Long-term care providers: The roles, rights, and needs of paid and unpaid caregivers

POLICY BRIEF 2

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Key messages

1. Long-term care (LTC) enables individuals of any age experiencing significant declines in intrinsic capacity to maintain their functional ability, consistent with their basic rights, freedoms, and human dignity.
2. Paid and unpaid caregivers represent the bulk of LTC providers globally and must have the necessary knowledge, skills, support, and recognition of labor rights to meet each person's LTC needs.
3. In the Americas, LTC providers operate under highly heterogeneous conditions, with major disparities in education, training, and support. Both paid and unpaid care work remain socially invisible and undervalued.
4. Unpaid caregivers – who represent around 80% of LTC providers – are mostly women and are systematically unrecognized and unsupported, reinforcing gender inequalities in the Region of the Americas.
5. Paid caregivers often face precarious working conditions, widespread informality, low wages (70% earn minimum wage or less), and lack of social protection, particularly in home care.
6. There is an urgent need to strengthen formal LTC provision, as this is associated with better care quality, greater workforce stability, improved work environments, and fewer avoidable hospitalizations.
7. LTC involves complex, multidimensional needs that require joint action across sectors to develop shared standards and systems that identify and address declines in functional ability.

Introduction and relevance

Long-term care (LTC) refers to a range of personal care and health- and social-related activities carried out by individuals and service providers,[1] or by means of environmental aids/adaptations, which enable individuals of any age experiencing significant declines in intrinsic capacity to maintain the highest possible level of functional ability, consistent with their basic rights, fundamental freedoms, and human dignity *(1)*. This type of care is provided in multiple settings (i.e., home, residential care, day centers), mostly by individuals such as family members, neighbors, volunteers, or friends, but also by care workers (i.e., paid caregivers and healthcare and social care providers in multiple roles:

[1] The Pan American Health Organization (PAHO) has adopted the term "long-term care workforce" to refer to unpaid caregivers and care workers. Statistics on the world of work use the term labor force or workforce to refer to a statistical indicator of the labor market, which reflects the sum of persons in employment plus persons in unemployment. This policy brief uses "long-term care providers" to refer to both paid and unpaid carers as a single group, with the goal of harmonizing the different existing conceptualizations.

direct care providers, supervisory or managerial roles, liaison, care coordinators). Paid and unpaid caregivers represent the bulk of the LTC providers globally *(1)* and should have the necessary knowledge, skills, resources, support, and recognition of labor rights to provide the level and type of LTC required to meet each person's LTC needs. This is particularly critical among unpaid caregivers, who represent approximately 80% of all LTC providers *(2, 3)*.

LTC is fundamentally different from other care activities, such as the care required in early-life development (e.g. child care) or the integrated care delivered to adults and older individuals with declines in physical and mental capacities, but whose functional ability is preserved. It requires specific knowledge, skills, and abilities related to optimizing functional ability while providing the support needed. Mainstream healthcare workers, such as those in general primary care, acute care, secondary care, and forensic settings, should understand the multiple trajectories of intrinsic capacity so that they can identify declines in functional ability in a timely manner and deliver seamless care to individuals across the continuum of health. For example, individuals with LTC needs admitted into hospital should have their LTC needs and goals taken into account within their acute care and discharge plans.

Receiving as well as providing LTC in decent conditions constitute basic rights *(4)*. However, paid caregivers currently face precarious working conditions, and unpaid caregivers are poorly trained and supported in the Region of the Americas, enduring multiple negative effects on their health, care-related poverty, and huge gender inequalities *(2, 5)*. Strengthening formal[2] provision of LTC is associated with enhanced quality care, as it promotes care skills *(6, 7)*, reduces care worker instability *(8)*, improves work quality, and prevents inappropriate or avoidable hospitalizations of people with LTC needs *(9)*. This is vital to move forward with decent working conditions for paid caregivers, as well as to support the health and quality of life of unpaid caregivers, as it helps reduce and redistribute the burden currently placed upon these individuals, who are mostly women *(10, 11)*.

As the number of people experiencing significant declines in capacity is increasing across the population, having sufficient and adequately trained LTC providers is vital to ensure the delivery of rights-based, sustainable, and equitable LTC *(1, 12–13)*. It also creates a better scenario for ensuring decent working conditions in LTC in the Region. In the coming years, investment in the formal provision of LTC can also prevent further exit of the skilled LTC workers from low- and middle-income to high-income settings where there is an enormous demand for LTC workers, particularly since the COVID-19 pandemic *(14, 15)*.

[2] PAHO documents refer to formal work as equivalent to paid work. For the International Labour Organization (ILO), formal work or employment refers to all economic activities performed by persons that are – both in law and in practice – covered by formal arrangements, such as labor legislation, payment of taxes, or social security coverage.

This brief is therefore aimed at highlighting the urgent need to invest in LTC providers in the Region, in line with both the Pan American Health Organization's (PAHO) *Policy on Long-term Care* (CD 61/8) *(16)* and the 112th Session of the International Labour Conference Resolution (ILC.112/Resolution V) *(17)*. In particular, it focuses on the roles, rights, and needs of unpaid and paid caregivers because these individuals form a largely marginalized group of LTC providers. This brief is part of a series aimed at featuring rapid information on various aspects of LTC.

Situational analysis

The characteristics and conditions of LTC providers are highly heterogeneous in the Americas, with markedly different levels of education, skills, and support. Both paid and unpaid care workers are socially invisible and undervalued. Among paid caregivers, high levels of vertical and horizontal gender-based occupational segregation persists, together with major pay gaps *(5)*. Unpaid caregivers continue to be systematically unrecognized as the main LTC provider and are severely unsupported, which contributes to persistent gender inequalities among women in the Region *(11, 18)*. Major barriers still exist in fully recognizing and establishing roles, competencies, as well as rights and responsibilities of LTC providers in relation to optimizing the functional ability of people with LTC needs. Crucially, the Region lacks professionalization of the LTC sector, which hampers the professional growth of LTC workers, the social and economic recognition of LTC, and quality standards in services, and perpetuates the reliance on the unpaid labor of women *(19)*. It also lacks development and adequate coverage of support mechanisms for unpaid caregivers, such as respite support and training. To a large extent, this reflects and reinforces the broader underdevelopment of LTC at a macro level (i.e., lack of government stewardship for LTC, lack of integrated governance and data systems for LTC, lack of centrality of LTC in country care agendas, inadequate protection for paid LTC caregivers, and limited investments in LTC). To address some of these deficits, the International Labour Organization (ILO) Resolution concerning decent work and the care economy states that "investing in the care economy promotes quality care and decent job creation, and can lead to enhanced human capabilities, productivity growth, quality education, improved health and well-being and gender equality, as well as decent work and stronger female participation in the labour market, and enables the transition to the formal economy." *(17, para. 21)*.

Current numbers and projections: Data on LTC are extremely limited in the Region – information related to LTC providers is conservative, based on broad assumptions and secondary health-related data (e.g., national census/broad health surveys), rather than on LTC-focused empirical evidence *(13)*. This existing

information shows that the number of LTC workers is largely insufficient, with an excessive reliance on unpaid labor (~80%) *(2, 3, 13)*. For example, a study using pre-pandemic microdata from labor and household surveys of 17 countries indicated that there are currently 8.9 million paid caregivers in the Region – at least 3.1 million are caring for older people and people with LTC needs *(12)*. Considering the population of older people with severe LTC needs without unpaid caregivers alone, the Region required nearly 5 million care workers in 2020 *(13)*. It is expected that this figure will rise to almost 9 million by 2035 and more than 14 million by 2050. Furthermore, the need for rehabilitation providers will increase from 2 million to more than 6 million from 2020 to 2050. Even in countries where the public LTC sector is more established, such as in Chile and Uruguay, significant gaps persist in the number of care workers currently available, as well as in the level of skills and training *(13)*. Canada and the United States also face serious shortages, particularly in relation to paid caregivers *(20, 21)*.

Competencies and training: There is currently a wide diversity of profiles and no set of recognized core elements that should inform LTC training. Training is provided by academic institutions, hospitals, primary care units, nongovernmental organizations (NGOs), and other bodies, with different durations, target groups, and nonstandardized content and goals. Absence of mandatory education and training, upskilling and reskilling, competence recognition, and competence certification for each type of LTC worker within each type of LTC setting is still a reality in most countries, which hampers improvements in LTC quality and capability building (e.g., identification and provision of sufficient care workers for the required LTC needs, creation and scaling-up of training programs, effective reduction in reliance on overall unpaid LTC caregivers) *(10)*. Similarly, unpaid caregivers are mostly untrained and unsupported in providing LTC. A recent study of 27 000 paid and unpaid caregivers (90% women) of older people from 25 countries in the Region showed that 1 in 4 paid caregivers worked without any training – only 3 in 10 had completed an extended course, and 8 out of 10 unpaid caregivers did not have any training at all *(22)*. Those who reported having more training had better outcomes related to mental well-being *(22)*. The professionalization of LTC provision through training and certification is crucial for improving care quality, enhancing worker retention, raising wages, and increasing recognition of care workers in social and labor contexts. The occupational hazards to which LTC caregivers are exposed are numerous. The most common risks include exposure to chemicals and ergonomic, physical, psychosocial, and biological hazards.

Another study including 109 surveys of paid caregivers working in residential and day-care centers for older people in Colombia, Costa Rica, and Uruguay showed that 63.3% had less than nine years of formal education, of whom 23.9% had lower than primary education, 45.9% had no specific training in care provision, and 20.2% had courses of less than 60 hours in total *(23)*. In 2023, ILO published a document on competence development within the broader

care sector (not specific to LTC) in Latin America including initiatives in eight countries, which demonstrates a growing interest in this area *(19)*. Although this represents some progress, the existing initiatives put great emphasis on care dependence and not on the optimization of the functional abilities of individuals with LTC needs, generally reflecting a vital need to improve knowledge and attitudes toward LTC at all system levels in the Region.

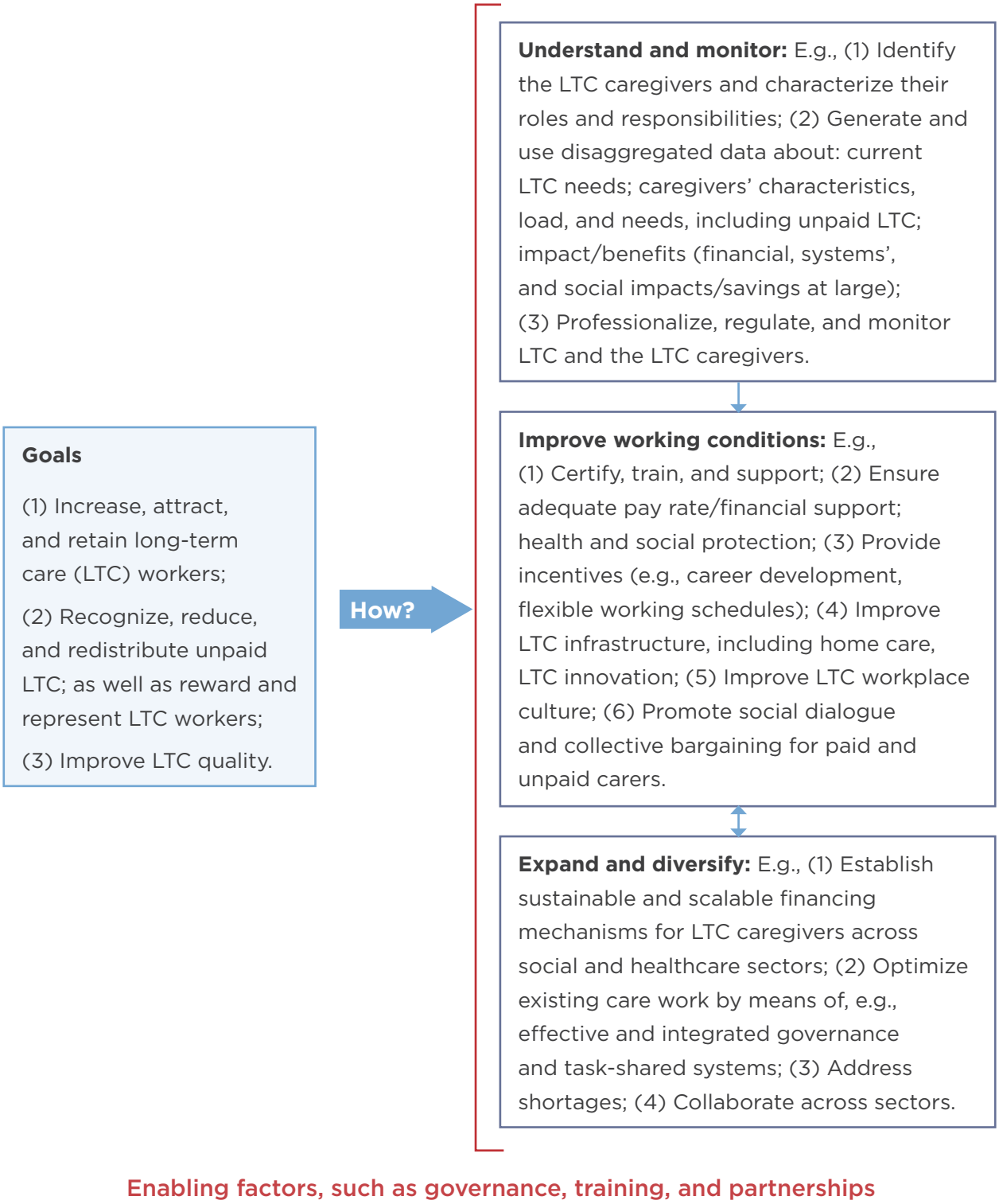
Health and well-being: Data on over 27 000 paid and unpaid LTC providers show that care provision is associated with high levels of stress and depressive symptoms among both paid and unpaid caregivers in Latin America *(22)*. In this sense, occupational health and safety is another critical area for LTC caregivers. A large proportion of unpaid caregivers have had to stop working due to caregiving *(22)*, which both introduces and reinforces poverty in the Region *(2)*. Despite a heavy workload, 70% of paid caregivers earn the minimum wage or less, with widespread informality and lack of social protection, particularly among paid home caregivers *(22)*. Care workers in the informal economy are excluded from national labor laws, which means they are not covered by occupational health and safety legislation and related social security provisions, denying them access to workers' compensation and social security schemes, increasing their vulnerability *(24)*. The great majority of paid caregivers are women, and therefore poor working conditions in the LTC sector also contribute to the high level of gender inequality and poverty among women *(10)*. Such data demonstrate how both paid and unpaid caregivers in the Region are undervalued and vulnerable to multiple health and social risks associated with their caregiving role.

Goals and recommendations for strengthening long-term care providers

The 5R Framework for Decent Care Work provides guidance on defining and advancing transformative care policies. The "Framework creates a virtuous circle that mitigates care-related inequalities, addresses the barriers preventing women from entering paid work, and improves the conditions of all care workers and ... the quality of care"*(10, p. xliv)*. The first three Rs – recognize, reduce, and redistribute unpaid care work – pose particular attention to the need to value and make visible unpaid care work, reduce the time spent in unpaid care work, and share the provision of care equitably both across society and within households. The additional two Rs refer mainly to paid care work: reward relates to generating decent working conditions, living wages, and safe environments for care workers in conditions of environmental sustainability; and represent refers to the need to ensure social dialogue and collective bargaining for care workers.

Building on this Framework, the strengthening of LTC providers should target unpaid caregivers as well as paid care workers through three main goals: (1) Increase, attract, and retain LTC workers; (2) Recognize, reduce, and redistribute unpaid LTC, as well as reward and represent paid LTC workers; and (3) Improve LTC quality. Examples of related actions are given in Figure 1.

Figure 1. Workforce strengthening goals and examples of related actions



Currently, data in the Region are often grouped by people with disabilities, older people with care needs, and child care, which makes it difficult to establish an accurate and all-encompassing picture specific to the LTC situation; it is also usually limited to public provision only. Investment in the scaling-up and enhancement of LTC providers should be informed by an up-to-date

and in-depth situational analysis, with accurate and disaggregated data of LTC needs, gaps, and strengths in each context. Such information needs to be carefully identified within the existing health- and social-care systems or expanded/created for ongoing data collection in both the public and private sectors. The information identified then needs to be managed through a dedicated set of governance processes. The availability of an integrated information system for LTC is essential to achieve this *(1)*, as it involves complex multidimensional needs that require a joint effort by different groups and sectors to establish shared understandings, methods, services, and standards to identify and address declines in functional ability *(19)*. Continuous collaborative work between different ministries (e.g., health, labor, education, social development), sectors (e.g., public and private, unions, and civil society), professional regulatory bodies, and service deliverers is therefore key to ensure the quality and national/international recognition of the training provided, as well as the implementation of the acquired competencies in practice, and its subsequent regulation and monitoring. PAHO's *Policy on the Health Workforce 2030* (CD 60/6) *(25)* provides a framework for strengthening caregivers' capacities for LTC through interprofessional and collaborative team-based care. Crucially, the development, implementation, and assessment of training and support mechanisms should be in line with up-to-date evidence on the best ways to improve individual health trajectories and abilities across the life course through person-centered approaches *(1, 26)*. This may include, for example, the establishment of learning pathways and microcurricula for LTC. The WHO's package for universal health coverage through LTC provides detailed information about effective LTC interventions and the resources required for each of them *(27)*, which can be used as a guide to ensure LTC providers are well equipped to deliver such interventions.

The professionalization of paid caregivers is crucial for improving care quality, enhancing worker retention, raising wages, and increasing recognition of both LTC and care workers in social and labor contexts. This also promotes professional growth, performance, access to lifelong learning opportunities, as well as reduction in the reliance on unpaid care *(19, 24)*. In addition, providing decent pay, access to social and occupational protection, as well as incentives related to career progression, flexible working-hour arrangements to support work–life balance, and impact visibility are important to promote staff satisfaction and well-being in LTC *(15, 24, 28–29)*. Investments in minimum infrastructure, including home-based LTC and LTC innovation, as well as a positive working culture are also vital to safeguard working conditions and occupational health and safety. All these aspects contribute to attracting and retaining LTC workers and reducing the current excessive reliance on unpaid LTC provided mostly by women *(12, 22, 28–29)*.

Unpaid caregivers must be recognized and valued as key LTC providers, and unpaid LTC should be taken into account in decision-making, such as in financing and workforce capacity-building *(1)*. A key role of paid LTC workers is

to support unpaid caregivers and provide them with information on the delivery of person-centered LTC *(1)*. Furthermore, developing and implementing respite care, information, and adequate financial support and coverage are key support mechanisms for unpaid caregivers. In the United States of America, for example, a program of cash and counseling provides an allowance that recipients can use to purchase home- and community-based LTC services instead of receiving them from an agency, enabling self-directed implementation of their preferred LTC plan through an assigned budget under the supervision of a counselor. Beneficiaries can choose to use a range of relevant LTC services, such as home-delivered meals, transportation to and from medical appointments, as well as respite care. This gives more choice and control for LTC service users and families, leads to better LTC outcomes, honors individual preferences, is cost-effective – being associated with a greater level of care continuity and considerably less turnover among workers – and results in more timely responses to LTC needs *(30)*.

Country examples

- **Bogotá (Colombia) has the program called Manzanas del Cuidado (Care Blocks) that aims to geographically concentrate public healthcare services in a way that allows people to access them without having to walk for more than 20 minutes. This helps unpaid caregivers to continue to attend school, work, and wellness activities. The program also aims to reduce care stereotypes by conveying a culture of co-responsibility of care among men, women, and institutions.**
- **In the Plurinational State of Bolivia, The Cochabamba Municipal Law 380/2019, Co-responsibility in Unpaid Care Work for Equal Opportunities, was the first of its kind in 2019. Then, the Tarija Municipal Care Law 351/2023 was approved on 7 November 2023, which promotes family, social, and state co-responsibility for care work. The ILO is also supporting the Municipality of El Alto with a preliminary draft care bill.**

A few examples of structured care training and professional development for paid caregivers can be found in Latin America *(19)*: I. In Chile, the Commission of the National System of Certification of Labor Competencies (ChileValora) has established competence and training profiles for sociocommunity assistants, psychosocial coordinators, directors of LTC residences, and unpaid caregivers; II. In Uruguay, the national certification program (Uruguay Certifica) managed by the National Institute of Employment and Vocational Training (INEFOP) has established certification and training/support standards for paid and unpaid caregivers *(19)*; III. In the Dominican Republic, the National Institute of Technical Vocational Training (INFOTEP) offers training and certification for personal assistants to support people with disabilities to have fuller participation in society *(31)*.

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Long-term care (LTC) refers to a wide range of personal, health-related, and social support activities provided to individuals experiencing significant declines in intrinsic capacity, enabling them to maintain functional ability and live with dignity. In the Americas, LTC is primarily delivered by paid and unpaid caregivers – most of whom are women – under conditions that are often invisible, undervalued, and unsupported. Unpaid caregivers, who represent around 80% of all those providing care, continue to be largely unrecognized, untrained, and without adequate support.

Paid caregivers also work under difficult conditions. The majority earn minimum wage or less and lack access to social protection and professional development. Training is limited or absent in most countries, and the absence of certification pathways hinders improvements in care quality and worker retention. In 2020, the Region of the Americas faced a shortage of nearly 5 million care workers to meet the needs of older people with severe functional decline, even before considering the contributions of unpaid labor.

Investing in the recognition, training, and support of caregivers is essential to ensure the delivery of equitable, person-centered, and rights-based care. Expanding formal provision helps improve care quality, stabilize the workforce, and prevent avoidable hospitalizations, while also reducing the excessive burden carried by women.

Developed by the Pan American Health Organization and the International Labour Organization, this technical brief highlights the urgent need to support LTC providers. It calls for coordinated, multisectoral action to professionalize care work, ensure fair working conditions, and strengthen formal care provision throughout the Region, at the same time that unpaid care is valued and supported.

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