

14th session of the Open-ended Working Group on Ageing
Guiding questions on the normative content related to right to health and access to health
services

Inputs by the Economic Commission for Latin America and the Caribbean (ECLAC)

State obligations

4. What are the measures that should be undertaken by the State to respect, protect and fulfil the human right of older persons to the highest attainable standard of physical and mental health, regarding the normative elements as provided above?

As highlighted in ECLAC's 2022 report "Ageing in Latin America and the Caribbean: inclusion and rights of older persons",¹ long-term care, especially of those living with disabilities, or mental or terminal illnesses, and palliative care, are key to respect, protect and fulfil the right of older persons to physical and mental health.

Although not all older persons require care, in Latin America and the Caribbean the increase in the number of people aged 60 years or over and, specifically, the rapid rise the proportion of the population aged 80 or more, poses a care challenge, since the demand for support services, accompaniment and specialized care is increasing and will continue to do so.

Long-term care has different characteristics than care in general, owing to its intensity, specific actions and activities, the need for support by specialized personnel, and the economic resources required to provide it with dignity. Accordingly, access to this type of care is limited and entails high physical and economic costs and emotional wear and tear, both for those who require it and for those who provide it. Consequently, long-term care policies must consider the fact that social groups facing multiple types of discrimination tend to have greater long-term care needs and face greater obstacles in accessing them. Care policies need to offer older persons a wide range of services that respond adequately to specific needs and guarantee the right to care under conditions of equality and non-discrimination.

The construction of long-term care systems and policies in the region is still limited in most countries. This is explained mainly by: (i) the variability of approaches to the concept of dependency; (ii) the lack of economic resources to provide health care to those who require long-term care; (iii) the lack of reliable and up-to-date information on the population with long-term care needs, on infrastructure (both existing and required), on qualified personnel to meet this challenge and on family or non-professional caregivers; (iv) the social construction of long-term care, which, in many countries, continues to be viewed as pertaining to the family domain, and (v) the failure to treat care as a right.

Expansion of long-term care infrastructure is one of the major hurdles to overcome in the next decade. In view of this, the region should encourage formulation and application of long-term care policies, as well as conducting research on care strategies with models centred on older persons and promoting long-term care as a positive social and economic investment and a source of job creation. National registry systems must be developed for long-term care institutions and workers, with legislative and administrative

¹ See [online] <https://www.cepal.org/en/publications/48568-ageing-latin-america-and-caribbean-inclusion-and-rights-older-persons>.

mechanisms within countries to regulate their work, thus guaranteeing full respect for the human rights of older persons living in such institutions.

Palliative care, in turn, plays a central role in dignifying life and death in the context of terminal illness. Making the right to palliative care a reality requires: measures that enable specialized interdisciplinary teams to receive instruction, training and refresher courses; expansion of in-hospital and out-of-hospital infrastructure to provide accessible, affordable, high-quality, person-centred services to those who need them; strengthened legislation; availability of medicines; and interdisciplinary research.

To provide these two forms of specialized care, considering that the labour market will require more personnel trained to provide specialized care for older persons, it is essential to support the rights of caregivers and encourage them to obtain training and keep up to date in gerontology, geriatrics and thanatology. Furthermore, as most care services are currently delegated to the family domain, and to women in particular, gender imbalances need to be taken into account.

Implementation

7. What are good or promising practices and main challenges faced by your country in the adoption and implementation of the normative framework on the human right to health of older persons

Some countries in Latin America and the Caribbean have made legislative progress and created long-term care infrastructure, but challenges remain. Argentina has created a federal care service map, which makes it possible to locate the availability of long-term care institutions. The country also has extensive training and certification programmes for formal and informal care workers, along with home care programmes and implementation of the National Registry of Home Caregivers. The Regulation on Long-Stay Residences for Older Persons (Resolution 612/2015 of the National Secretariat for Children, Adolescents and Family of the Ministry of Social Development) provides a regulatory model that is aligned with the Inter-American Convention on the Protecting the Human Rights of Older Persons.

Since 2021, the Plurinational State of Bolivia has kept an up-to-date register of long-term care institutions. In 2019, the Protocol for Intervention in Long-Stay Care Centres for Older Persons was approved; and, in 2021, basic standards were approved for the care of older persons in long-stay care centres. Brazil also has a national register of this type and, between 2019 and 2020, invested a total of R\$ 4,366,891.89 in equipping such centres for older persons.

Chile reports five actions: (i) development of quality standards for long-stay facilities for older adults (2016); (ii) implementation of protocols for long-stay residences funded from the National Service for Older Adults (SENAMA) (2017 to date); (iii) development of the citizen's guide to rights in long-stay facilities for older adults (*Soy residente, tengo derechos*) (2017); (iv) strengthening of the self-regulation process (2019), which allows long-term care institutions to carry out voluntary monitoring using their own facilities, people and resources, with the aim of incorporating future improvements; and (v) diagnostic assessment of long-term care facilities, based on the user care quality standard (2020).

Colombia has established a system for departmental, district and municipal health secretariats to monitor the provision of services in long-term care institutions. In particular, this system safeguards the rights of users through the Public Prosecutor's Office, represented by the Municipal Citizens' Bureaus (*personerías municipales*), the Attorney General's Office and the Ombudsperson's Office. The aforementioned agencies make it possible to check the conditions of the older persons who are cared for in these centres. In Cuba,

the annual public infrastructure improvement programme makes it possible to repair and maintain these institutions. Mexico, Paraguay and Peru also report the updating of records of long-term care institutions, as well as strategies for monitoring their operation. In Uruguay, Ordinances 483 of 2017 and 1032 of 2019, relate to informed consent, use of the user record, and the definition of careers that enable social area professionals to exercise their profession in long-term care centres, as well as the conditions under which a person under 65 years of age is admitted.

Caribbean countries report a meagre supply of long-term care institutions, which also face human resource and infrastructure constraints in providing quality services. Although not all countries have registers of these institutions, Bermuda registers them through the Department of Ageing and Disability Services and regularly monitors compliance with the regulations. Given the limited supply of institutional care, many Caribbean governments have invested in developing (or improving) home care programmes that provide nursing care and assistance to older persons in situations of dependency, and the delivery of prepared meals to older persons in their homes. The Barbados National Assistance Board recently launched the Elder Care Companion Programme to complement the Home Help Programme. The new programme supports older persons in activities such as cooking, cleaning, washing, or bathing; and it focuses on emotional and psychosocial well-being, tackling the problems of loneliness and isolation among older people

Major areas of opportunity persist in long-term care, particularly in terms of consolidating national registers of public and private long-term care institutions and those run by civil-society organizations. Argentina, Brazil and Chile report strategies for registering and monitoring such institutions. At the regional level, the lack of up-to-date national registries clearly impedes a diagnostic assessment of infrastructure, service quality and emergency response capacities in situations such as the COVID-19 pandemic.

With respect to palliative care, in Argentina, the National Directorate of Policies for Older Adults (DINAPAM) created the National Programme for the Training of Home Caregivers in Palliative Care for Older Persons in 2019, to meet the care needs of older persons who are suffering from an illness that does not respond to curative treatment, in advanced, progressive or terminal stage. Argentina has also legislated to require “national and trade union social works” and prepaid medicine firms to finance palliative care services.

In Brazil, the Ministry of Health, acting through the Tripartite Inter-agency Commission of the Unified Health System (SUS), approved Resolution No. 41 of 31 October 2018, which provides guidelines for organizing palliative care, conceptualizes such care and defines its objectives and guiding principles. It also underscores the need for palliative care to be provided at any point in the care network, including primary, home, ambulatory, urgent and emergency, and hospital care.

In Colombia, Law No. 1733 of 2014, regulated in 2018, governs palliative care services for the comprehensive treatment of patients with terminal, chronic, degenerative and irreversible diseases, at any stage of the disease that has a high impact on quality of life. This law establishes the rights to palliative care, to information, to a second opinion, to sign the advance directives document, or to participate actively in the palliative care and decision-making process, and the rights of family members.

Costa Rica launched the National Palliative Care and Pain Control Plan 2017–2021 in November 2017, setting out guidelines for palliative care actions under the principles of universality, timeliness, solidarity and equity.

In Chile, Law No. 21375 on access to non-oncological palliative care, which includes home care and accompaniment at the end of life with interdisciplinary teams, came into force in March 2022.

Since the creation of its National Pain and Palliative Care Programme for Oncology Patients in 1992, Cuba has contributed important experiences to the region, such as the implementation of the Pain and Palliative Care Clinic for research and training on the management of opioids and the linking of palliative care with primary care at the municipal level, bringing this service closer to the community through home visits and consultations. In Cuba, a new service has been created for persons with advanced-stage cancer and their caregivers, with the aim of preserving subjective wellbeing and improving the quality of life for both, through personalized, interdisciplinary, comprehensive and continuous care, taking the physical, social, emotional and spiritual dimensions into account.

Mexico reports the consolidation of its palliative care programmes in both the Mexican Social Security Institute (IMSS) and the Institute for Security and Social Services for State Workers (ISSSTE). In 2021, ISSSTE approved the Institutional Palliative Care Programme 2019–2024 (PALIATIVISSSTE), which has 23 representations throughout the country.

In Panama, the *Estamos Contigo* programme is a pilot plan to provide home care, medicines, mobilization and palliative care for older persons with illnesses that keep them bedridden or unable to fend for themselves. In 2018, Peru adopted Law No. 30846, creating the National Palliative Care Plan for Oncological and Non-oncological Diseases.

In Uruguay, the Comprehensive Health Care Plan has included a palliative care service as a mandatory benefit since 2008. In 2016, the Palliative Care Programmatic Area of the Ministry of Public Health conducted the National Palliative Care Survey. Data provided by the service providers indicates coverage of 43%, thus meeting the target of greater than 40% established in the National Health Objectives 2020. All of the country's departments have some form of palliative care. A total of 55 providers indicate that they provide palliative care in different modalities. Of these, 41 do so specifically through palliative care units, 13 are public health centres (located in five departments: Montevideo, San José, Durazno, Río Negro and Salto), 27 are private, and one is a public-private partnership (in San José).

In Caribbean countries, there is a large deficit in the availability of palliative care systems and an absence of planning to develop them, coupled with a shortage of health personnel trained to provide palliative care. There is also a critical shortage of trained support services outside hospital systems for ongoing palliative care (for example, community volunteers, social workers and counsellors). Only two countries (Antigua and Barbuda and Dominica) reported that palliative care is available in the public health system and in community home care. Three countries, Bahamas, Saint Vincent and the Grenadines, and Trinidad and Tobago, stated that palliative care was available in community home care systems.