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
2023

CAF
DEVELOPMENT BANK
**OF LATIN AMERICA
AND THE CARIBBEAN**

Executive Summary

This report seeks to identify gaps in support and care in Latin America and the Caribbean as well as opportunities and good practices with a view to developing comprehensive support and care systems that support independent living and community life for people with disabilities.

This report uses the term "support and care" to describe the assistance that people with disabilities may require to carry out daily activities and to participate actively in their communities. "Support" symbolizes the paradigm shift towards autonomy and independence championed by the Convention on the Rights of People with Disabilities. "Caregiving" underscores assistance throughout the life cycle, especially in childhood, as well as the connection between services and support networks for people with disabilities and the care agenda.

Support and caregiving systems refer to the combination of services, networks, people, and products that help an individual with a disability to make decisions or carry out daily living activities to enable the person to exercise the right to live independently in the community. These encompass a wide range of formal and informal services including:

- support for decision-making and the exercise of legal capacity;
- human support to carry out activities of daily living;
- support and mobility technologies;
- transportation and housing assistance;
- financial assistance to cover additional costs related to support and care needs;
- counseling and support programs for families;
- other community services needed to prevent institutionalization and ensure independent living in the community for people with disabilities.

Support and care systems are instrumental for people with disabilities to exercise their rights and a necessary condition for them to live and participate fully in their communities. They are also key to ensuring the redistribution and reduction of unpaid care which, due to the lack of services and the traditional division of roles, is mostly provided by the women in the families. The COVID-19 crisis has underscored the importance of support and care systems for people with disabilities and their families. While there has been progress in building a care agenda in Latin America and the Caribbean, people with disabilities and their organizations often find themselves on the margins of these efforts.

SUPPORT AND CARE SYSTEMS FOR PEOPLE WITH DISABILITIES IN LATIN AMERICA AND THE CARIBBEAN

People with disabilities represent 15 percent of the population of Latin America and the Caribbean. Throughout their lives, they 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.

There is a severe lack of data on the magnitude of the gaps in support needs for people with disabilities in Latin America and the Caribbean. The limited information available shows that people with disabilities have high human support needs and often these needs are not met (between 30% and 60% of people with disabilities have unmet support needs). Moreover, the gaps are greater in the rural context and among younger adults. Furthermore, most of the support and care provided to people with disabilities is provided by family members, mainly women and girls, on an unpaid basis. This has a negative impact on the education, income, employment, and decision-making power of women and girls inside and outside the home.

International human rights law, in particular the Convention on the Rights of People with Disabilities (CRPD), requires governments to ensure that people with disabilities have access to the support they may need to exercise their rights and to be fully included and participate in the community. All Latin American and Caribbean countries have ratified the CRPD. Therefore, they have the obligation to respect, protect, and fulfill the right of people with disabilities to live independently and to be included in the community. The implementation of comprehensive systems of support and care for people with disabilities is an avenue for making this right a reality.

LEGISLATION AND POLICIES ON SUPPORT AND CAREGIVING FOR PEOPLE WITH DISABILITIES

A study of the legislation and public policies of 18 countries in Latin America and the Caribbean shows that the governments make unequal progress in the construction of support and care systems for people with disabilities and prioritize certain needs and demands for support and care over others.

Much remains to be done to establish a legal and policy framework that guarantees the right of people with disabilities to live independently in the community. Although significant progress has been made in the legislative arena, especially in terms of communication, support technologies and financial assistance, progress in areas such as transportation and housing has been limited. In addition, there is often a disconnect between legislative commitments and the implementation of public policies and programs with the exception of cash transfer programs for people with disabilities, which are on the rise.

Among the countries analyzed, Uruguay has made the most progress in the development of support and care systems for people with disabilities. Although many services are still mainly concentrated in Montevideo, the inclusion of people with disabilities in the National Comprehensive Care System has made it possible to expand the supply of services and better coordinate resources and programs. In contrast, some countries have made little progress in adopting legislation to provide support and care, while others, in spite of legislative advances, have made little progress in implementing support and care policies.

The fact that several countries in Latin America and the Caribbean are working on the design and implementation of care 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. Ensuring that the policies and programs are

oriented towards achieving autonomy, independent living, and human rights for all the people who are part of this agenda, both caregivers and care recipients, is necessary.

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 caregiving systems for people with disabilities by including 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.

CAF DEVELOPMENT BANK
OF LATIN AMERICA
AND THE CARIBBEAN

www.caf.com/en
@AgendaCAF