National Care Policy Intersectoral Commission was created and provisions were issued for its operation.

⁴ National Care System Bill (2021). Senate of the Republic of Mexico.

⁵ Bill 2735, Recognition of the Right to Receive Care and Creation of the National Care System (SNC in Spanish) (2022). Congress of the Republic.

support system for the exercise of their legal ability. In **Peru**, Legislative Decree 1384/2018, which recognizes and regulates the legal capacity of people with disabilities, introduces the figure of support as a form of assistance chosen freely by people in order to facilitate the exercise of their rights including support in communication, in the understanding of legal procedures and their consequences, and in the expression and interpretation of the will of the person who requires support. Likewise, in **Colombia**, Act 1996/2019 establishes a system for adults with disabilities to exercise their legal rights, regulates mechanisms to set up support for compliance with legal actions and, in addition, creates a support assessment service that can be provided by public or private entities. In **Mexico**, at the close of this report, the Chamber of Deputies approved a new National Code of Civil and Family Procedures that eliminates interdiction and introduces supported decision-making. Although the final version of its regulatory text has not yet been published, the code is expected to go into force in 2027.

These countries are not the only ones that have made progress in terms of legal capability and supported decision-making. In **Argentina**, the National Civil and Commercial Code, approved by Act 26994/2014, establishes the possibility of designating support for the exercise of the legal capability (arts. 32 and 43) in spite of restricting, as an exception, certain actions a person may take. In **Brazil**, Act 13146/2015, the General Act for the Inclusion of People with Disabilities, amended the Civil Code to limit guardianship and established a system of support and safeguards (arts. 115-123). More recently, in **El Salvador**, Decree 672/2020, the Special Act for the Inclusion of People with Disabilities, recognizes the legal capability of people with disabilities on equal terms with all other people and commands the creation of a support mechanism for the exercise of rights and the decision-making process that guarantees and protects their fundamental rights and freedoms as well as respects their autonomy, will, preferences, and interests (art. 29). This provision, however, has not been followed by the harmonization of Salvadoran civil legislation with the CRPD.

In terms of mental health services, several countries have also recognized the importance of support measures for the exercise of legal capabilities. **Chile**⁶ and **Mexico**,⁷ for instance, have introduced said concept into their reform of mental health-related legislation via the designation of caregivers or through advance directives. Likewise, in terms of access to justice, Documenta A.C.'s Program "Justice Facilitators" implemented with financial support from the Superior Court of Justice of Mexico City must be mentioned. This provides communication support during criminal proceedings for people with intellectual or psychosocial disabilities who are victims, defendants, or witnesses of a crime (Justice Facilitators, n.d.). The program had benefited 752 people with disabilities as of 2021 (Support Life in Community, 2023).

Despite these legislative advances, **the recognition of support measures and mechanisms within the legal systems of most of the countries analyzed has not been accompanied by positive actions** to guarantee that people with disabilities have effective access to formal or informal mechanisms for supported decision-making either by facilitating the link between the person and natural support networks in the family or the community or by developing services that make it possible to provide care for those who do not have any natural support

⁶ Act 21331/2021, Recognition and protection of the rights of people in the mental health care service.

⁷ Decree amending, adding to, and repealing several provisions of the General Health Law regarding Mental Health and Addictions, DOF: 05/16/2022.

or who want support outside the family. So far, such mechanisms have been facilitated by the families themselves and civil organizations without any governmental investment. In **Argentina**, there are efforts in place to progressively transform part of the network of public advisors and managers into support providers for exercising legal capacity (Services MPD, n.d.).

3.3. Personal assistance and other individualized support services

Personal assistance is a crucial tool for providing individualized support for an independent life within the community. It refers to human support that is made available to people with disabilities as an instrument to provide support for their autonomy and their daily life activities (General Comment No. 5, 2017). Although the methods of personal assistance may vary, there are certain elements that make it different from other forms of human support such as personalized support and the control the person with a disability has over the assistance (General Comment No. 5, 2017). Note that, given the absence of programs for personal assistance, family members and networks close to people with disabilities are the ones who provide such human support without any payment.

Of the 18 countries analyzed, only **Costa Rica** and **Uruguay** have legal frameworks that regulate the right to personal assistance and its provision.⁸

In **Costa Rica**, Act 9379/2016, the Advancement of Personal Autonomy of People with Disabilities Act, regulates access to economic benefits for personal assistance based on individualized support plans. This law created the Program for the Advancement of Personal Autonomy of People with Disabilities under the responsibility of the National Council of People with Disabilities (Conapdis in Spanish). Access to this program is limited to those people who, in order to exercise their right to personal autonomy, are in need of personal human assistance and do not have the financial resources to pay for that support. The program is available nationwide and provides a monthly cash transfer of 430,000 colones (approximately \$795 US dollars). Conapdis gives the beneficiaries support in finding personal assistants. The program had 171 beneficiaries as of June 30, 2022 (CONAPDIS, 2022).

In the case of **Uruguay**, Act 18651/2010, the Comprehensive Protection of People with Disabilities Act, establishes a financial benefit to hire personal assistants for those who can prove their need for this service to carry out their basic daily activities. The personal assistance program is managed by the National Integrated Care System (SNIC in Spanish) and benefits people with severe dependency who are no more than 29 years of age or over 80 and who reside in private households (Quinquennium Report, 2021). The subsidy covers the value corresponding to 80 hours of care per month and the labor payments associated with hiring an assistant. The activities are agreed upon by all parties, i.e., the person who receives the assistance, the assistant, and the family providing care. In order to work as a personal assistant, individuals must be registered in the Personal Assistant Registry of the SNIC. In 2021, 4,022 people received this benefit, but this number represented a drop of 22.43% compared to the same period in 2020 (Social Security Bank of Uruguay, 2022). Uruguay is currently implementing a pilot plan that sets up a new channel for personal assistants to

⁸ Several countries such as Argentina, Colombia, Mexico, and Peru have bills that seek to regulate the provision of personal assistance. These bills are still under discussion.

provide their services through work cooperatives or social cooperatives (Personal Assistants Program Uruguay, 2022). Furthermore, Uruguay has a home teleassistance program that allows people over 70 years of age, with or without disabilities, to notify their family, neighbors, or medical service of any incident that occurs in their house.

In other countries, such as **Argentina**,⁹ **Chile**,¹⁰ **El Salvador**,¹¹ **Panama**,¹² **Peru**,¹³ and **Venezuela**,¹⁴ the law establishes very general obligations with regard to the provision of support for people with disabilities to live independently or within a community. Of these countries, **Argentina**, **Chile**, and **Panama** have taken major steps to guarantee a public policy for the provision of personal and/or home assistance services.

In **Argentina**, the City of Buenos Aires has implemented the Independent Living Support Program that provides support for access to personal assistance (Independent Living Support Program Buenos Aires, n.d.). The program targets people with disabilities between the ages of 18 and 60 who require a high level of support. The program had 134 beneficiaries in 2022 which is a decline from 165 beneficiaries in 2021 (Life in Community Support, 2023). Based on Resolution 43-GCABA-MDHYH/23, the monthly subsidy is 25,000 pesos (approximately US\$122) per beneficiary. The Commission for Full Involvement and Inclusion of People with Disabilities (COPIDIS in Spanish) also organizes a training session for independent living personal assistants once a year. In the Province of Chaco, a regulatory framework for personal assistance for people with disabilities has been adopted through Act 3580-G/2022.

In **Chile**, there are various initiatives for fostering access to human assistance. For example, the Local Support and Care Network Program provides home care service including the provision of basic care service in the beneficiary's home, which contributes to reducing the overload on the caregiver (Chile Serves, 2022). Likewise, the Transition to Independent Living Program of the National Disability Service (Senadis in Spanish) seeks to encourage the social inclusion of people with disabilities and dependency, between 18 and 59 years of age, under a human rights, autonomy, self-determination, and quality of life approach. The program offers up to \$3,612,000 Chilean pesos (approximately US\$4,457) in financing of individual benefits as well as projects from public or private non-profit organizations that provide support services (Chile Cares Transition to Independent Living, 2022).

In **Panama** work is being done on the design of a personal assistance model for people with disabilities who need a high level of care with the support of the Inter-American Development Bank. The implementation of a pilot plan to benefit 875 people with disabilities, who are beneficiaries of the Guardian Angel program, has been projected (Social Inclusion Program, n.d.).

⁹ Act 24901/1997, System of Basic Benefits in Comprehensive Empowerment and Rehabilitation of People with Disabilities as amended by Act 26480, articles 18 and 39.

¹⁰ Act 20422/2010, which establishes the Rules on Equal Opportunities and Social Inclusion of People with Disabilities, articles 4 and 12.

¹¹ Decree 672/2021, Special Law on Inclusion of People with Disabilities, articles 37 and 79.

¹² Act 42/1999, which establishes equal opportunities for people with disabilities as amended by Act 15/2016, article 16.

¹³ Act 29973/2012, General People with Disabilities Act, art. 11.

¹⁴ Act 38598/2007, People with Disabilities Act, article 14.

Note that there are initiatives in several countries in the region from civil society, in particular, organizations of people with disabilities, that seek to encourage the autonomy and the independent living of people with disabilities even by means of developing centers for independent living, peer support, and the training and availability of personal assistants.¹⁵ Government financial support could help many of these programs in terms of consolidation and expansion.

Finally, several countries in the region have also regulated the access of visually impaired people with companion animals to any place accessible to the public (**Argentina**,¹⁶ **Chile**,¹⁷ **Ecuador**,¹⁸ **Mexico**,¹⁹ **Panama**,²⁰ **Paraguay**,²¹ **Peru**,²² **Uruguay**,²³ and **Venezuela**²⁴). In **Chile**, the Transition to Independent Living Program finances the hiring of a guide dog trainer, but excludes the purchase, feeding, and care of this animal (Chile Cares Transition to Independent Living, 2022). No other programs or services that facilitate access to assistance animals were identified. These programs or services can only be accessed through donations from international organizations.

3.4. Support in Communication

Communication support is another form of assistance that, although central to daily life, is often neglected. The lack of this service puts different groups of people with disabilities at risk of social exclusion including deaf people, deaf-and-blind people, and those who require augmented or alternative communication systems since this lack affects the exercise of several of their rights such as health, education, work, and access to justice. Although access to information and communication may reduce the demand for communication support (for instance, captioning service at public events or on television), such support will always be necessary in the daily life of many people with disabilities.

In the case of the Deaf Community, the vast majority of the countries analyzed have formally recognized the existence of a national sign language²⁵ and, of these, 12 countries have made providing sign language interpretation in public entities and/or services open to the public an

¹⁵ For example, the Blue Association in Argentina, the Independent Living Network in Bolivia (REVIVO in Spanish), the Center for Independent Living in Brazil, and the association Luchando Contra Viento y Marea (Fighting against the Wind and the Tide) in Peru.

¹⁶ Act 26858/2013, People with disabilities accompanied by a guide or assistance dog.

¹⁷ Act 20025, which amends Act 19284, issued to regulate the use of guide, signal, or service dogs by people with disabilities.

¹⁸ Organic Law on Disabilities 2012, art. 59.

¹⁹ General Law for the Inclusion of People with Disabilities, DOF 27-10-2022, article 16

²⁰ Executive Order 36/2019, which dictates health-related provisions on guide or service dogs for the care of people with disabilities.

²¹ Act 6057/2018, Right to access, move around, and remain in public places and to public transportation services for all people with disabilities accompanied by a guide or assistance dog.

²² Act 29830/2012, Law that fosters and regulates the use of guide dogs by visually impaired people.

²³ Act 18651/2010, Comprehensive Protection of People with Disabilities Act, article 80.

²⁴ Act 38598/2007, People with Disabilities Act, article 34.

²⁵ Argentina, Bolivia, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Mexico, Panama, Paraguay, Peru, Uruguay, and Venezuela. In the Dominican Republic, although Dominican Sign Language has not been formally recognized, the Ministry of Education has published an Official Dictionary of Sign Language.

obligation (**Argentina**,²⁶ **Bolivia**,²⁷ **Brazil**,²⁸ **Chile**,²⁹ **Colombia**,³⁰ **Costa Rica**,³¹ **Ecuador**,³² **El Salvador**,³³ **Panama**,³⁴ **Paraguay**,³⁵ **Peru**,³⁶ **Uruguay**,³⁷ and **Venezuela**³⁸). Of these, only a few have implemented measures to make these services available, and in most cases, this is only partial since they have prioritized interpretation for public facilities and services. For example, in **Brazil**, Brazilian Sign Language Interpretation Centers have been established in different states and municipalities starting in 2013. To date, there are 30 of these centers throughout the country (Sign Language Interpretation Centers Brazil, n.d.). One of the limitations to the expansion of such services in other countries is the lack of accredited sign language interpreters, which is due to the absence of both training and certification courses.

Faced with this challenge, some countries are implementing relay centers and using remote interpretation mechanisms. In **Colombia**, the Ministry of Information and Communications Technologies and the National Federation of the Deaf of Colombia have set up a Relay Center that provides free Colombian sign language interpretation services for deaf people and people who wish to communicate with the deaf (Relay Center Colombia, n.d.). The services offered include call relay, interpretation of WhatsApp messages and audios into sign language videos, and online interpretation services. People with disabilities can access these services free of charge 24 hours a day by contacting the Relay Center online via WhatsApp or a mobile app. The Relay Center handled 516,000 communication messages using the call relay and online interpretation services during 2021 (Management Report MINTIC, 2022).

Paraguay has also established a Relay Center which, free of charge, makes it easier for the deaf and people with low levels of hearing to communicate with people who hear well and entities or services of their choice (Relay Center Paraguay, n.d.). This service can be accessed by telephone or through the Internet. It is available Monday to Friday from 6:00 a.m. to 9:00 p.m.

Other countries that have been implementing online solutions are **Chile** and **Peru** (SENADIS Vi-sor Web, 2020; MIMP, 2020). In this regard, it should be noted that, as was pointed out by the World Federation of the Deaf, although remote interpreting can be an effective solution to the shortage of interpreters in some areas, especially remote and rural areas, it should not be seen as a replacement for in-person interpreting since remote interpreting can affect both

²⁶ Federal Law on Argentine Sign Language, adopted on April 3, 2023. To be published at the close of this report.

²⁷ Act 223/2012, General People with Disabilities Act, art. 36.

²⁸ Act No. 10.436 of 2002 regulating the Brazilian Sign Language - Books, arts. 2 and 3.

²⁹ Act 20422/2010, which establishes the Rules on Equal Opportunities and Social Inclusion of People with Disabilities, articles 26.

³⁰ Act 324/1996 which created some regulations in favor of the deaf population, art. 7.

³¹ Act 9822/2020, Recognition and Advocacy of Costa Rican Sign Language (LESCO), art. 15.

³² Organic Law on Disabilities 2012, art. 70.

³³ Decree 672/2021, Special Law on Inclusion of People with Disabilities, articles 34 and 41.

³⁴ Act 42/1999, which establishes equal opportunities for people with disabilities as amended by Act 15/2016, article 29-M.

³⁵ Act 6530/2020, grants official Recognition to the Sign Language of Paraguay, art. 4.

³⁶ Act No. 29535/2010, Law granting official recognition to the Peruvian Sign Language, art. 4.

³⁷ Act 17378/2001, Uruguayan Sign Language, art. 5.

³⁸ Act 38598/2007, Persons with Disabilities Act, Sec. 14; Public Interpreters Act of 2022, Sec. 15.

the comprehension and the reliability of the interpretation (World Federation of the Deaf, 2019).

In the case of deaf-and-blind people, **Brazil**,³⁹ **Chile**,⁴⁰ **Colombia**,⁴¹ and **Peru**⁴² have laws that regulate the services of interpreter guides and other forms of communication assistance. In the case of **Brazil**, the Brazilian Sign Language Interpretation Centers are the ones that provide such services. There were 63 centers throughout the entire country in 2022. There is no information available regarding the implementation of such services in the other countries. In most of them, communication support for deaf-and-blind people is given by families and non-profit organizations that do this work without government help.

In addition, some countries have put subsidies and discounts in place to facilitate access to communication for people with disabilities. For example, in **Trinidad and Tobago**, people with disabilities can benefit from subsidies for the purchase of telephones (Telecommunications Authority of Trinidad & Tobago, 2022). **Bolivia** has set up a solidarity fee so that people with disabilities can get access to telecommunications services (Administrative Regulatory Authority, 2018) There are also discounts for land-line and mobile telephone services in **Ecuador**.⁴³

Finally, the lack of interest in augmentative and alternative communication (AAC) systems is concerning. Many people with disabilities, including people with cerebral palsy and those with autism, may require AAC to augment, maintain, improve, or supplement their communication skills. Without access to AAC training or tools, a person who cannot use verbal language to communicate may end up isolated from society, excluded from school and other opportunities, and denied their legal capacity.

3.5. Support technologies

Support or assistance technologies encompass support products and their related systems and services that enable people with disabilities and older people with functional impairment to live healthy, productive, independent, and worthwhile lives (Global Report on Assistive Technology, 2022). Supportive products can assist a person in key functional domains, such as cognition, communication, hearing, mobility, self-care, and vision. These may be physical products, such as wheelchairs, hearing aids, prosthetics, and orthotics; they may be digital, such as software and apps that support communication and time management; or adaptations in the physical environment such as portable ramps or handrails (Global Report on Assistive Technology, 2022). Just as in the case of accessibility, access to technological aid can give people more independence and lessen their need for human assistance thus reducing investment in support and care systems (Nicolson et al., 2012).

³⁹ Act No. 10098/2000 establishes general rules and basic criteria for promoting accessibility for people with disabilities or reduced mobility, and other provisions.

⁴⁰ Act No. 21403/2022 recognizes being blind-and-deaf as a unique disability and encourages the full social inclusion of the blind and deaf

⁴¹ Act No. 1618/2013 whereby provisions are established to guarantee the full exercise of the rights of persons with disabilities, arts. 11 inc. 2.j) and 13 inc. 3.b); Act No. 982/2005 establishes rules for the equalization of opportunities for deaf and deaf-blind people and other provisions.

⁴² Act No. 29524 of 2010 is a law that recognizes deaf-blindness as a unique disability.

⁴³ Organic Law on Disabilities 2012, art. 73, inc. 3 and 4.

Based on a recent report prepared by the World Health Organization and UNICEF, approximately **2.5 billion people in the world are in need of at least one support product, i.e., one in three people** (Nicolson et al., 2012). **This number is expected to reach 3.5 billion people by 2050.** However, access to such products varies considerably among countries, ranging from 2.6% to 89.8%, with greater access in those countries that have a higher human development index (Nicolson et al., 2012). For example, in **Chile**, according to the II National Disability Study of 2015, 33% of people with disabilities reported a need for technical aid, but did not have it (Disability & Development Report, 2018). A survey of users of outpatient rehabilitation services provided by the public health system in São Paulo, **Brazil**, also revealed gaps of up to 50% in terms of access to support products, in particular hearing aids (Disability & Development Report, 2018).

The provision of support devices for people with disabilities who need them is regulated in most of the legal systems in Latin America and the Caribbean.⁴⁴ Nevertheless, there are significant differences in terms of coverage and requirements for access to such assistance. For example, in several countries, access to support devices is reserved for those people who contribute to social security systems or who are poor. This excludes many people who may not be considered poor but still cannot afford to pay for their support devices (Cote, 2021).

Some countries, such as **Argentina, Brazil, Costa Rica, Chile, Ecuador, Panama, Paraguay, Uruguay, and Venezuela**,⁴⁵ have programs or projects for providing support technologies to people with disabilities (Technological Support Argentina, n.d.; National Plan for Support Technology, 2021; CONAPDIS, 2022; Technological Help Chile, n.d.; Technological Help Ecuador, n.d.; FODIS, n.d.; Technological Help Paraguay, n.d.; CENATT, n.d.;). However, there is insufficient information (for instance, on coverage, availability, budget, quality standards, or human resources) to fully understand their operation, scope, and impact. In some cases, there are programs with a very low number of beneficiaries.⁴⁶ Likewise, some programs lack the resources required to meet the demand (SENADIS Participatory Public Account, 2022).

To reduce the cost of support technologies, several countries have established tax benefits for purchasing or importing them or for vehicles adapted to such technologies by exempting them or taxing them at a reduced rate.⁴⁷

Note that when the government does not invest in improving the systems for the provision and financing of support technologies, people with disabilities and their families are forced to pay for that expense directly in a market that offers few alternatives, or are left at the mercy of occasional donations of products that have not been adapted to their needs from local governments and non-profit organizations. As a result, many people simply do not have access to them, and this significantly impacts their independence and life in their community. Improving access to support technologies requires the development and reinforcement of

⁴⁴ Argentina, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Mexico, Dominican Republic, Panama, Peru, Uruguay, and Venezuela.

⁴⁵ José Gregorio Hernández Mission.

⁴⁶ See, for example, Panama, National Secretary for Disability, Statistics 2021, <https://www.senadis.gob.pa/documentos/estadisticas/ESTADISTICAS-2021.pdf>

⁴⁷ Argentina, Bolivia, Brazil, Chile, Costa Rica, Ecuador, El Salvador, Jamaica, Mexico, Panama, Paraguay, Peru, Dominican Republic, Trinidad and Tobago, Uruguay, and Venezuela. In the case of Colombia, Act 1979/2019 grants this benefit to war veterans.

four key components: products (range, quality, affordability, supply), provision (universalization, customization, community approach), human resources (availability, training), and policies (political will, legislation, financing, good governance) (Global Report on Support Technology, 2022).

3.6. Financial assistance

People with disabilities and their families may need financial assistance to cover the **additional costs of living with a disability. Based on several studies, these costs can be significant and fluctuate between 12% and 40% of the country's average salary** with higher percentages for people who require a high level of support (Mont & Cote, 2020).

Traditionally, financial transfers to people with disabilities are in the form of disability or handicap pensions and are intended to compensate for their loss of income due to the inability to work and earn their own income. All countries in the region have pensions for disability or inability to work that are linked to the contributory social security systems. However, this model has several limitations. First, many people with disabilities are unable to enter the labor market and, therefore, cannot generate the money necessary to contribute to these pension funds. Second, these systems are usually based on the premise that these people cannot work without taking into account the fact that, in many cases, they could work if the necessary adjustments and support were available to them. This also leads to an incompatibility between disability pensions and employment that discourages people with disabilities from participating in the labor market. Last of all, the average amount these pensions provide is far below the costs that people with disabilities must cover in order to live independently within the community and have the same options that others do.

In view of the low coverage in the social security systems for people with disabilities, and in recognition of the high levels of poverty in the households of people with disabilities (Garcia Mora et al., 2021), practically every country analyzed has established non-contributory cash transfer programs for people with disabilities (See Box No. 2). Twelve of the eighteen countries that were analyzed have incorporated such programs into their legal systems.⁴⁸ Likewise, some countries include or give priority to households with children and adolescents with disabilities in their conditional cash transfer programs (See Box N° 2). The beneficiaries and conditions for getting access to these cash transfers vary with most countries limiting it to people with disabilities in poverty or extreme poverty, or to those in need of high levels of support.

Box No. 2 Cash transfer programs that benefit people with disabilities

Country	Non-contributory transfers for disability	Conditional transfers to households
Argentina	Non-contributory disability pension; Disability allowance for disabled child	
Barbados		
Bolivia	Solidarity income for people with severe and very severe disabilities; Bonus for visually impaired people	Juancito Pinto Bonus

⁴⁸ Argentina, Bolivia, Brazil, Chile, Costa Rica, Ecuador, El Salvador, Mexico, Panama, Peru, Dominican Republic, and Uruguay.

Brazil	Continuous Cash Benefit; Special Pension for Thalidomide Syndrome; Special Pension for Children with Congenital Zika Virus Syndrome	
Chile	Basic Solidarity Disability Pension; Mental Disability Subsidy	Unified Family Subsidy
Colombia		More Families in Action
Costa Rica	Non-contributory basic pension system; Poverty and Disability; Family Allowance subsection H	
Ecuador	Joaquin Gallegos Lara Bonus; Pension for the Elderly and Pension for People with Disabilities (Supplement to the Human Development Bonus)	Human Development Bonus
El Salvador	Basic solidarity pension	
Jamaica		Programme of Advancement Through Health and Education
Mexico	Pension for the Welfare of Permanently Disabled People	Social Inclusion Program (PROSPERA)
Panama	Guardian Angel Program	
Paraguay		Tekoporã
Peru	National Program for Granting Non-Contributory Pension to People with Severe Disabilities in Poverty (CONTIGO)	
Dominican Republic	Solidarity Pensions under the Subsidized System	Progress with Solidarity
Trinidad and Tobago	Disability Assistance Grant	
Uruguay	Special assistance	
Venezuela	José Gregorio Hernández Bonus	

Source: ECLAC, Database of non-contributory social protection programs in Latin America and the Caribbean.

These different forms of cash transfers, although positive, only provide a partial answer to the high additional costs faced by households with disabled people. They provide the disabled and their families additional income, but the coverage is limited, the amounts assigned are not sufficient to cover the additional costs of living with disabilities and, in many cases, such benefits are incompatible with being employed.

Finally, some countries have established subsidies to reduce the burden of disability-related expenses (Vasquez and Huertas, 2021). In several countries, as mentioned above, technological aids and adapted vehicles are exempt from value added and/or import taxes, or are taxed at a reduced rate. However, in some countries, the subsidies are quite extensive. For example, in **Panama**, Act 134/2013 sets forth a broad list of discounts that cover, medical services, therapies and medicines; prostheses and technological aids; means of transportation; hotels and restaurants; recreational activities; public utilities (energy, water); cable television; internet; passports; airport fees; and funeral services. In **Ecuador**, the Organic Law on Disabilities of 2012 includes, among other provisions, exemptions from and reductions in income and property taxes; exemption from notary, consular and registry fees; reimbursement of value added tax on the purchase of goods and services for personal use and consumption; and discounts on utilities (energy, phone service, water), and public entertainment. In-depth studies are required to understand the economic and social impact of these measures.

3.7. Transportation Support

Transportation is critical for people with disabilities in terms of their participation in community life and progress. It connects them to schools, universities, health services, and workplaces, and allows them access to goods and services. Nonetheless, overland public transportation is often inaccessible for people with disabilities, not only for the ones who have physical disabilities but also for those with visual and intellectual disabilities (Pfeiffer et al., 2021). In **Chile** and **Peru**, for example, **38% and 39% of people with disabilities, respectively, perceive the public transportation system as a barrier to participation** (SENADIS, 2016; INEI, 2014).

This means that many people with disabilities in Latin America and the Caribbean have to use other means of local transportation, including taxicabs and private vehicles, or have assistance when using public transportation. This obviously increases the cost of transportation for the disabled and their families and affects their educational and employment opportunities. To this we must add that, in many countries in the region, public transportation is provided, to a large extent, by informal operators using minibuses and other low-capacity vehicles with little or no government control. This makes it very difficult to improve accessibility (Best Practice in Accessible Transportation, 2014). Moreover, in several Latin American cities, commuting times are excessively long (Daude et al., 2017). In this context, the design and implementation of comprehensive public transportation solutions that are inclusive and accessible to people with disabilities are required.

In recognition of these difficulties, several countries now offer subsidies and discounts for overland public transportation. **Argentina**,⁴⁹ **Brazil**,⁵⁰ **Paraguay**,⁵¹ **Peru**,⁵² **Uruguay**,⁵³ and **Venezuela**⁵⁴ have made public ground transportation for people with disabilities free. In other countries such as **Bolivia**,⁵⁵ **Chile**,⁵⁶ **Ecuador**,⁵⁷ **Mexico**,⁵⁸ and **Panama**,⁵⁹ the transportation fares incorporate discounts and subsidies (Zero Fare, 2022).⁶⁰ In some cases, these benefits are extended to a person who accompanies the disabled individual and to other means of transportation. Likewise, in some countries these benefits are restricted to people with disabilities who need a high level of support. The impact of these subsidies and discounts on public transportation for people with disabilities may be limited by the lack of accessibility in the urban environment and the transportation system as well as the limited publicity about them and control over these measures (Ombudsman's Office Bolivia, 2020).

⁴⁹ Act No. 25635/2002 amends Act No. 22431 with the amendments introduced by Act No. 24314.

⁵⁰ Act No. 8899/1994 grants people with disabilities free access to the interstate public transportation system. States have their own state laws on gratuities.

⁵¹ Act No. 3365/2005, which exempts people with disabilities from the payment of ground transportation fares, as amended by Act No. 6556/2020, art. 1.

⁵² Act 29973/2012, General People with Disabilities Act, art. 20.

⁵³ Act 18651/2010, Comprehensive Protection of People with Disabilities Act, article 83.

⁵⁴ Act 38598/2007, People with Disabilities Act, article 39.

⁵⁵ Act 223/2012, General People with Disabilities Act, art. 48 inc. II.4.

⁵⁶ Act No. 20378/2019 creates a national subsidy for paid public passenger transportation.

⁵⁷ Organic Law on Disabilities 2012, art. 71.

⁵⁸ General Law for the Inclusion of People with Disabilities, DOF 27-10-2022, article 19

⁵⁹ Act 134/2013, establishes economic equalization for people with disabilities, art. 2 inc. 2.

⁶⁰ Some cities such as Kingston in Jamaica and Bogotá in Colombia have also established public transportation benefits for people with disabilities.

A few countries have gone a step further and have developed point-to-point transportation systems that serve people with a major need for mobility support and who are excluded from other modes of transportation. In **Brazil**, for example, the city of Curitiba has implemented a point-to-point transportation service (ACESSO) for people with disabilities that complements the already accessible public transportation system in place (Transportation Access; Pedraza et al., 2020). ACESSO benefited 1,500 passengers per month, on average, in 2019 (Bloomberg Cities, 2019). Other countries that have been implementing point-to-point transportation systems are **Trinidad and Tobago** and **Uruguay** (ELDAMO, n.d.; Transportation of people with reduced mobility, n.d.).

The provision of subsidized door-to-door services could be a first step to serving people who are excluded from using other means of transportation, especially those who do not have sufficient resources to pay for a private service. However, their implementation should be considered a complement rather than an alternative to accessible public transportation (Best Practice in Accessible Transportation, 2014).

3.8. Housing support

Access to adequate housing is a human right that is of paramount importance for the enjoyment of other rights. Housing is the foundation of stability and security for individuals and families. It is the center of our social, emotional, and sometimes economic life and should be a sanctuary where we can live in peace, security, and dignity (Right to Adequate Housing, n.d.). As Leilani Farha, the former Special Rapporteur on adequate housing, has noted, for many people with disabilities, access to safe and secure housing, water and sanitation in the home, and community living with the right to services and forms of support marks the difference between life and death, safety and abuse, belonging and isolation.⁶¹ However, people with disabilities face significant barriers to getting access to adequate housing, including discrimination, family dependency, poverty, homelessness, and institutionalization.⁶² This situation is aggravated in **Latin America and the Caribbean where almost a quarter of the population lives in settlements with inadequate and informal housing** (Daude et al., 2017). In some countries, this proportion is even higher such as the case in Haiti and Bolivia (Cuervo and Delano, 2019). Hence, solving the problems of access to adequate housing for people with disabilities requires systemic responses to improve the supply of housing including low-income housing as well as improving the employability and income of people with disabilities.

Of the countries analyzed, **Bolivia**,⁶³ **Brazil**,⁶⁴ **Colombia**,⁶⁵ **Ecuador**,⁶⁶ **Mexico**,⁶⁷ and **Venezuela**⁶⁸ expressly recognize the right of people with disabilities to decent and adequate housing in their legislation. **Jamaica** established a prohibition against discrimination against

⁶¹ Leilani Farha, Adequate housing as a component of the right to an adequate standard of living and the right to non-discrimination in this context, A/72/128, 2017.

⁶² Ibid.

⁶³ Act 223/2012, General People with Disabilities Act, art. 15.

⁶⁴ Act 13146/2015, General Law for the Inclusion of People with Disabilities, art. 31.

⁶⁵ Act 1618/2013 whereby provisions are established to guarantee the full exercise of the rights of people with disabilities, art. 20.

⁶⁶ Organic Law on Disabilities 2012, art. 56.

⁶⁷ General Law for the Inclusion of People with Disabilities, DOF 27-10-2022, article 18

⁶⁸ Act 38598/2007, People with Disabilities Act, article 36.

persons with disabilities in the sale, rental, or provision of housing.⁶⁹ More widely, the legislation of several countries has established quotas, subsidies and/or preferential treatment in favor of people with disabilities and households with members with disabilities in public housing programs.⁷⁰ However, information on the implementation of these benefits is only available from a few countries. For example, in **Bolivia**, during 2020, the State Housing Agency allocated 6% of the total low-income housing for families that had a person with a disability (422 homes) (State Housing Agency Bolivia, 2021). In **Colombia**, 79 family housing subsidies were given to households of people with disabilities between June 2021 and May 2022. This represented 3.2% of the subsidies allocated (Report to Congress, 2022).

Some countries have established specific home accessibility improvement programs for people with disabilities. In **Mexico**, for example, the National Workers' Housing Fund Institute (Infonavit) has the "Hogar a tu medida" Program (A home to fit you program), which provides certain facilities so that people with disabilities or family members with disabilities can apply for loans to carry out home remodeling (INFONAVIT, 2018). A total of 359 grants were awarded in 2017 (INFONAVIT, 2017). In **Argentina**, the government has also initiated a program to improve the livability of housing in emergency situations while prioritizing people with transplants, oncology patients, people with disabilities or chronic diseases ("Improve your Home") (Tolosa Paz, 2023).

However, assisted housing models do not seem to have been fully explored in Latin America and the Caribbean. Instead, in the framework of various deinstitutionalization processes, some countries such as **Argentina, Brazil, Chile, Paraguay, Peru, and Uruguay**⁷¹ are investing in the creation of "protected homes," "substitute homes," "protected residences," "supported residences," or "inclusive residences" that offer collective housing solutions to people with psychosocial or intellectual disabilities who do not have support networks (City of Buenos Aires, n. f.; SUAS, 2014; Social Welfare Institute, n.d.; Technical Standard on Sheltered Homes Chile, 2020; Technical Standard on Sheltered Homes Peru, 2018). In principle, these services seek to support the development of their residents' autonomy and transition to independent living. The maximum number of residents varies by country. For example, in Brazil, a residence can have up to 10 people; in Chile, a residence can have up to 12; in Peru, a home can have up to eight; in Argentina, some residences have up to 18 people (Warnes Residence, 2021). **Peru** currently has 87 protected homes throughout its territory (El Peruano, 2022); Chile had 1,850 beneficiaries in homes and residences as of 2021 (Residences and Protected Homes Program, 2021). Although initial evaluations are positive (Herrera-López et al., 2018; Protected Homes and Residences Evaluation, 2020) from a human rights perspective, there is concern that the organization, sanitary nature, and number of residents of such services do not guarantee that residents with disabilities are able to make decisions, have choices, and exercise control personally and individually in all spheres of their lives. Given their rapid proliferation, an evaluation of the implementation of such services from an independent living perspective is urgently needed.

⁶⁹ The Disabilities Act, 2014, arts. 38 y 39.

⁷⁰ Bolivia, Brazil, Chile, Colombia, Costa Rica, Ecuador, Mexico, Panama, Peru, Dominican Republic, Uruguay, and Venezuela. El Salvador also provides housing loans through the Fund for the Protection of the Disabled and Handicapped (FOPROLYD).

⁷¹ Ordinance No. 1488/2019 Replaces Appendix I of Ministerial Ordinance 1046/2019 of August 23, 2019.

Finally, note that, of the countries analyzed, only one group has established obligations related to deinstitutionalization. **Brazil**, one of the pioneers in deinstitutionalization in the region, established financial assistance by law for people with disabilities who are discharged from mental health facilities as part of the "Back Home" program.⁷² The program had 4,207 beneficiaries in 2022, who received a monthly amount of R\$500 reals (approx. US\$95). **Argentina**,⁷³ **Chile**,⁷⁴ **Mexico**,⁷⁵ and **Uruguay**,⁷⁶ in turn, have made the commitment, by law, to close and/or transform their psychiatric hospitals and single-patient asylums in favor of community mental health facilities. In the case of **Argentina**, the National Mental Health Act required the closure of all psychiatric institutions within ten years, but the goal is far from having been met (Urgent closing of asylums, 2020). In **Peru**, although Act No. 30947/2019, the Mental Health Act, does not order the closure of psychiatric hospitals, it does decree the deinstitutionalization of people with disabilities in mental health facilities.

There is still little evidence of the pending deinstitutionalization agenda outside the realm of mental health systems such as social welfare, religious, and private institutions. Several human rights organizations have denounced this situation and the precarious conditions of services (Rodríguez et al., 2020; González Benítez et al., 2020; Ríos-Espinoza, 2018). Likewise, in most countries there is a significant number of people in prisons and forensic centers for reasons of non-imputability or being unfit for trial that require an urgent solution.⁷⁷ Progress in the implementation of care policies and systems must not reinforce the institutional paradigm of disability care but, on the contrary, reinforce individualized solutions that respect their right to live independently and in the community.

3.9. Support for families and caregivers

Families play an important role in the inclusion of people with disabilities in their communities. They play a fundamental role in the self-esteem, autonomy, development, and social relationships of their members with disabilities. In fact, in most parts of the world, they are the main source of support and assistance for people with disabilities. Hence, the importance of empowering and supporting families to help their members with disabilities exercise their right to live independently and be included in the community (Independent Living Observation, 2018).

Disability legislation in Latin America and the Caribbean has generally placed little emphasis on families and caregivers having access to support services. For example, in **Ecuador**, although the Organic Act on Disabilities of 2012 protects and recognizes the rights established in the law "to relatives up to the fourth degree of consanguinity and second degree of affinity, spouse, common-law partner or legal representative who have a person with disabilities under their responsibility and/or care" (arts. 5, inc. d), and 16), this recognition is primarily

⁷² Act No. 10708/2003 establishes psychosocial rehabilitation aids for patients with mental disorders discharged from hospitalization.

⁷³ Act 26657/2010, National Mental Health Law, art. 27.

⁷⁴ Act 21331/2021, Recognition and protection of the rights of people in the mental health care service, article 26.

⁷⁵ Decree amending, adding to, and repealing several provisions of the General Health Law regarding Mental Health and Addictions, DOF: 05/16/2022, article 74.

⁷⁶ Act 19529, Mental Health Act, art. 38.

⁷⁷ See National Reports on Compliance with the Inter-American Convention on the Elimination of All Forms of Discrimination against People with Disabilities (CIADDIS); Costa Rica.

intended to extend the benefits that the law grants to people with disabilities to family members (in some cases, distorting its purpose), rather than establishing specific measures to support the work of family members to further the independent living of people with disabilities. In **Colombia**, Act No. 1618/2013, which establishes provisions to guarantee that people with disabilities can fully exercise their rights, does include an article on support and assistance for families including training, self-care and the situation of people with disabilities who provide care (art. 8).

In some countries instead, the families are the subject of obligations. In **Bolivia**, Act No. 223/2012, General People with Disabilities Act, imposes on families the obligation to "provide the person with disabilities with protection and welfare by furthering their autonomy and respecting their self-determination" (art. 7). Likewise, in **Costa Rica**, Act No. 7600/1996, the Equal Opportunities for People with Disabilities Act, establishes that all members of the family must contribute to the development of a life of dignity and the full exercise of the rights and duties of the person with disabilities (art. 11).

The care agenda has led to progress in establishing leaves of absence and workplace accommodations to facilitate the work of families in caring for people with disabilities. For one thing, in recognition of the increased burden of care that the birth of a child with a disability can entail, some countries have made progress in establishing extended maternity leave for the birth of a child with a disability. This is the case with **Argentina**⁷⁸, **Colombia**,⁷⁹ **Ecuador**⁸⁰, **Mexico**⁸¹, **Peru**⁸², **Trinidad and Tobago**⁸³ and **Uruguay**⁸⁴. Some countries, in turn, such as **Bolivia**,⁸⁵ **Brazil**,⁸⁶ **Chile**,⁸⁷ **Ecuador**,⁸⁸ **El Salvador**,⁸⁹ **Panama**,⁹⁰ and **Peru**⁹¹ recognize the right of workers to have leaves of absence and accommodations in the workplace to provide assistance to family members with disabilities. **Bolivia**,⁹² **Ecuador**,⁹³ **El Salvador**,⁹⁴

⁷⁸ Act No. 24716/1996 establishes a special leave of absence for working mothers in a dependent relationship, as a consequence of the birth of a child with Down Syndrome.

⁷⁹ Act 2114/2021 whereby paternity leave is extended, shared parental leave is created, flexible part-time parental leave is created, Article 236 is amended and Article 241A of the Labor Code is added, and other provisions are enacted.

⁸⁰ Organic Law on Disabilities 2012, art. 52.

⁸¹ Federal Labor Act, DOF 12-06-2015, art. 170, inc. II.

⁸² Act No. 29992/2013 a law that amends Act No. 26644, establishing the extension of the postnatal rest for cases of the birth of children with disabilities.

⁸³ Maternity Protection Act, Chapter 45:57.

⁸⁴ Act 18651/2010, Comprehensive Protection of People with Disabilities Act, article 61.

⁸⁵ Supreme Decree No. 1455/2013 granting the benefit of "special leave."

⁸⁶ Act No. 13370/2016 amends § 3 of Art. 98 of Act No. 8112 to extend the right to special hours to federal civil servants who have a spouse, child, or dependent with any type of disability and repeal the time compensation requirement.

⁸⁷ Act No. 20535/2011 grants permission to parents of children with disabilities to be absent from work.

⁸⁸ Organic Law on Disabilities 2012, art. 52.

⁸⁹ Decree 672/2020, Special Act on Inclusion of People with Disabilities, article 68.

⁹⁰ Act 42/1999, which establishes equal opportunities for people with disabilities as amended by Act 15/2016, article 17.

⁹¹ Act No. 30119/2012 is a law that grants the right to leave of absence to public and private workers for medical assistance and rehabilitation therapy for people with disabilities.

⁹² Act 223/2012, General People with Disabilities Act, art. 34 inc. II.

⁹³ Organic Law on Disabilities 2012, art. 51.

⁹⁴ Decree 672/2020, Special Act on Inclusion of People with Disabilities, article 68.

Panama,⁹⁵ and **Venezuela**⁹⁶ have also established measures to guarantee job stability for family members of people with disabilities.

Finally, the care agenda is beginning to contribute to the development of information, training, and support services for families. As mentioned above, in **Chile**, the Local Support and Caregiving Network Program helps caregivers maintain or decrease their level of overload through home assistance and specialized services, including psychological care (Chile Atiende, 2022). In addition, the "people with disabilities caregiver payment program" has been created. This consists of a monetary contribution of about \$30,879 Chilean pesos per month (approx. 38 US dollars) for the care of a person with high support needs. In **Colombia**, the District Care System of the Mayor's Office of Bogota provides respite, recreation, training and certification services for women who do unpaid domestic or caregiving work in their homes (Sistema Distrital de Cuidado). Although the program targets all women caregivers in Bogota, it seeks to be inclusive and provide services to women who assist people with disabilities as well as women with disabilities who are caregivers (Supports for Community Living, in press). It also includes benefits for people with disabilities who require care such as community-based rehabilitation and self-care training. Apart from the case of Chile and Bogota, no information is available on the implementation of relief services to provide breaks for family caregivers or persons with disabilities themselves in other countries and cities.

Box No. 3. Summary of legislation on the provision of support and caregiving

	Argentina	Barbados	Bolivia	Brazil	Chile	Colombia	Costa Rica	Ecuador	El Salvador	Jamaica	Mexico	Panama	Paraguay	Peru	Dominican Republic	Trinidad and Tobago	Uruguay	Venezuela
General framework																		
Recognition of the right to live independently in the community									x					x				
Recognition of the right to receive care							x										x	x
Legal capability																		
Recognition of legal capability on an equal footing						x	x				x			x				
Access to supported decision-making mechanisms	x			x		x	x							x				
Human and/or animal assistance																		
Personal assistance							x										x	
Use of assistance animals	x				x			x			x	x	x	x			x	x
Communication																		
Official recognition of sign language	x		x	x	x	x	x	x	x		x	x	x	x			x	x
Sign language interpreters in public entities and/or services open to the public	x		x	x	x	x	x	x	x			x	x	x			x	x
Interpreter guides for the blind and deaf				x	x	x								x				

⁹⁵ Act 42/1999, which establishes equal opportunities for people with disabilities as amended by Act 15/2016, article 45-A.

⁹⁶ Organic Act on Labor, Workers and Women Workers of 2012, art. 347.

Support technologies																		
Provision of technical aids	x			x	x	x	x	x	x		x	x		x	x		x	x
Tax benefits	x		x	x	x		x	x	x	x	x	x	x	x	x	x	x	x
Financial assistance																		
Non-contributory disability cash transfers	x		x	x	x		x	x	x		x	x		x	x		x	
Transportation and housing																		
Subsidized or discounted transportation	x		x	x	x			x			x	x	x	x			x	x
Housing support	x		x	x		x	x	x			x	x		x	x		x	x
Deinstitutionalization	x				x						x			x			x	
Families and caregivers																		
Maternity leave for a disabled child	x					x		x			x			x		x	x	
Adjustments and leave for caregivers			x	x	x			x	x			x		x				

Source: Prepared by authors

Box No. 4. Summary of policies and programs for the provision of support and caregiving

	Argentina	Barbados	Bolivia	Brazil	Chile	Colombia	Costa Rica	Ecuador	El Salvador	Jamaica	Mexico	Panama	Paraguay	Peru	Dominican Republic	Trinidad and Tobago	Uruguay	Venezuela
General framework																		
Disability-inclusive care system and/or policy					x		x										x	
Legal capability																		
Support program for the exercise of legal capability																		
Support assessment service or program						x												
Human and/or animal assistance																		
Personal assistance service or program	x				x		x										x	
Training of assistance animals					x													
Communication																		
Sign language interpretation service	x			x		x								x			x	x
Remote interpretation or relay centers					x	x							x	x				
Interpreter guide service				x		x												
Subsidies for telephone and internet services			x					x				x				x		
Technical support																		
Technical aid program	x			x	x		x	x				x	x				x	x
Financial assistance																		
Non-contributory cash transfer program	x		x	x	x		x	x	x		x	x		x	x	x	x	x
Transportation and housing																		
Point-to-point transportation services (paratransit)				x												x	x	
Programs and benefits for housing access			x		x	x	x	x		x		x	x	x		x	x	
Home improvement programs			x	x	x	x	x	x			x	x		x	x		x	x
Families and caregivers																		

Family guidance and support programs					x	x												
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Source: Prepared by authors

Chapter 4

INVESTMENT IN SUPPORT AND CARE FOR PEOPLE WITH DISABILITIES

The level of investment in support and care systems and programs is increasing globally. This is largely due to population aging. Thus, several countries have increased investment in long-term care programs and services, particularly those focused on the elderly. For example, it is estimated that, on average, 1.5% of the GDP of OECD countries is invested in long-term care programs and services with some countries pumping 3.5% or more of their GDP into these services (Mueller & Morgan, 2020). However, even in OECD countries, there is no breakdown of the data on the investment targeted specifically at the support and care of people with disabilities. Moreover, it is worth noting that most of the investment in long-term care in OECD countries goes to residential institutions. Thus, although the investment made by OECD countries is high, it is still directed to institutions. It is imperative that investment in services and support and care systems be directed to services that promote independent and community living and support deinstitutionalization.

in low- and middle-income countries, data on investment are significantly more limited. Investment levels are estimated to be significantly lower than OECD countries. For example, an estimated 0.01% of the Philippines' GDP in 2019 was directed to people with disabilities in general. In Fiji, an estimated 0.22% of the 2020 GDP was directed to people with disabilities (Budget Data Visualization, CIP). Hence, specific investment in these countries in support and caregiving programs for people with disabilities represents only a fraction of these percentages. The only estimate of the percentage of GDP directed to support and care for people with disabilities comes from India: investment in support services for people with disabilities is estimated to have represented approximately 0.04% of the GDP in fiscal year 2020 - 2021 (Balasubramanian, CIP).

With respect to social protection programs for people with disabilities, the investment gaps are equally large between high-income and low- and middle-income countries. For example, while 80% of high-income countries invest at least 1.0% of their GDP in social protection programs specifically for working-age individuals with disabilities, only six low- or middle-income countries invest more than 0.3% of their GDP (Brazil, Georgia, Kyrgyzstan, Mauritius, Namibia, and South Africa) (Kidd et al., 2019). However, in some countries such as Brazil and Uzbekistan, the level of investment reaches 1.5% and 1.4% of their GDP respectively when social security programs that target people with disabilities are considered (Kidd et al., 2019). In addition, most low- and middle-income countries invest more than 0.5% of their GDP in pensions for the elderly which also benefit a number of people with disabilities (Kidd et al., 2019). Still, investment levels in low- and middle-income countries are lower than in high-income countries.

In both Latin America and the Caribbean specifically, data on the level of investment in support and caregiving for people with disabilities are limited or non-existent. However, data from some countries related to their investment in their caregiving systems or long-term caregiving programs may give an indication of the current level of investment in programs benefiting people with disabilities. For example, the OECD estimates that Chile and Mexico invested about 0.1% of their GDP in long-term care in 2017 (Fabiani et al., 2022). Specific investment in caregiving or support programs for people with disabilities is likely to be lower.

Moreover, Uruguay invested 3.256 billion pesos (approx. US\$81.4 million) in its National Caregiving System in 2019 of which about 38% went to the personal assistant program (Memoria Quinquenio, 2021). Investment in the National Caregiving System represented about 0.14% of Uruguay's GDP in 2019. Thus, investment levels in Chile, Mexico, and Uruguay are significantly lower compared to the average for OECD countries. Although data for other countries in the region are limited or non-existent, investment is expected to be equal to or lower than in Chile, Mexico, or Uruguay. This theory is even more feasible if we consider the fact that most countries do not have formalized support or care systems for either people with disabilities or other groups such as the elderly and children.

In view of the aging and increasing disability in Latin America and the Caribbean, it is essential that we assess the extent to which current levels of investment are sufficient to meet the present and future needs of the population. For example, one study estimated that just to provide support or care for 35% of the adults over 65 years of age who need assistance with at least one daily living activity, the countries of Latin America and the Caribbean should invest an average of 0.27% of their GDP in these programs (Fabiani et al., 2022). This is considered a situation of low coverage for people over 65 years of age. Even so, it is a much higher percentage than the current investment in Chile, Mexico, or Uruguay. If we also include people with disabilities under the age of 65 who need support or care, the investment would need to be even higher.

In order to accurately estimate the level of investment specifically needed to support and care for people with disabilities, it is essential to find the current level of investment. In addition, this would facilitate a comparison, which would include the cost, of programs and policies in different countries. Finally, information on this investment must be broken down in order to identify the extent to which countries are making the transition to community-based care or support models.

Chapter 5:

TOWARDS THE DEVELOPMENT OF SUPPORT AND CAREGIVING SYSTEMS FOR PEOPLE WITH DISABILITIES

As has been made evident throughout this report, much remains to be done to secure a legislative and policy framework that ensures the right of people with disabilities to live independently and in the community. Most of the progress has been in the legislative arena, particularly in the areas of communication, support technologies, and economic assistance as well as, to a lesser extent, in the areas of transportation and housing. However, these commitments do not always correspond to public policies and programs. The exception is cash transfer programs targeting people with disabilities, the number of which continues to increase (Ullman et al., 2020).

Of all the countries analyzed, Uruguay is the one that has made the most progress in the development of support and care systems for people with disabilities. While many services are still primarily provided in the capital city, Montevideo (Support for Community Living, 2023), the inclusion of people with disabilities in the National Comprehensive Care System has allowed services to be expanded and resources and programs to be better coordinated. Meanwhile, there are countries such as Barbados, Jamaica, the Dominican Republic, and Trinidad and Tobago which have made little progress in adopting legislation related to the provision of support and care, and others, such as El Salvador and Mexico which, in spite of legislative advances, have made very little progress in their support and care policies.

The fact that several countries in the region are working on the design and implementation of caregiving systems represents an important opportunity to address the support and care gaps identified in this report. Seizing this opportunity requires, however, rethinking traditional care systems and practices and ensuring that policies and programs are oriented towards achieving autonomy, independent living, and the human rights of all people who are part of this agenda: caregivers and care recipients (OHCHR, 2023). People with disabilities have the right to receive support and care, provide support and care, and exercise self-care like all other people.

Although the development of support and care systems for people with disabilities cannot have a "single dynamic" (Bango & Cossani, 2020), there are important factors that states should consider in their design and implementation:

Policy and regulatory framework

Progress is needed in the adoption of regulatory frameworks that guarantee the availability, access to, and quality of various services and support networks for people with disabilities. Regional experience shows that there is a certain correlation between the adoption of legislation and the development of policies, services, and programs. This can be achieved by including the rights of people with disabilities in caregiving legislation, or by including the issue of support and care in national disability laws. Central to this is the recognition of support and care systems as a right and as an integral part of the right of people with disabilities to live independently and in the community. It is also essential to have a comprehensive policy framework that covers different demands for support and care

throughout the life cycle. Ensuring that care systems and policies include people with disabilities as a target population and consider them active subjects from a human rights approach is a must.

Institutional framework

An institutional framework that makes it possible to coordinate and implement support and care policies and programs based on a model of social co-responsibility is required. Inclusion of people with disabilities in caregiving systems as well as in policy coordination, decision making, and monitoring is key. In addition, coordination between the different sectors and levels of government should be facilitated in order to avoid fragmentation and gaps in access as well as flexibility and portability. In all these efforts, people with disabilities and their representative organizations should be ensured a leading role including in the design, coordination, implementation, and monitoring of policies and programs.

Raising awareness

It is important to increase awareness of the importance of support and care systems for people with disabilities. Although there are advances in accessibility, support technologies, and inclusion, the need, importance, and potential of individualized support for people with disabilities and their families remains unknown (Vasquez et al., 2021). Although support needs are high, demand is low. More awareness of the impact of the lack of investment in support and care systems for people with disabilities on gender equality also needs to be fostered. Improving awareness can help change attitudes, enhance identification of support needs, increase demand, and mobilize political will and action (Vasquez et al., 2019). In addition, implementing disability and human rights training is crucial to reinforcing awareness and ensuring that support and care systems have a human rights approach.

Information and knowledge management

As this report has shown, there is insufficient and inadequate information on support and care systems for people with disabilities and on the actual demand for support and care. The limited information available is fragmented by sector or service and, in most cases, is not broken down by gender, age, or disability. Further progress is needed in including disability in national censuses and surveys as well as in time-use surveys. Likewise, disability rating and certification systems need to be reviewed so that they systematically collect information on the demands for support and care among the disabled population and thus contribute to policy planning.

Investment in services and support and care networks

Investment in support and caregiving systems remains very low. As a result, most of the support and care received by people with disabilities is provided by families and, to a lesser extent, by non-profit organizations. The state is required to play a proactive role to ensure that people with disabilities and their families have access to support and care services and networks. First of all, this requires sustained investment in the creation and expansion of services either directly or in collaboration with the private sector and communities including non-profit organizations and organizations of people with disabilities themselves. Secondly, it is necessary to invest in the communities themselves to transform attitudes, strengthen existing support and care networks, and make the most of community resources. As part of

these efforts, and in view of the growing interest in cash transfer programs, the linking of these programs with other benefits and services ("cash plus") as well as mechanisms for "personalizing" support should be explored while the challenges should be addressed (Carey et al., 2019). In all cases, ensuring that investment in support and caregiving has a rights-based approach and moves away from models that encourage institutionalization is essential.

Human Resources

Progress in support and care systems for people with disabilities also requires investment in human resources. In some sectors, there is a need to increase the number of skilled workers such as support technology or sign language interpreting and interpreter guide services. To this end, an active role by governments is needed to facilitate the training, accreditation, and recognition of these workers as well as to encourage an attractive labor market with better working conditions. Likewise, recognizing and developing the skills of unpaid caregivers and support workers who need visibility, recognition, guidance, training, and services is necessary.

Humanitarian contexts

Although there is insufficient information on the situation of people with disabilities in humanitarian contexts in the region, the experiences with regard to human freedom of movement in recent years call for greater attention to the demands for support and care of people with disabilities in these contexts. Indeed, internal conflicts, natural disasters, and violence can generate increased demand for services and support technologies. Designing systems of support and care that are appropriate for humanitarian contexts is required as is building the capabilities of national and international agencies responsible for the provision of humanitarian aid.

Recommendations:

- Recognize support and care systems as a fundamental right for independent living in the community.
- Adopt regulatory frameworks for support and caregiving that include the rights of persons with disabilities.
- Guarantee comprehensive support and care policies throughout the life cycle and consider people with disabilities to be active subjects from a human rights perspective.
- Establish an institutional framework that makes it possible to coordinate and implement support and care policies and programs based on a model of social co-responsibility.
- Facilitate coordination between the different sectors and levels of government to avoid fragmentation and gaps in access, and ensure that people with disabilities have a leading role in the design, coordination, implementation, and monitoring of policies and programs.
- Raise awareness of the importance of support and care systems for people with disabilities and encourage greater awareness of the impact on gender equality.
- Ensure sufficient and appropriate information on support and care systems for people with disabilities while providing for the inclusion of disability in national censuses and surveys as well as in time-use surveys.

- Review disability rating and certification systems so that they collect systematic information on the support and care requirements of the disabled population and thus contribute to policy planning.
- Increase investment in support and care systems for people with disabilities including investment in the communities themselves to reinforce existing support and care networks and make the maximum use of community resources.
- Ensure that any investment in support and care systems has a rights-based approach and distances itself from models that foster segregation and institutionalization.
- Invest in the training and accreditation of skilled workers to ensure the availability of adequate support and care services.
- Recognize and develop the skills of unpaid caregivers and provide them with visibility, recognition, guidance, training, and services.

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