

Framework for countries to achieve an
**integrated continuum
of long-term care**



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Contents

Acknowledgements.....	iv
Executive summary.....	v
1. Introduction.....	1
1.1 Background.....	1
1.1.1 Envisioning long-term care through universal health coverage.....	2
1.1.2 Learning from the COVID-19 pandemic.....	2
1.2 Objectives of this document.....	2
1.3 Target audience for this document.....	3
1.4 How to use this document.....	3
2. Healthy ageing and long-term care.....	5
2.1 What is healthy ageing?.....	5
2.2 Long-term care definition and scope.....	6
2.2.1 What is long-term care?.....	6
2.2.2 What is the goal of long-term care?.....	7
2.2.3 Where is long-term care delivered? Achieving ageing in place.....	8
3. Towards an integrated long-term care system.....	9
3.1 What is a long-term care system?.....	9
3.2 How can a long-term care system be established?.....	9
4. Framework for countries to achieve an integrated continuum of long-term care.....	11
Element 1. Governance.....	12
Key aspects to consider for long-term care governance.....	14
Element 2. Sustainable financing.....	16
Key aspects to consider for long-term care sustainable financing.....	18
Element 3. Information, monitoring and evaluation systems.....	20
Key aspects to consider for long-term care information, monitoring and evaluation systems.....	22
Element 4. Workforce.....	24
Key aspects to consider for the long-term care workforce.....	26
Element 5. Service delivery.....	28
Key aspects to consider for long-term care service delivery.....	30
Element 6. Innovation and research.....	32
Key aspects to consider for long-term care innovation and research.....	33
References.....	37
Annex 1. Checklist of key action points for strengthening long-term care systems.....	41
Annex 2. Methodology for development of the framework.....	47
Annex 3. Rapid review: macro and meso levels of long-term care.....	49
Glossary.....	53

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Executive summary

Despite the increasing number of older people globally, late life experiences of health and well-being vary dramatically and are not distributed equally either between or within populations, resulting in huge disparities in how ageing is experienced globally. For many, the increase in life expectancy seen worldwide has not meant more years of life with good health; instead, in some locations, a large proportion of those additional years are spent in poor health.

Approximately two thirds of people who achieve old age will probably need care and support from others to perform activities of daily living, such as feeding, moving around and bathing, at least at some point in their longevity pathway. Fluctuations of functional ability are multidirectional, meaning that there is not a single path for everyone or the same trajectory of functional ability within one person's ageing trajectory.

Such needs may arise suddenly, as a consequence of an acute problem potentially determining chronic sequelae, or they can develop gradually as a consequence of a progressive and chronic condition. Nevertheless, many health and social care systems are currently not able to meet the long-term care and support needs of older people.

"Long-term" includes activities provided by carers and care workers, in different settings, "to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity".¹ It refers to a range of activities that address the health, personal care and social needs of individuals. These services may be continuous or intermittent but are delivered for sustained periods to individuals who have demonstrated needs, usually by measuring aspects of functional ability. Long-term care is essential to ensure that older people with significant loss of intrinsic capacity can still enjoy healthy ageing.

Intrinsic capacity and functional ability of individuals vary in a continuum across the second half of the life course. Preventing and compensating for permanent or transient losses of intrinsic capacity are of paramount importance in maintaining functional

ability over time. Differences in intrinsic capacity and functional ability are not defined by chronological age, are not necessarily continually decreasing, and will differ markedly among individuals. Not all people will go through similar trajectories during their lives. Optimizing functional ability to achieve healthy ageing should therefore be a goal for everyone regardless of their current state of health.

The World Health Organization (WHO)'s integrated continuum of long-term care concept aims to uphold these principles of optimizing functional ability and achieving healthy ageing for those with significant declines in intrinsic capacity.

The continuum of long-term care emphasizes coordination across health and social sectors through effective governance, seamless transition across settings (home-based, community, facility care, acute care), and coordinated provision and collaboration across various care roles (prevention, rehabilitation, palliative care, acute care), spanning all levels of intensity of care and providing care in a timely manner.

Integrated long-term care entails integration of both health and social services along the whole spectrum from information systems to care delivery, so that long-term care can be provided and received in a non-fragmented way.

Ultimately, to achieve an integrated continuum of long-term care, services should:

- be person centred and aligned with the person's values and preferences;
- optimize functional ability over time and compensate for loss of intrinsic capacity;
- be provided in the community;
- provide integrated services in a continuum;
- include services that empower the older person;
- emphasize support for carers and care workers.

WHO defines **long-term care systems** as "national systems that ensure integrated long-term care that is appropriate, affordable, accessible and upholds the rights of older people and carers alike".² Long-term care systems do not need to constitute a new and

¹ World Health Organization: World report on ageing and health, 2015.

² World Health Organization: Towards long-term care systems in sub-Saharan Africa, 2017.

separate system but can, and ideally should, be built within the existing workforce, health and social care systems of each country, as long as they contribute to optimizing the physical and mental capacities and functional abilities of their users.

The characteristics of long-term care systems vary markedly among, and even within, countries to accommodate differences in cultural, political, epidemiological and socioeconomic profiles. At one end of the continuum there are countries with no or very little in the way of a long-term system, leaving long-term activities (almost) entirely to families, without any additional support or guidance. At the other end, there are some countries with well developed formal care systems. However, despite differences in characteristics, specific standards and principles underlying long-term care must be universal across systems.

It is urgent that long-term care systems at national and subnational levels be prepared to address chronic and complex needs related to functional ability and underlying diseases that are more common among older people, alongside the acute health issues, by ensuring affordable access to integrated long-term care services across the continuum of care and throughout the lifespan. The scarcity of resources demands more than ever that countries review their existing health and social care systems, that they identify gaps in structuring integrated and person-centred care services requiring better allocation of resources, and that they consider setting up specific long-term care services that are not being sufficiently provided by existing formal services, but that are needed for older people with significantly reduced intrinsic capacity.

As we embark on the United Nations Decade of Healthy Ageing 2021–2030, WHO's role will be to support countries in establishing sustainable and equitable long-term care systems and providing technical advice to achieve provision of long-term care to meet the needs of older people. Through this document, WHO aims to provide guidance by highlighting key components of long-term care systems so that countries are supported in their journey to establish sustainable and equitable long-term care provision.

Framework for countries to achieve an integrated continuum of long-term care

The framework for countries to achieve an integrated continuum of long-term care identifies key aspects necessary to achieve an integrated continuum of long-term care service provision and to facilitate the integration of long-term services within existing health and social care systems.

Considering this huge diversity there is no single system of long-term care that can be applied in every setting, not even in countries with similar resource constraints. However, every long-term care system around the world should consider the following key principles to establish provision of an integrated continuum of long-term care services in countries.

- National governments together with local governments must take overall responsibility for the stewardship of long-term care systems.
- Long-term care provision should build on existing health and social care systems and, most importantly, mainstream long-term care through primary health care.
- Long-term care must be affordable and accessible and should particularly ensure access to services by disadvantaged people.
- Long-term care must uphold the human rights of older people (and their carers) to enhance their dignity and enable their self-expression and, where possible, their ability to make choices, while also taking account of the rights and needs of the long-term care workforce.
- Long-term care must be oriented around the needs of the older person (person centred), rather than the structure of the service, and must be provided in a non-fragmented way and in a continuum with other services.

The framework will guide countries in assessing system-level components to implement sustainable and equitable long-term care actions. By applying this framework, countries can begin to develop and shape their long-term care systems as part of their universal health coverage programmes and promote investment in long-term care and the health workforce, including carers. The framework will further:

- promote a global common understanding of long-term care, given the need for a shared understanding of long-term care in terms of its definition, package of services, and key elements that countries should envision to strengthen long-term care systems sustainably and equitably,

regardless of country differences in income or cultural, social, institutional and political contexts;

- facilitate assessment of existing long-term care systems and services by identifying gaps in organizational elements, service provision, quality standards, and implementation strategies, and by anticipating the need for integration across health and social systems;
- offer guidance to countries on the key system elements that should be considered to develop and strengthen long-term care actions in accordance with the objectives expressed in the WHO Global Strategy and Action Plan on Ageing and Health, the United Nations Decade of Healthy Ageing (2021-2030), and the Sustainable Development Goals;
- facilitate the integration of long-term care actions within existing health and social care systems.

The framework document will also present the challenges faced by countries and guide countries in identifying opportunities and realizing the goals throughout the Decade of Healthy Ageing (2021-2030) and beyond.

How to use this document

The document is primarily intended to be used by governments and policy-makers, both national and subnational, to assist countries in fulfilling their goal of establishing effective and sustainable long-term care provision (care workers and carers). In addition, many of the actions are relevant for other stakeholders at the country level, such as nongovernmental organizations, the private sector, health care providers and development partners. Those in academic institutions may also find this document useful for identifying areas requiring further research.

This document should be used with the accompanying checklist (Annex 1), which will help countries to visit their existing systems, identify potential gaps, and ultimately help in planning for next steps. The checklist should be used as a general reference tool for assessing the country long-term care situation at macro and meso levels in conjunction with other more in-depth harmonized normative products on long-term care. The checklist can be adapted to national and local contexts by taking account of a country's policies, guidance, local risks, requirements, standards and practices. The checklist can be used periodically to monitor the progress of a country's readiness to provide an integrated continuum of long-term care services.

Key elements of the framework for countries to achieve an integrated continuum of long-term care

The framework depicts each element important to establishing a long-term care system, namely (a) governance; (b) sustainable financing; (c) information, monitoring and evaluation systems; (d) workforce; (e) service delivery; and (f) innovation and research, and actions that can be taken to guide national planning processes and decision-making for the implementation of long-term care.

The sections elaborate on the importance of each element and recommend actions, without intending to provide a "one-size-fits-all" approach. For each element, a country example is provided to illustrate how it can work in practice. At the end, a checklist is given with key aspects to consider for each element so that countries can assess their current state of development and implementation of an integrated continuum of long-term care by rating each aspect as "not available", "partially functional", or "fully functional". By doing so, countries can have an overview of the current state of their long-term care systems, identify current gaps and strengths, and elaborate strategies to advance their long-term care provision to leave no one behind.

1. Introduction

1.1 Background

Longevity is an important human achievement, with people today living twice as many years as those born in 1900. Yet, good health in older age is not distributed equally either between or within populations, resulting in huge disparities in how ageing is experienced globally (1).

Currently, there is an average difference of 31 years of healthy life expectancy at birth and 11 years for healthy life expectancy at 60 years of age between countries. Such differences underline that health across the life course is influenced by the impact of various social and economic determinants that accumulates as people grow older (1). The impact of such determinants is particularly evident in some groups – for example, compared to men and people from white ethnic groups, older women and older people from other ethnicities present significantly poorer health outcomes due to lifelong exposure to inequities (2–4).

Additionally, for many, the increase in life expectancy seen globally has not meant more years of life with good health – in some locations, a large proportion of those additional years are spent in poor health (5). Some people at the oldest ages (90+ years) have the same functional ability (health-related attributes that enable people to be and to do what they have reason to value) as those at younger ages (60–64 years), whereas others of the same age group can experience severe losses in physical and mental capacities (1).

Approximately two thirds of people who achieve old age will probably need care and support from others to perform activities of daily living, such as feeding, moving around and bathing, at least at some point in their longevity pathway (6). Many health and social care systems are currently struggling, and to a certain extent failing, to meet the care and support needs of older people. There are at least 142 million older persons worldwide (14% of the global older population living in 42 countries) who are unable to meet their needs – to dress themselves, to get and take their own medication, or to manage their own money, bills or finances (1).

Long-term care is essential to ensure that older people with limited functional ability can still enjoy healthy ageing. It is therefore urgent that long-term care systems at national and subnational levels are

prepared to address chronic and complex needs related to functional ability that are more common among older people, alongside the acute health issues, by ensuring affordable and equitable access to an integrated continuum of long-term care. The scarcity of resources demands more than ever that countries review their existing health and social care systems, that they identify gaps in structuring integrated and person-centred care services requiring better allocation of resources, and that they consider setting up specific long-term care services that are not being sufficiently provided by existing formal services, but that are needed for older people with significantly reduced functional ability.

Long-term care includes activities “to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity” (6). Long-term care may be continuous or intermittent but should be delivered for sustained periods to individuals who have demonstrated needs, usually related to aspects of functional ability.

Long-term care forms a central part of the global agenda and the World Health Organization (WHO) response to population ageing in the Global Strategy and Action Plan on Ageing and Health (7) adopted by the World Health Assembly in May 2016. The United Nations (UN) Decade of Healthy Ageing (2021–2030) adopted by the UN General Assembly in December 2020 also has, as one of its core actions, the provision of long-term care for older people who need it (8). It emphasizes that even though long-term care is not just for older people and includes a diverse range of users, the fundamentals are the same: providing services to those that are in need of long-term care in order to ensure a life consistent with their basic rights, fundamental freedoms and human dignity (9). Additionally, the UN System-wide Plan of Action for the Third UN Decade for the Eradication of Poverty (2018–2027) has also specified the importance of providing long-term care through integrated social care systems along the life course to meet the needs of older persons (10), once again recognizing the importance of achieving sustainable long-term care.

1.1.1 Envisioning long-term care through universal health coverage

To achieve healthy ageing, the Global Strategy and Action Plan on Ageing and Health (7) and the Decade of Healthy Ageing (2021–2030) outline the role of health systems in optimizing physical and mental capacity and the importance of integrating long-term care services in the context of universal health coverage. Universal health coverage means that all individuals and communities receive the health services they need, including the full spectrum of essential, quality health services, without suffering financial hardship. Considering that long-term care encompasses both social support and traditional health services, it will be impossible to achieve sustainable and equitable long-term care without universal health coverage. Furthermore, it will be impossible to attain the vision of universal health coverage without considering the long-term care needs of the ever-increasing number of older people with significant declines in physical and mental capacity (11).

It is recognized that there can be variability in how each country provides long-term care services, some of which may or may not be provided by existing health care systems and delivered through other forms of universal coverage. Regardless of how countries attain sustainability, long-term care costs must not be a cause of impoverishment through catastrophic expenditure by service users and families.

1.1.2 Learning from the COVID-19 pandemic

Despite the difficulties faced during the pandemic, the global crisis has provided many lessons and a window of political opportunity for long-term care. The pandemic has prompted countries to urgently examine the need to transform health and social care systems so that long-term care services are readily integrated and provided alongside the traditional continuum of care (9).

Globally, the COVID-19 pandemic has exposed the fragmentation of long-term care services within existing systems of health and social care, along with inherent weaknesses in the current overarching governance structure for long-term care, including lack of legislation, poorly qualified and low-paid staff, and inadequate national strategies and frameworks for long-term care. Around the world, but particularly in low- and middle-income countries, long-term care facilities represent a diverse sector that operates without proper regulation, which contributes to the poor quality of care provided to residents (12).

Sectoral informality, with poor and unreliable information about long-term care facilities and the lack of a national registry database, has delayed coordinated governmental responses to control virus transmission and avoid deaths, particularly in low- and middle-income countries. The pandemic has highlighted the need for strengthening relationships between different levels of government involved in social care and health care and developing concrete vertical and intersectoral coordination mechanisms (9).

The global crisis has reinforced the importance of identifying mechanisms to ensure quality services in both the regulated and the unregulated long-term care sectors and to strengthen accreditation to ensure health sector oversight of long-term care facilities in order to prepare for future pandemics and guarantee human rights (9).

1.2 Objectives of this document

As we embark on the United Nations Decade of Healthy Ageing, WHO's role will be to support countries in establishing sustainable and equitable long-term care systems and providing technical advice to achieve provision of long-term care to meet the needs of older people.

The framework for countries to achieve an integrated continuum of long-term care will guide countries in assessing system-level components and implementing a sustainable and equitable integrated continuum of long-term care. By applying this framework, countries can begin to develop and shape their long-term care systems and promote investment in long-term care. The framework will further:

- promote a global common understanding of long-term care, given the need for a shared understanding of long-term care in terms of its definition, package of services, and key elements that countries should envision to strengthen long-term care systems sustainably and equitably, regardless of country differences in income or cultural, social, institutional and political contexts;
- facilitate assessment of existing long-term care systems and services by identifying gaps in organizational elements, service provision, quality standards, and implementation strategies, and by anticipating the need for integration across health and social systems;
- offer guidance to countries on the key system elements that should be considered to develop and strengthen long-term care actions in accordance with the objectives expressed in the WHO Global Strategy and Action Plan on

Ageing and Health, the United Nations Decade of Healthy Ageing 2021–2030, and the Sustainable Development Goals;

- facilitate the integration of long-term care actions within existing health and social care systems.

Regarding the last aim, all countries have some form of long-term care that is implemented and provided for publicly, privately or individually by families and friends. These existing services and activities should, as much as possible, be integrated into existing health and social care systems to be delivered efficiently, equitably, sustainably and in a person-centred manner, from the home to residential care. This framework will help to facilitate the effective provision of long-term care activities through existing platforms that countries have, without the need to reinvent a whole new system.

The framework document will also present the challenges faced by countries and guide countries in identifying opportunities and realizing the goals throughout the United Nations Decade of Healthy Ageing (2021–2030) and beyond.

1.3 Target audience for this document

Governments and policy-makers, both national and subnational, are the key audience. In addition, many of the actions are relevant for other stakeholders at the country level, such as nongovernmental organizations, the private sector, health care providers and development partners. Those in academic institutions may also find this document useful for identifying areas requiring further research.

1.4 How to use this document

The document is primarily intended to assist countries in fulfilling their goal of establishing an equitable and sustainable integrated continuum of long-term care. This document should be used with the accompanied checklist (Annex 1), which will help countries in visiting their existing systems and identifying potential gaps, and will ultimately help in planning for the next steps.

The checklist should be used as a general reference tool for assessing the country long-term care situation at a macro level in conjunction with other more in-depth harmonized normative products on long-term care development by WHO. The checklist should be adapted to national and local contexts by taking account of a country's policies, guidance, local risks, requirements, standards and practices. The checklist can be used periodically to monitor the progress of a country's preparedness to deliver an integrated continuum of long-term care services.

2. Healthy ageing and long-term care

2.1 What is healthy ageing?

In 2015, WHO articulated **healthy ageing** as being “the process of developing and maintaining the functional ability that enables well-being in older age” (6). **Functional ability** is key to healthy ageing and is defined as the “health-related attributes that enable people to be and to do what they have reason to value” (6). It comprises the abilities of older people to (a) be mobile and move around; (b) build and maintain relationships; (c) meet their own basic needs; (d) learn, grow and make decisions; and (e) contribute to society (Figure 1) (6).

Healthy ageing does not mean staying free from disease, chronic conditions, multimorbidity or frailty, but the optimization of people’s mental and physical capacity and functional ability during the life course to enable them to live a life with well-being, meaning and dignity. It reflects the ongoing interaction between the person and the environment they inhabit, which results in trajectories of both intrinsic capacity and functional ability (Figure 2).

Figure 1. Domains of functional ability

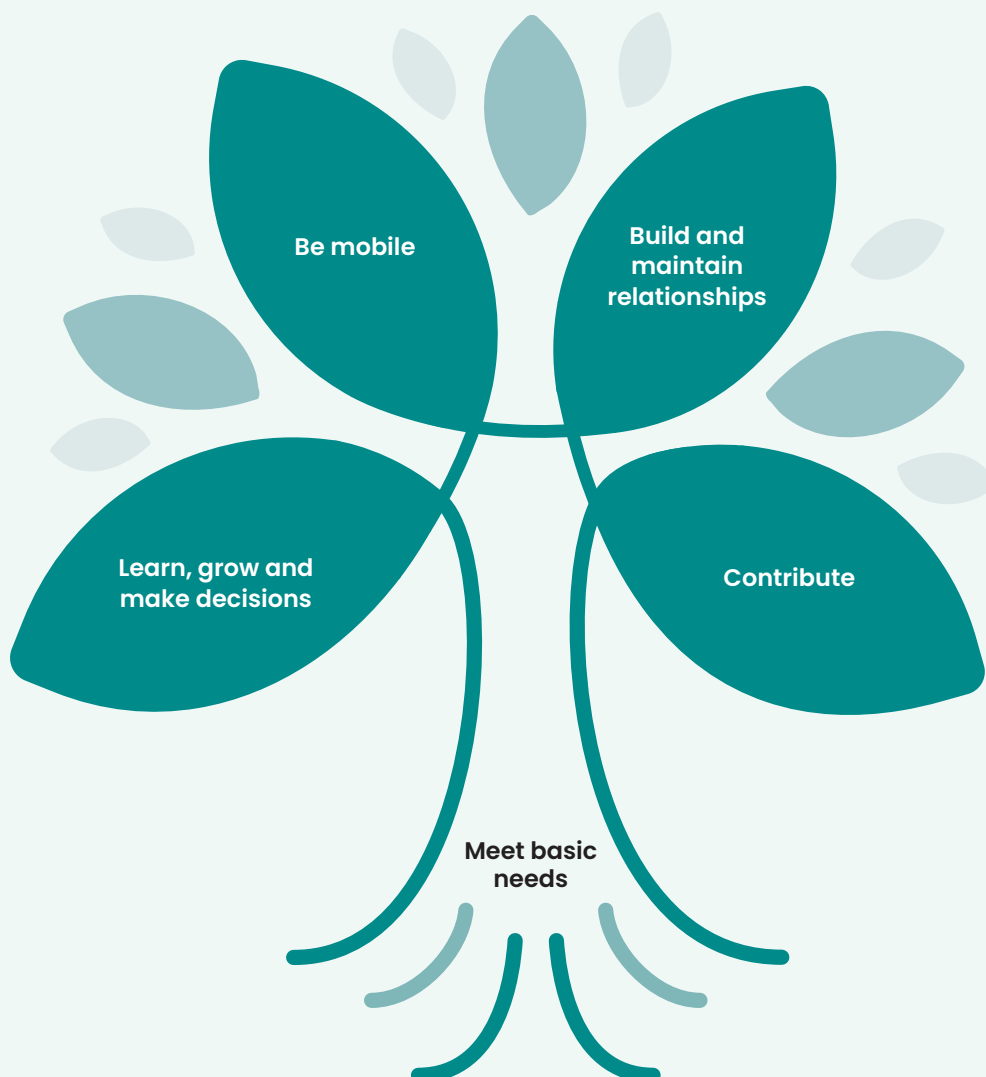
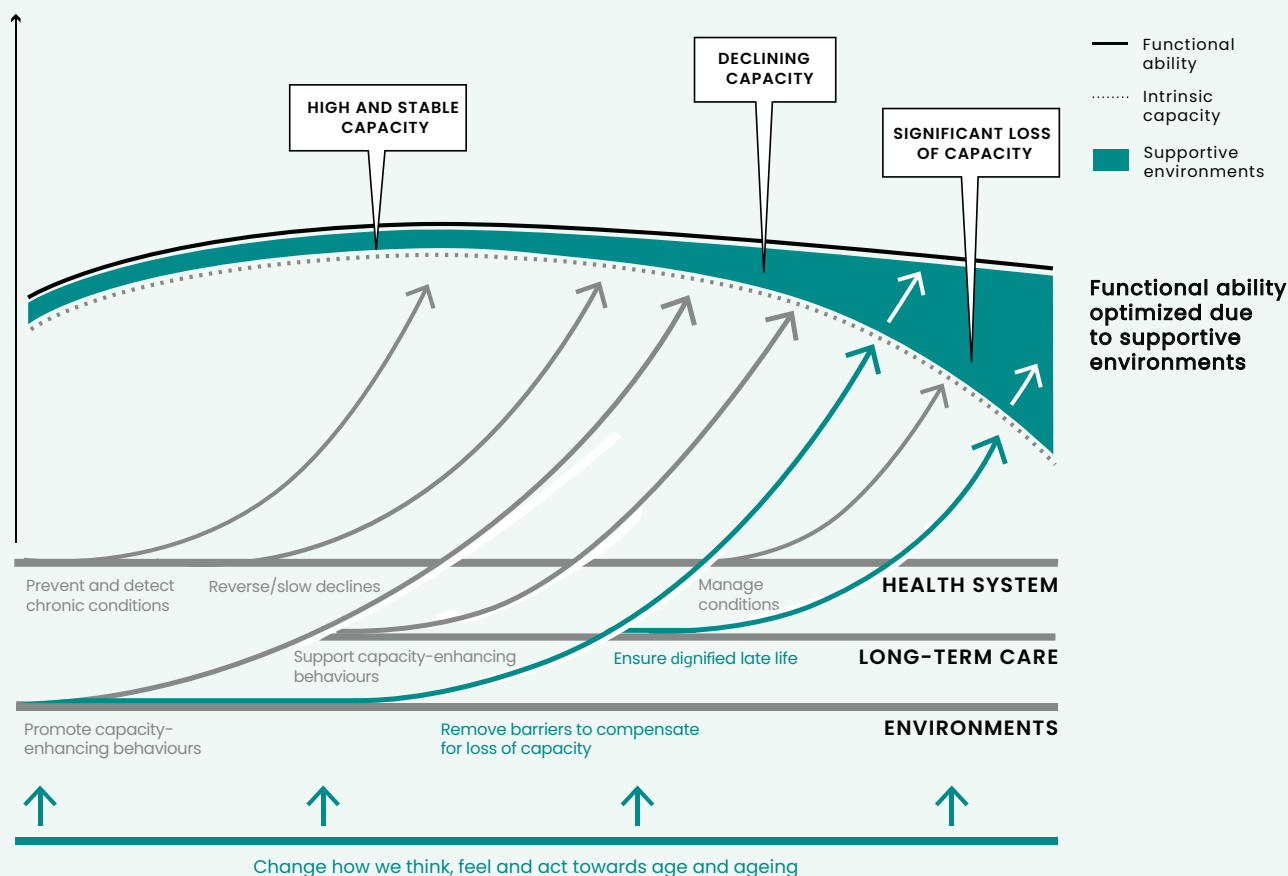


Figure 2. Public health framework for healthy ageing



Intrinsic capacity is “the composite of all the physical and mental capacities of an individual”. The **environment** comprises “all the factors in the extrinsic world that form the context of an individual’s life. These include – from the micro level to the macro level – home, communities, and broader society,” “including the built environment, people and their relationships, attitudes and values, health and social policies, the systems that support them, and the services that they implement” (6).

Figure 2 shows how intrinsic capacity and functional ability can vary in a continuum across the second half of the life course. Preventing and compensating for permanent or transient losses of intrinsic capacity are key to maintaining functional ability over time. Overall, these trajectories can be divided into three common periods: a period of relatively high and stable mental and physical capacity, a period of declining capacity, and a period of significant loss of capacity. These periods are not defined by chronological age, are not necessarily continually decreasing, will differ markedly among individuals, and not all people will go through the three trajectories during their lives.

Therefore, optimizing functional ability to achieve healthy ageing should be a goal for everyone

regardless of their current state of health. Whatever the spectrum of functional ability (Figure 2), WHO envisions healthy ageing as achievement of meaningful living even in the presence of significant declines in physical and mental capacity.

2.2 Long-term care definition and scope

2.2.1 What is long-term care?

For almost all people, a time in life will come when their capacity to do the things they need or wish to do has declined significantly and actions such as the provision of assistive care may be required to ensure a meaningful life. There also may be environmental factors that will impede meaningful activities despite the existence of adequate capacity. Individuals with significantly reduced capacity will therefore need day-to-day help with activities such as washing and dressing or help with household activities such as cleaning and cooking. This care and support to maintain functional ability is the core of long-term care.

Long-term care includes activities “to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity” (6). Long-term care should address the health, personal care and social needs of individuals; it may be continuous or intermittent but should be delivered for sustained periods to individuals who have demonstrated needs related to functional ability.

The need for long-term care can arise suddenly, as a consequence of an acute problem potentially determining chronic sequelae (such as a heart attack, stroke or hip fracture), or it can develop gradually as a consequence of a progressive and chronic condition (such as dementia or frailty). Fluctuations of functional ability are multidirectional, meaning that there is not a single path for everyone or the same trajectory of functional ability within one person’s ageing trajectory. Assistive care components of long-term care (assistance provided to help a person perform a particular task to optimize functional ability and promote independence), for example, may be short-term services that can optimize functional ability in situations in which function could potentially be restored, or may be provided long term for those experiencing impaired functional ability that is less amenable to rehabilitation.

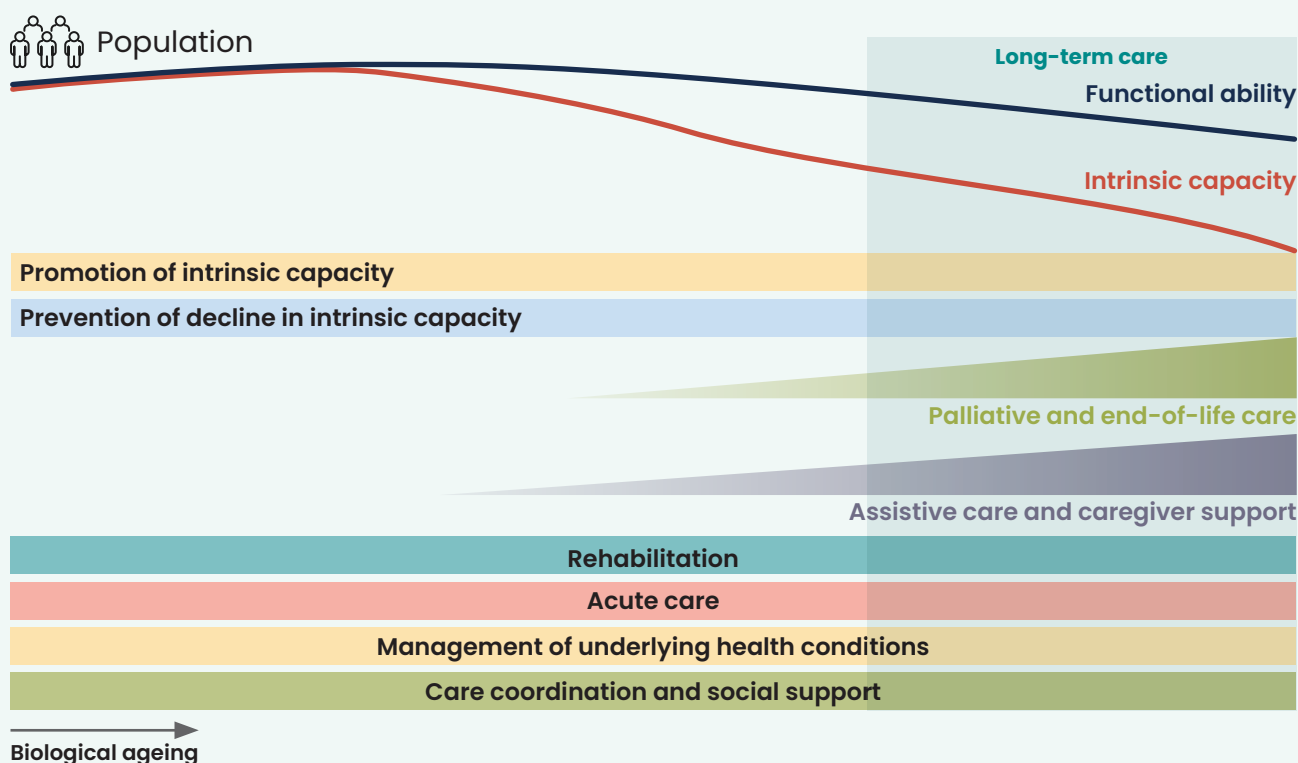
People therefore follow different paths of long-term care needs, reflecting differences in their health and functional status, variations in individual and family preferences and values, economic circumstances and geographical location. In combination, these factors shape both the options and the resources available to people needing long-term care and how they understand and evaluate their choices. Long-term care can help stabilize or delay progression of chronic conditions whenever possible, as well as prevent acute ones, and identify and treat them rapidly when they occur, helping promote functional ability and well-being.

2.2.2 What is the goal of long-term care?

The goal of long-term care is to ensure that an individual who has significant declines in physical or mental capacity can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity. The goal of long-term care also includes the provision of comfort and well-being for individuals at the end of life and for their families. To achieve these goals and attain the vision of an integrated continuum of long-term care, services should uphold the following values.

- **Be person centred and aligned with the person’s values and preferences.** Long-term care activities should be adapted and tailored to the level of capacity of each individual and their values and preferences in a person-centred manner, providing older people or their trusted person (for example, in cases of severe cognitive impairment that prevents independent decision-making) with the education and support they need to make informed decisions in relation to their care. Older people and their carers have the right to and deserve the freedom to realize their continuing aspirations to well-being, meaning and dignity, and a good life, even in the event of significant loss in intrinsic capacity or the risk of such a loss. The values and preferences of the people who are involved in care provision (such as carers) also need to be considered (13).
- **Optimize functional ability over time and compensate for loss of intrinsic capacity.** Along with addressing older people’s physical and basic needs (such as nutrition and hygiene), long-term care systems should promote their ability to move around, build and maintain relationships, learn, grow, decide, and contribute to their communities as much as possible. Long-term care should aim to keep the trajectories of people’s intrinsic capacity and functional ability as optimal as possible over time, optimizing and rehabilitating temporary functional loss, as well as compensating for permanent losses, in order to achieve healthy ageing (1).
- **Be provided in the community.** Older people and their carers value services and interventions that have the potential to enhance their daily lives and provide practical solutions to allow older people to age in their preferred place of living, whilst participating in and contributing to their families and to their community for as long as possible.
- **Provide integrated services in a continuum.** Formal long-term care involves a package of services that include aspects of prevention, promotion, treatment, rehabilitation, palliation, assistive care and social support to varying degrees, depending on the needs of the individual. To maximize the mental and physical capacities and functional ability of older people and to support their carers, these service components should be delivered seamlessly in a continuum and integrated into service packages to effectively respond to changes in the functional ability of older people (Figure 3).
- **Include services that empower the older person.** Long-term care should empower and enable persons to do as much as possible themselves, rather than replace their existing or potential ability

Figure 3. Public health service composition of implementing integrated care for healthy ageing



with a social service that may ultimately decrease their function and increase care dependency (6).

- **Emphasize support for carers and care workers.** Such support should ensure they do not endure the negative impact of caring on their physical, emotional, social and financial well-being.

Long-term care upholds the basic approach provided by the integrated care for older people (ICOPE) implementation framework, which is applicable throughout long-term care (14) (Figure 3).

2.2.3 Where is long-term care delivered? Achieving ageing in place

Long-term care can be delivered in several settings, including the older person's own home, community centres, hospitals or long-term care facilities (6). Population surveys from the United States of America, for example, indicate that about 90% of older people intend to remain in their current homes for the next five to 10 years (15). With the provision of effective services in homes and community centres, older people can be empowered to age in the most adequate and preferred place.

Ageing in place is the "ability to live in one's own home and community safely, independently and comfortably, regardless of age, income or level of capacity. Ageing in the right place extends this concept to the ability to live in the place with the

closest fit with the person's need and preferences – which may or may not be one's own home" (6).

Everyone has their own reasons for wanting to spend their remaining years in a familiar environment. Although decisions should be made on a case-by-case assessment to avoid emphasis on "one-size-fits-all" solutions, older people must have the right to age in the residence of their choice. Staying at one's home can help maintain a sense of connection, security and familiarity, as well as a sense of identity (6). However, staying in one's own home may result in feelings of isolation, or may place the older person at greater risk of frailty and disability due to unmet needs, as may happen in the case of people living in unsafe or unsupportive neighbourhoods. Declines in capacity can be addressed through various adaptations that ensure safety and well-being, more targeted services, or in some cases relocation to a residence with more services on a continuous basis to meet their needs.

To accommodate those who choose to live in long-term care facilities, workers in these settings should fully provide person-centred and integrated services of diverse levels of complexity so as to facilitate care transitions and prevent unnecessary hospitalizations. Regardless of the available options, older people (or their most trusted person in cases of lack of capacity to decide independently) should always have a voice in the decisions related to their care and living arrangements so as to protect their agency, dignity and autonomy, and to avoid abuse and discrimination.

3. Towards an integrated long-term care system

3.1 What is a long-term care system?

WHO defines **long-term care systems** as “national systems that ensure integrated long-term care that is appropriate, affordable, accessible and upholds the rights of older people and carers alike” (16).

Long-term care systems do not need to constitute a new and separate system but can, and ideally should, be built within the existing care workforce, health systems and social care systems of each country, as long as they contribute to optimizing the physical and mental capacities and abilities of their users.

Integration in long-term care means seamless integration of both health and social systems, from governance to information systems and care delivery, so that long-term care can be provided and received in a non-fragmented way.

A continuum in long-term care emphasizes a continuum of care that is inclusive of prevention, promotion, curative, rehabilitative, palliative and assistive care, and social support. It also highlights the importance of coordination across health and social sectors, a seamless transition across settings (home-based, community day care centre, residential facility care), and harmonized management across various care roles (for example, health and care workers, caregivers and family), spanning all levels of intensity of care and providing care in a timely manner.

A long-term care system – which can mirror the health system – consists of all organizations, people and actions whose primary intent is to promote, restore or maintain the health or abilities of those who have significant limitations in functional ability and need care, or are at risk of needing care (16). This includes efforts to influence the determinants of health of people in need of long-term care, as well as their carers. A long-term care system is, therefore, more than publicly owned facilities that provide long-term care. It includes, for example, a carer providing assistance to an older mother who cannot perform independently basic activities of daily living such as feeding, dressing and grooming, as well as private providers, behaviour change programmes, health insurance and social care (16).

3.2 How can a long-term care system be established?

Many services that are relevant to long-term care are already being delivered in countries through their wider health and social care systems, such as home visits by primary health care teams, carer training and support, provision of assistive products and palliative care services. Rather than creating new systems, efforts should be made to transform the existing models of care that are disease focused to include a wider narrative that takes into consideration aspects of functional ability and is centred around a person’s needs.

To establish a long-term care system, countries will need to identify such existing services and ensure they are provided in a timely, person-centred, integrated, affordable and equitable manner. New types of long-term services should be created and expanded according to national and local contexts and projections. There should be continuous investment in building the capacity of care workers and carers (Box 1), and quality assurance mechanisms for long-term care services should be implemented not only to

Box 1. Definitions of long-term care workforce

Carers or caregivers (for example, informal caregivers, informal carers): individuals who provide care for a member or members of their family, friends or community. They may provide regular, occasional or routine care or be involved in organizing care delivered by others. Carers and caregivers are distinct from providers with a formal service delivery system, and most often provide unpaid care.

Care workers (for example, professional, formal caregivers and carers, social workers and nurses): care providers associated with formal service delivery systems of long-term care.

(See glossary for these and other definitions.)

ensure quality, but also to prevent negative outcomes such as abuse of or discrimination against older people. The sustainability of such a system can be ensured via governance, legislation and financing systems, all of which should be informed by robust data that are disaggregated (for example by region, sex and age group), and strengthened by transparent accountability measures and public participation.

The characteristics of long-term care systems vary markedly among, and even within, countries to accommodate differences in cultural, political, epidemiological, resource and socioeconomic profiles. At one end of the continuum there are countries with no or very little in the way of a long-term system, leaving long-term activities (almost) entirely to families, without any additional support or guidance. At the other end, there are some countries with well developed formal care systems. However, despite differences in characteristics, specific standards and principles underlying long-term care must be universal across systems.

Systems with a higher level of development include a wide variety of health and social care services, with the contribution of other sectors such as transportation and education. Formal services may include home-, community- and facility-based care for older people with loss of capacity, but also training of and support for carers (such as respite care). Most importantly, in such developed long-term care systems, activities are oriented to the needs of the older person, rather than to the needs of the services, to enable integrated care and support.

Care may be provided by some combination of family, civil society, the private sector and the public sector. However, governments should take overall responsibility and the coordinating role for mobilizing resources and ensuring the proper functioning of the system (16–18). It is imperative that countries move towards public long-term care financing systems to mandate universal coverage; ensure entitlement (as is the case for medical care) and equitable access; and reduce the stigma associated with the negative consequences of means-tested long-term care support (19).

Considering this huge diversity there is no single system of long-term care that can be applied in every setting, not even in countries with similar resource constraints. However, every long-term care system around the world should consider the following key principles in order to achieve an integrated continuum of long-term care services in countries.

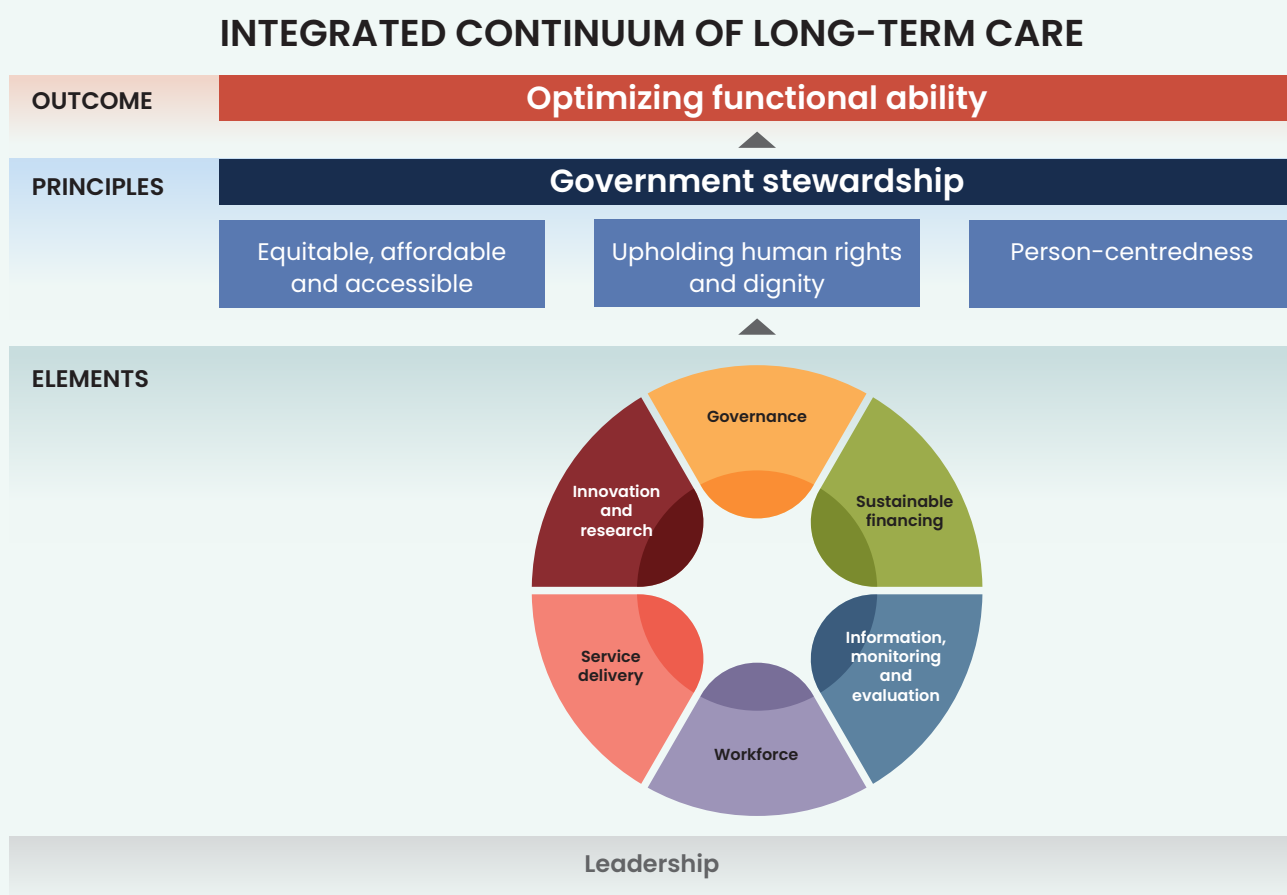
- National governments together with local governments must take overall responsibility for the stewardship of long-term care systems (6).
- Long-term care provision should build on existing health and social care systems and, most importantly, mainstream long-term care through primary health care. In countries with more developed health systems, long-term care could make use of the existing health system infrastructure as a basis for strategies and synergies to establish sustainable and equitable long-term care provision; whereas in countries with more limited health systems, the focus could be on mainstreaming long-term care into primary health care provision as part of a wider reorientation of primary health care to noncommunicable diseases. A key resource for building long-term care policies is leveraging existing experiences, particularly in low- and middle-income countries (20).
- Long-term care must be affordable and accessible and should particularly ensure access to services by disadvantaged people.
- Long-term care must uphold the human rights of older people (and their carers) to enhance their dignity and enable their self-expression and, where possible, their ability to make choices, while also taking account of the rights and needs of the long-term care workforce.
- Long-term care must be oriented around the needs of the older person (person centred), rather than the structure of the service, and must be provided in a non-fragmented way and in a continuum with other services.

4. Framework for countries to achieve an integrated continuum of long-term care

The framework for countries to achieve an integrated continuum of long-term care (Figure 4) highlights six key system elements necessary to achieve an integrated continuum of long-term care and to facilitate the integration of long-term services within existing health and social care systems (17, 18). These are (a) governance; (b) sustainable financing; (c) information, monitoring and evaluation; (d) workforce; (e) service delivery; and (f) innovation and research. It also shows the actions that can guide national planning processes and decision-making for the implementation of long-term care.

It is recognized that elements and actions will have different significance in countries with different levels of social or economic development, degrees of long-term care orientation and health system development. The actions hereafter described are intended to be applicable to a wide range of countries, not all of which will be appropriate or should be prioritized in every country. It is suggested that actions are taken in the context of country needs to accelerate efforts to improve long-term care.

Figure 4. Integrated continuum of long-term care framework



Element 1. Governance

Governance refers to “ensuring that strategic policy frameworks exist and are combined with effective oversight, coalition building, regulation, attention to system design and accountability” (20). Governance of a long-term care system involves multiple sectors, different ministries, and various government levels, making effective coordination very important.

Long-term care systems consist of a mixture of public, private for-profit and private not-for-profit service providers, making accountability and regulation difficult. Due to such nuances, public health officials may have the negative perception that long-term care is a complex vortex that requires indefinite resources and investment, resulting in lack of prioritization and greater governance challenges compared to other systems. However, it must be recognized that these complexities are not just faced by long-term care systems, but are aspects encountered throughout health systems, especially as those systems mature. As is the case with medical care, beginning with a designated government entity that coordinates the various multisectoral stakeholders is a first step to simplify these wrongly held notions of the comparative complexity of long-term care.

In most low- and middle-income countries, governments have focused on delivering public sector services rather than embracing the broader vision of governance that integrates public and private sectors (21, 22). Some countries have private sectors as primary providers of long-term care services, whereas in others unpaid care forms much of the workforce. Governments must transform governance for long-term care so that it is inclusive of delivery of public and private services.

For strong governance, governments must take into consideration and engage the full range of actors, including not only those directly involved in the health and social care sector but also those sectors that are indirectly involved but still require guidance, such as infrastructure and transportation. This will help ensure seamless delivery of services as well as accessibility and micro-level integration of health and social care services.

Beginning with a designated government entity that coordinates the various multisectoral stakeholders is a first step.

Another important dimension in improving governance is recognizing the increasing importance of communities. For long-term care systems to be more responsive, the pivotal role of communities must be recognized and strengthened to enable early recognition of local concerns and effective advocacy for emerging needs. Community engagement in the governance structure of long-term care may facilitate more agile and flexible responses and enhance accountability, resulting in more equitable and higher-quality care. This can be achieved by allowing community representatives to adopt formal roles in local governance structures of long-term care coordinating bodies. Such local governance must be embedded in supportive national and subnational long-term care systems.

Governance structure

In most countries, long-term care falls between different ministries, typically called health care and social affairs, development or social care. This division affects the quality of long-term care services as it can lead to fragmentation and complex arrangements for financing, regulation, information systems and management of services. A carefully designed governance plan can help mitigate such risk.

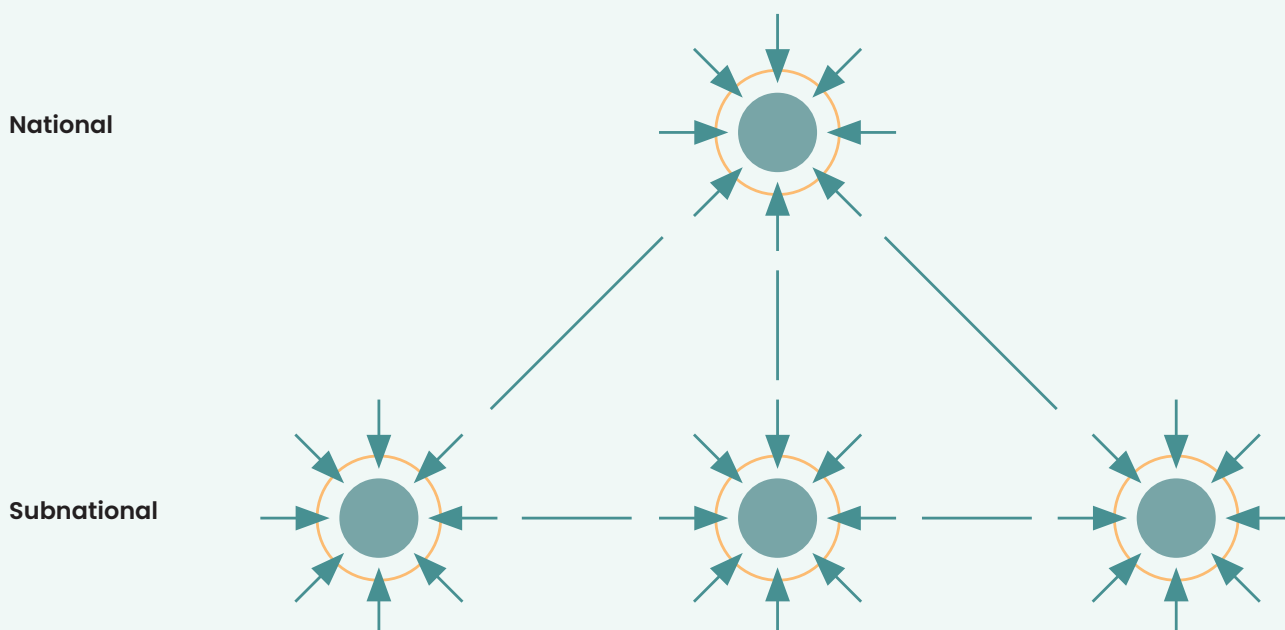
It is important to have a dedicated focal multisectoral coordinating body at the national level and at the subnational level facilitating coordination and communication of long-term care (Figure 5). This is key to ensuring integration among the various relevant sectors and the delivery of coordinated and integrated long-term care. Such a coordinating body will ensure communication between multiple ministries, including non-health-related and social sectors, and will also include nongovernmental organizations and civil society organizations, which play a key role in the delivery of services in many countries (23).

Such a coordinating body would also enhance ease of provision and contribute to quality of care. The governance plan for long-term care systems should include procedures related to decision-making, control of expenditure, accountability (performance monitoring) and structures or pathways within the long-term care system to give overall direction to services and users (23).

Long-term care legislation

Long-term care legislation at the national level is a starting point for formulation of subsequent strategies and roadmaps for long-term care. Legislation will provide the foundation for countries to

Figure 5. Dedicated focal multisectoral coordinating body at national and subnational levels



establish governance structures, secure sustainable financing, build the workforce for long-term care and establish monitoring and surveillance mechanisms through development of indicators for quality of care, performance and minimal standards of care. Such legislation development should consider the views of multiple stakeholders (such as service providers, professional societies and accrediting bodies) and also of older people themselves and their carers. Such legislation should involve not only securing the provision of long-term care delivery for those who need it, but also ensuring the social care, rights and entitlements of older people and carers.

Long-term care strategy

With the establishment of legislation, a dedicated national long-term care plan, strategy or framework accredited by the relevant government entity (focal ministry) or legislative body (such as parliament) will help to ensure the provision of quality, sustainable and equitable long-term services to older people in need. A national strategy or framework would be a written organized set of principles, objectives or actions for reducing the burden attributable to care dependence in a population. These may be stand-alone instruments specifically for long-term care or integrating long-term care provision into other relevant policies, plans, strategies or frameworks

(for example, health care or social welfare policy, ageing policies). Establishing a fully integrated system of long-term care implies the development of policies, strategies, plans or frameworks through a comprehensive multisectoral approach.

Accountability mechanisms

Accountability refers to the obligation to answer to someone or an institution (such as a stakeholder or shareholder) and to demonstrate doing so by meeting agreed-upon objectives (20). Long-term care systems should thus have well defined accountability measures to ensure that all actors in the system are held publicly accountable (24). This requires transparency; performance monitoring of responsible bodies and of services and procedures (for example through impact assessment); active engagement of older people, families, carers, civil society and local service providers in policy and service development; and monitoring of the long-term care performance. Other accountability mechanisms include service accreditation, regulatory approaches (for example, enacting legislation on long-term care or putting in place compliance systems), aligning fiscal accountability measures with performance criteria, and providing regular independent public performance reports (24).

Key aspects to consider for long-term care governance

Box 2 presents the key aspects that should be considered for long-term care governance, while Box 3 presents country examples.

BOX 2. GOVERNANCE: KEY ASPECTS

Key aspects that should be considered for long-term care governance are as follows.

- ✔ Include long-term care within the portfolio of national and regional or municipal governments with the designation of a dedicated focal coordinating body aiming at reaching leadership and engaging community representatives and other relevant stakeholders.
- ✔ Formulate legislation for long-term care that includes a mandate for governance structure, financing mechanism, service provision with a defined target population, and monitoring of quality care and performance.
- ✔ Formulate legislation to ensure protection of rights and entitlements of both older people and carers.
- ✔ Establish an overarching national (and relevant regional) plan, strategy or framework that sets the directions and outcomes to achieve an organized and sustainable long-term care system operationalized at subnational level with a specified target population.
- ✔ Map key stakeholders in the development of policy and strategy for long-term care.
- ✔ Formulate an explicit long-term care policy document developed as a stand-alone national document, usually including a multistage stakeholder process, led or supported by the focal governmental entity dedicated for long-term care.
- ✔ Steer roles of national, regional and municipal government in the assurance, financing, regulation and provision of long-term care services, including the roles of public and private providers and nongovernmental organizations.
- ✔ Establish a detailed action agenda with essential implementation strategies.
- ✔ Create and support a regular decision-making body for integrating all levels of the long-term care sector, including collaboration of health and social workforce organizations, aiming at fostering dialogue and formulating processes, norms, standards and regulations.
- ✔ Define strategies and actions to facilitate leadership, foster collaboration between health and social systems, and enable alliances to promote more integrated models of long-term care.
- ✔ Define how public funds will be allocated and distributed for the implementation of the national or subnational plan in a sustainable manner.
- ✔ Allocate and coordinate budgets across multiple levels of governance to implement an integrated long-term care system.
- ✔ Promote intersectoral collaboration (health and other government sectors, as well as representatives from private, voluntary and non-profit groups) to build on common goals and to allocate resources.
- ✔ Establish mechanisms to review and share progress towards the national long-term care policy goals as defined in the plan or framework.
- ✔ Establish and constantly refine the measures to track and monitor the long-term care national plan to ascertain whether it is implemented as intended and strategies are met.
- ✔ Configure audit activities to measure performance and transparency of responsible bodies.
- ✔ Monitor performance of long-term care services in terms of their effectiveness, efficiency, economy, compliance with laws and regulations, contract requirements, grant requirements, and organizational policies and procedures.
- ✔ Set out labour standards, procedures and regulations for carers and care workers, such as working conditions, wages, working time arrangements, compensation mechanisms and strategies to overcome informality.

- ✔ Promote the recognition of the long-term care workforce and the observance of workplace health and safety standards.
- ✔ Provide an ongoing training programme for carers (whether unpaid or paid) and formulate legislation for training and certification requirements to accredit people's caregiving expertise.
- ✔ Partner with national, subnational and local stakeholders and groups to identify and strengthen mechanisms to engage and empower communities in the processes of governance.
- ✔ Formulate and regulate quality standards for long-term care services, whether provided by public, private or non-profit organizations, by setting minimum quality standards for providers through licensing and certification and carrying out periodic inspections to ensure their compliance and monitor their performance on quality.

BOX 3. GOVERNANCE: COUNTRY EXAMPLES

Germany

The Department of Long-Term Care, as part of the Federal Ministry of Health, is responsible for the governance of long-term care. Many actors are involved in health and long-term care governance, including the federal government, regional and local authorities, and the self-governing associations of service providers. The Long-Term Care Insurance Act and regulations on the support for care as part of social assistance regulations comprise the main legislation regulating long-term care. Local authorities also contribute to long-term care financing by providing social assistance to cover high cost sharing for families that cannot afford these payments from their income, savings or assets. The integrated delivery of long-term care is reinforced through the promotion of neighbourhood development and the allocation of care counselling to municipalities. There is growing interest in enhancing the coordination of health services and long-term care and strengthening the role of local authorities (25).

Denmark

Governance of the health system is highly decentralized. Historically, the Ministry of Social Affairs and the Interior had responsibility for regulating services and support for older people, but since 2015 this has been transferred to the Ministry of Health. This ministry is responsible for regulating, overseeing and planning performance, including supervising care delivery. Through stakeholder participation, the Ministry of Health determines and implements national policies and designs legislation related to the functioning and organization of the health and long-term care systems. The ministry is also in charge of setting the overall financial framework. The five administrative regions of the country determine the funds to be allocated to services, establish collective agreements, and have overall responsibility for providing services. Each region owns the public hospitals and specialized mental health care units within its territory and contracts services directly. Municipalities are responsible for providing and ensuring the quality of social services and certain health services, and also provide long-term care services and purchase services from private providers. Municipalities are autonomous regarding the provision of long-term care, including needs assessment and care pathways (26).

Element 2. Sustainable financing

Financing long-term care services for the growing older population with significant loss of intrinsic capacity can pose many fiscal challenges to countries globally. Carers currently provide the largest bulk of the long-term care for older people, especially in low- and middle-income countries. However, counting on these individuals to meet all the needs of increasing populations is neither fair nor sustainable.

A solid long-term care system is often perceived to be costly. However, long-term care actions can reduce existing public costs through enabling persons (commonly women) who are carers of an older family member to continue to work. A simulation study applied to seven Latin American countries showed that a long-term care system with a relatively generous package of services and with universal coverage for people aged 60 and over would cost governments between 0.5% and 1.0% of gross domestic product (GDP) (27).

Quality long-term care may reduce inappropriate use of acute health services, including lengthy or unnecessary hospital stays, and help families avoid impoverishment through catastrophic health care expenditure. The number of people requiring care and assistance and the proportion of people available to provide this care is increasingly unbalanced. A long-term care system could potentially decrease the financial burden of chronic disease and foster social cohesion and solidarity across generations. Some needs are today informally covered by persons at costs that are hidden; formalizing long-term care would therefore mean structuring, qualifying and organizing (at least some of) these activities in a systemic context, alleviating the burden of carers. Most carers are women and providing unpaid care is a fast-growing form of gender injustice, as it often prevents them from fulfilling other activities (such as work, education or leisure) and has a detrimental impact on their well-being and financial protection.

Despite the global need for and the emphasis on long-term care, the availability of publicly funded long-term care services is low. Some data show that 48% of older persons are not covered by any type of formal provision of services; 46% are excluded from any coverage that does exist by some form of means testing; and only 5.6% of older persons worldwide are covered by national legislation that provides coverage for all (28). The average public expenditure is less than 1% of GDP globally. Such public underfunding jeopardizes access to long-term care for the majority of older people in need, particularly in low- and middle-income countries (6).

For older people and their families, especially older people living in low-resourced settings, a high level of care dependency frequently results in compromising income and assets to meet the costs of long-term services. For countries where formal long-term care services are lacking there is heightened financial burden on families, with higher emergency and inpatient hospital admissions from avoidable causes (such as urinary tract infection, falls or poor management of chronic conditions) and longer hospital stays, increasing unnecessary health costs (29, 30).

A good long-term care financing system is one that raises adequate funds to ensure that people can use the services they need and are protected from financial impoverishment associated with having to pay for them. It also provides incentives for providers and users to be efficient (20, 31).

The sustainability of the long-term care sector depends on having a strong system to finance it, as well as clarity on the population who should be covered by long-term care services in order not to leave anyone behind. Public financing also depends on having strong political and public support for the value of public spending in this area (compared to other areas of public spending). In addition, there needs to be clear and accessible information on the total and stratified expenditures on long-term care in comparison to other social and health care issues, as well as what service is financed and by whom (for example, insurers, individuals or government).

Even though long-term care is a right for those who need it and a duty of governments to ensure it, establishing an efficient long-term care system has economic advantages, especially in low- and middle-income countries where there are high levels of youth unemployment and threats to jobs due to advances in

technology. For example, training younger people to work with and care for older persons can be an economic stimulus and help develop skills of value to other gainful employment. Older persons play a significant role in the economy by providing care to younger grandchildren, allowing the middle generation to work. Providing some support to older persons who require long-term services can allow them to continue to play a role as carers themselves in intergenerational households.

The objective of a strong financing system is to offer long-term care to all individuals who need it without causing them financial hardship.

Additionally, long-term care is one of the most powerful drivers of job creation globally, and initiatives to train human resources and offer home care services are flourishing (32, 33). By modernizing the long-term care sector (for example, by improvement of facilities and wider use of technologies) it should be possible to generate revenue, promote investment in other sectors and expand opportunities for employment. The consequent improvement of long-term care infrastructure will facilitate sustainability and generate the virtuous cycle described in the WHO *World report on ageing and health* (6).

The objective of a strong financing system is to offer long-term care to all individuals who need it without causing them financial hardship. Currently, a large part of long-term care financing is provided in kind by carers. This has fiscal implications, as many carers are not able to contribute to social security and taxes.

Financing mechanism

The financing system for long-term care services can take many forms, such as via public, insurance-based, private or individual funding. There is no single best financing mechanism for long-term care systems, with countries doing it differently across the globe. However, despite their choices, there needs to be a clear and protected source of financing available for budget raising as well as clear measures for spending (covering older people and their carers).

Ideally, a balance should exist between public and private long-term care provision, with financial mechanisms in place to secure a sustainable fiscal source (such as pooled insurance or tax based) secured through legislation and equitable mechanisms of service delivery (21). Countries should aim for very little to be paid out of pocket to ensure everyone can have access to the services they need, of similar quality, and without the risk of impoverishment. Additionally, financing mechanisms should always be structured to support integrated care for older people, including a broad coverage of health and social care services from which older people can choose (31).

Expenditure

To spend well and sufficiently, countries are advised to have a set of desired actions (such as targeting care benefits where needs are the highest), move towards forward-looking financing policies, and facilitate the development of financial instruments to pay for the board and lodging cost of long-term care in residential facilities (34). To extract better value for money, countries should encourage home

and community care, improve productivity in long-term care, encourage healthy ageing and prevention, facilitate appropriate utilization across health and long-term care settings and care coordination, and address institutional efficiency (35–37).

It is also important that countries have a broader but in-depth understanding of their total and stratified domestic expenditure on the range of services available and the means of provision for long-term care, in two ways: (a) how much is spent by each setting – home, community, facility based? and (b) in relation to the country's GDP, how much is spent on the range of services available for people and the means of provision for long-term care in comparison to other health and social care needs?

Incentives for provision of long-term care services

There are several incentives that can encourage providers to extend access to comprehensive long-term care services that have worked well in different countries. For example, governments could establish outcomes-based financing and pay-for-performance systems for both public and private services to ensure quality service delivery. Cash transfers can also help support carers through payments for respite care schemes, and tax discount initiatives could be implemented for employers to grant leave for carers. Such mechanisms can ensure that family members can continue to provide care for older people whilst protecting their own health and well-being. Risk adjustment schemes may provide an opportunity to incentivize insurers to focus their attention on those population groups that would benefit the most from more integrated, person-centred care arrangements, such as those with chronic conditions and vulnerable groups more broadly (13).

Population coverage

Countries need to have a clear picture of their current long-term care provision situation. This can be done by identifying the profile and number of people who might need long-term care services and by establishing equitable and clear eligibility criteria (from clinical to socioeconomic factors). Some countries have a public health care system (free at the point of access) and follow a means-tested approach for assessing financial eligibility for social care access (23). Besides assessing the needs of older persons and their carers, the social system can provide higher public long-term care subsidies to lower-income households, by which only individuals with income or assets below the means-tested level

would be entitled to receive publicly funded social care. However, such a means-tested approach might imply that an individual with long-term care needs would need to deplete their assets before financial support was provided, placing a burden on users and disincentivizing those who need such services. A further disadvantage of this approach is that older people with moderate means might face the risk of extremely high long-term care costs and may end up experiencing deep financial loss (38).

Service coverage

Service coverage should go beyond facility care towards considering the type of services (whether cash benefits, community services in kind, day care or residential care) and their intensity (the amount of care provided per user in a set period of time) (39). The latter should be based on evidence on the efficacy of each type of care and the individual's level of need or functional ability (14, 40). Most importantly,

coverage should always reflect the long-term care needs of older people and their carers.

In countries where public health and social care systems are already in place, governments will need to analyse how much of the funds have been used to provide the existing range of services and decide whether the current situation is ideal or ought to be reassessed to ensure the range of services is available to everyone who needs it. For example, in instances where countries find that only a small percentage of the population is covered by the range and intensity of long-term care services needed or that individuals and families are using out-of-pocket resources to pay for the services they need, adjustments should be made to ensure that no one is left without the care they need in cases where families are no longer able to pay for or provide that care, and that carers do not have to shoulder all the costs of care and risk impoverishment.

Key aspects to consider for long-term care sustainable financing

Box 4 presents the key aspects that should be considered for sustainable financing for long-term care, while Box 5 presents a country example.

BOX 4. SUSTAINABLE FINANCING: KEY ASPECTS

Key aspects that should be considered for sustainable financing for long-term care are as follows.

- ✔ Establish a public long-term care financing system with a defined set of eligibility criteria that is used to determine access to and entitlement for a publicly funded range of services that should be available for people, as well as the responsibilities for long-term care, recognizing that this does not need to be a stand-alone financing system, but a predictable financing system for long-term care that is well integrated with other health and social systems.
- ✔ Ensure that public revenues are allocated and pooled for redistributive purposes to support equitable access to long-term care, and allocate a sustainable budget to fund long-term care and related aspects (for example, long-term care information systems).
- ✔ Establish financing mechanisms to ensure equitable use and universal coverage of long-term care and to support integrated care for older people (for example, outcomes-based financing, pay for performance and bundled payments).
- ✔ Ensure that public financial management systems are based on key local population needs and are able to allocate, distribute, execute and account for funds.
- ✔ Implement mechanisms to ensure that those who are not able to contribute to the social insurance system (such as those not formally employed) are still covered if needed.
- ✔ Set up accurate measurement tools for current expenditure on long-term care as a proportion of other expenditures (for example, total health expenditure or GDP) as part of a national health accounts methodology.
- ✔ Ensure that financing is based on accurate data related to costs (see element 3).
- ✔ Set up measures and subsidies for reducing costs experienced by informal carers (for example, cash allowance, paid leave, respite services or informal care leave).

BOX 5. SUSTAINABLE FINANCING: COUNTRY EXAMPLE

Japan

As a result of the expected shift from traditional family care to social care, the Japanese Government implemented in 2000 the national long-term care insurance (LTCI) system to reduce the financial and labour burden on carers (41). This was informed by the LTCI Act (42). This system aims to meet the care needs of older people and to provide care services suited to each one of seven levels of need: two requiring support (levels 1 and 2) and five requiring long-term care (levels 1–5). The total number of older people certified as requiring one of these care levels was reported to be 5.69 million in 2013 (42), which is twice the number it was at the time the system was implemented in 2000 (43). Because of this, the sustainability of the system has been a major issue.

All Japanese citizens are required to pay for “LTCI premiums” when they reach the age of 40 in addition to the regular health care insurance premiums. The LTCI premiums for people aged 65 and over are determined by the “standard amount” calculated by each municipality and the income status of the person and the household. The standard amount is calculated by dividing the portion of the cost required for long-term care benefits in the municipality that is borne by people aged 65 and over by the number of people aged 65 and over living in the municipality. The higher the income of the older person and household, the higher the payment. When using LTCI services, average citizens must pay 10% of the service fee, and those with high income must pay 20–30%. Welfare recipients are exempt from both nursing care insurance premiums and co-payments when using services.

The LTCI system established a long-term care market. A wide variety of providers, including for-profit providers, have been allowed into the community care marketplace. LTCI service users may contract with the service providers and choose the type and frequency of services they need. There is competition between providers. Since the creation of the LTCI system, the number of older people has consistently increased, the related market has continued to grow, and government payments have increased. Controlling the payments has become a key issue for the government.

Hence, although the original purpose of LTCI was to support older people with physical or cognitive impairment, its focus has been shifting from supporting disabilities to promoting self-management and building community activities to maintain functional ability, which can reduce the use of long-term care services. In the partial revision of the LTCI Act in 2018, with the aim of strengthening the community-based integrated care system, an incentive system was launched aiming to improve the effectiveness of insurers’ efforts. Objective indicators are set to evaluate the achievements of municipal efforts, and the amount of financial grant is determined according to the score of each insurer (that is, the total score calculated from the indicators). The local or municipal government is encouraged to support the insurers, and likewise, the national government formulates the objective indicators for prefectures and distributes financial grants to the prefectures according to their scores. In the first year (2019), 20 billion yen was used for this incentive grant, and the following year the budget was doubled. The budget is expected to increase in the future based on revisions of the indicators and operations.

Element 3. Information, monitoring and evaluation systems

Lack of information on and poor quality of monitoring of long-term care systems usually result from fragmentation in governance and financing (9). Relatively few countries have information about and monitoring of long-term care provision and outcomes, and health and social care data are usually consolidated in separate systems, leading to difficulties in linking data for the same individual. Lack of stratification of long-term care information on individuals or populations reflects the overall situation of limited data sources about older people in general. Furthermore, the lack of overarching information makes the needs of the population who require long-term care invisible, limiting policies only to support of older people in poverty or with disabling conditions (44).

Data generation, systematization and use, and monitoring and evaluation through well functioning information systems that generate reliable data, are important for decision-making and learning at the local, national and global levels. Integrated long-term care information systems (including both the private and public sectors) can help service providers and macro-level decision-makers to monitor and evaluate health progress (of both older people and carers) and review service performance to ensure responsiveness and achieve quality long-term care provision.

Effective assessment and monitoring of long-term care performance should rely on a broad and updated range of data sources, including facility-based information systems, public health surveillance systems and population-based surveys. Long-term care information systems should be integrated with health care systems to ensure person-centred approaches wherever the person is being cared for at any given time, and in a way that covers both people in care facilities and those relying on care in the community.

Integrated long-term care information systems can help service providers and macro-level decision-makers to monitor and evaluate health progress and review service performance to ensure responsiveness and achieve quality long-term care provision.

Facility-based information systems provide real time information about service utilization and coverage, individual care and health outcomes, and are essential for improving service delivery. However, long-term care provision should be strongly cemented in homes and the community. Thus, public health and social surveillance systems that draw from community-based sources play a critical role in community linkages with facilities and home care. The use of population-based surveys will help to better understand broader population needs, level of access to services and options for improving the effectiveness of coverage.

What kinds of data are needed?

Health status and needs

Population-based information. The collection of health-related population-based information helps support adequate provision of care, as well as preparedness for future trends in long-term care needs locally and regionally. Useful data, with examples, include current and projected life expectancy (median age, life expectancy), population growth (fertility rate, migration trends), need for care (need for help with activities of daily living, cognitive impairment), the leading causes of multimorbidity (quality of older people's diet), disability trends (disability-adjusted life-years, leading causes of disability), and levels of well-being (life satisfaction, autonomy).

Health and well-being of older people. The comprehensive assessment of needs should include the regular evaluation of the health status of older people, early detection of intrinsic capacity decline, environmental modifications and provision of assistive products, outcomes from interventions being provided, and the anticipation of future needs (14).

Carers' health and well-being. Assessment should be made of the frequency, intensity and duration of help that is being provided by carers, levels of strain experienced by them, health conditions and needs, social support networks and opportunity for respite (14).

Service coverage

Databases should also include the reported or estimated number of people receiving each type of long-term care in each setting (home, facility, day care, respite care, community centre) and by each financing mechanism (for example, private versus public) in relation to the total number of older people. Measures such as waiting time, user satisfaction (both quantitatively and qualitatively), or use of acute settings for reasons that could be

prevented or resolved in the community (such as falls or dehydration) can help determine how many have access to the type of long-term care services they need and when they need them. Also, registries regarding each type of service provider are important. Some countries still do not have accurate information on the numbers of private and nongovernmental organizations delivering long-term care services.

Risk protection

Risk of unmet needs can be measured by comparing information on coverage, health status and need for care with information on how many individuals are currently using home-based or community services (including day centres) or long-term care facilities (both private and non-private) to determine how many (and who) need care and their level of access to it. Other key variables for risk protection include the socioeconomic status of older people nationally and regionally (including family size and place of residence) stratified by different levels of intrinsic capacity and functional ability; household income status and poverty rates among older people; lifestyle-related risk factors, such as physical activity, smoking and alcohol consumption; and availability of long-term care services, for example number of long-term care strategies developed and implemented, and reported or estimated number of people receiving long-term care services (34, 45). Another important factor is the level of strain and overload experienced by carers, which might impair their capability to provide sufficient care to older people. In this sense, anticipating the impact of burnout on carers' health conditions is critically important for avoiding emergency visits, hospital admissions and unmet needs.

Workforce

It is recommended that countries collect data on the number and demographics of care workers and carers (including headcount, staff ratios, roles, sex, origin). Information on social protection and the well-being of carers should also be considered. There should also be information on the type of health and social care practitioners delivering long-term care services (for example, medical practitioners, nurses, social workers, psychologists, geriatricians,

community health workers, occupational therapists, physiotherapists, gerontologists and community nurses) and working at the service interface (for example, social workers as case managers, nurses as discharge managers) (46). Information should ideally also include number of care workers and carers properly trained and qualified to respond to the clinical and social complexities characterizing older persons in long-term care.

Monitoring

One way to achieve quality care is through systematic monitoring of long-term care outcomes (see element 5 for aspects related to quality assurance). Aspects that could be monitored include effectiveness (for example, improved health and social outcomes); efficiency (for example, reduced waste of resources and maximum benefit); accessibility (not only geographically, but also with regard to other barriers such as cultural and language barriers); responsiveness (care provided in a timely manner, for example short waiting times); patient-centredness (for example, user satisfaction, measures of person-centredness, user involvement in decision-making); safety (for example, reduced rates of preventable adverse outcomes or injuries that stem from the care provided); and equity (people with similar needs have access to services of similar quality regardless of their sociodemographic characteristics).

Long-term care systems should guarantee that information is equally provided and connected to all the knots of the network (not only to hospitals). Besides guaranteeing information continuity, it is also important that long-term care services standardize the collection of integrated administrative, clinical and social data in order to be more reactive when facing emergent and urgent situations such as a pandemic. Additionally, besides collection of quality data, it is important that system monitoring is regularly updated to provide a realistic vision of the situation at hand (at the individual and system levels). One of the issues during the COVID-19 pandemic was a lack of understanding of the situation in long-term care facilities, for example due to absence of data or obsolete information, which hindered appropriate measures being taken to contain the outbreaks, protect health and save lives (47).

Key aspects to consider for long-term care information, monitoring and evaluation systems

Box 6 presents the key aspects that should be considered for long-term care information, monitoring and evaluation systems, while Box 7 presents a country example.

BOX 6. INFORMATION, MONITORING AND EVALUATION SYSTEMS: KEY ASPECTS

Key aspects that should be considered for long-term care information, monitoring and evaluation systems are as follows:

- ✔ Identify current and forecasted life expectancy (for example, median age, life expectancy), population growth (for example, fertility rate, migration trends), and old-age dependency ratio (working age population relative to older people).
- ✔ Survey populations, underlying chronic health conditions and risk factors for the decline and loss of intrinsic capacity and functional ability to estimate and anticipate needs.
- ✔ Monitor and evaluate the levels of care and support needs among older people and carers.
- ✔ Integrate and link long-term care information systems with health information systems to ensure person-centred approaches.
- ✔ Track and monitor long-term care performance based on a broad and updated range of data sources, including facility-based information systems, public health surveillance systems and population-based surveys.
- ✔ Survey socioeconomic status of older people (family size, place of residence, household income status, poverty rates).
- ✔ Survey disability trends (for example, disability-adjusted life-year, leading cause of disability).
- ✔ Set up measures of well-being (for example, life satisfaction, health-related quality of life) and health status of older people and carers.
- ✔ Create integrated minimum data sets (clinical outcomes, integrated service targets, composite quality measures) used routinely to support the sharing of and improve the quality of information between all stakeholders.
- ✔ Determine intersectoral indicators of care distribution, quality and equity (for example, provision of home modifications, transportation and food and nutrition security).
- ✔ Identify the number and geographical distribution of community social centres and number of people using these services.
- ✔ Audit the number of long-term care facilities, their geographical distribution, complexity levels, number of beds and number of care workers per number of beds.
- ✔ Map the number of health practitioners delivering long-term care services (for example, generalist medical practitioners, nurses, social workers, psychologists, geriatricians, physiotherapists, occupational therapists, gerontologists, community nurses and carers).
- ✔ Map the number of practitioners working at the interfaces or transitions of care (for example, medical liaisons, social protection worker care managers, nurse discharge managers).
- ✔ Audit the number and characteristics of older people receiving long-term care and their carers.
- ✔ Formulate measures for quality assessment (such as rates of avoidable hospital admission, service integration, clinical outcomes, user satisfaction, waiting time).

- ✔ Map and generate reports of the characteristics of the services provided (type, private versus public, size, quantity, geographical and quality distribution), including home-based services (outreach programmes, day care services, support services in primary care facilities), community-based centres (day care centres and services, respite care, support services in primary care facilities), and long-term care facilities (nursing homes, assisted living facilities, residential care homes, hospices).
- ✔ Generate detailed data on financing (for example, out-of-pocket expenditures for long-term care, coverage based on eligibility, number of people who are entitled to long-term care who have received a needs assessment in the past year, proportions of each type of long-term care services provided and by which sector, funding from health care systems versus dedicated funding for long-term care, proportion of care provided by informal carers and its costs).

BOX 7. INFORMATION, MONITORING AND EVALUATION SYSTEMS: COUNTRY EXAMPLE

Republic of Korea

The public long-term care insurance (LTCI) was implemented in the Republic of Korea in 2008, mainly covering people aged 65 or older with certain levels of disability regardless of income level (48). The LTCI is operated by the National Health Insurance Services (NHIS), the single public insurer of both the LTCI and the national health insurance under the Ministry of Health and Welfare. The NHIS is responsible for operating the LTCI, including assessing eligibility, issuing standard plans supporting care use, monitoring the quality of long-term care institutions, managing qualifications for insurance coverage, charging appropriate premiums to beneficiaries, and reimbursing providers for services to the beneficiaries.

To facilitate the tasks described above, the NHIS introduced in 2016 a nationwide, integrated information system for the LTCI that provides all long-term care institutions across the country with computerized, standardized forms that facilitate the exchange of data and information between providers and the insurer, thus promoting user-centred services (49, 50). As an update of an earlier information system, the system also supports the NHIS in monitoring, reviewing and assessing the profiles of long-term care institutions and the process of providing long-term care services. The personal data of beneficiaries are encrypted in the system to protect privacy. Mobile- and geographical information system (GIS)-based systems are also installed, which can be used by NHIS staff during visits to beneficiaries' homes to assess their level of care need or by long-term care institutions for quality monitoring. As the NHIS is the insurer of both the national health insurance and the LTCI, the long-term care and health care records of nationals eligible for both the national health insurance and the LTCI can be linked and analysed by this single insurer for strategic planning, policy formulation and decision-making.

Using this integrated and comprehensive LTCI information system and other related information systems, the national health insurance routinely releases the *LTCI Statistical yearbook*, which includes detailed information on the profiles of beneficiaries, providers, and long-term care institutions, as well as service provision and expenditures (51). In particular, detailed financing and quality reports on all providers reimbursed by the LTCI are collected through the information systems and analysed to plan for future system sustainability. The information systems also promote long-term care research; de-identified, longitudinal databases linked to the national health insurance and LTCI are available to the public for research purposes after research proposals have passed a thorough review process by the NHIS (52). Recent surveys on long-term care institutions, older people, carers and care workers have also strengthened the existing administrative data-based information systems (53).

Element 4. Workforce

Around the world there is considerable variability with regard to who provides long-term care, with the care provided by carers still forming the most common kind of long-term care (54). Poor pay and working conditions, as well as low proportions of professionally qualified staff, have been a long-standing concern in long-term care (55–57). Care workers within the health and social care systems account for 130.2 million jobs worldwide (3.9% of global employment), mostly women, and include all occupations engaged in the continuum of care, including promotion, prevention, treatment, rehabilitation, and palliative and assistive care (58). In many countries, migrant care workers form a large proportion of the long-term care workforce (54, 59, 60). It is common for such care workers to have temporary contracts, resulting in further marginalization of a socially vulnerable group. This situation is aggravated in low- and middle-income countries.

Providing long-term care has economic advantages, especially in low- and middle-income countries where there are high levels of youth unemployment and threats to jobs due to advances in technology and other factors. Training younger people to work with and care for older persons can be an economic stimulus and develop skills that can be applied to other gainful employment.

Globally, the extent to which countries rely on unpaid care remains substantial, with women continuing to perform the majority of care for older people (76.2% of the total of hours provided) (58). Despite this high reliance, worldwide policies to support carers, such as leave policies, social care benefits, and family-friendly working arrangements, remain limited. Carers often experience severe strain, which affects their physical and mental health (6). High levels of carer burden can lead to reduced labour force attachment, lower income, abuse of and discrimination against older persons, and ultimately higher poverty rates, as carers are forced to adjust or give up their jobs to provide care, all of which can result in suboptimal care strategies, with detrimental consequences for both carers and older people.

Currently, there is an average of five long-term care workers per 100 older people in Organisation for Economic Co-operation and Development (OECD) countries; this workforce includes certified nurses' aides, home health care aides, registered nurses, social workers, physical therapists, occupational therapists, physicians, and home and personal care workers who help with personal care attending to the activities of daily living (eating, bathing, dressing, and using the toilet) (54). In more than half of OECD countries, however, population ageing has already

overtaken the supply of the formal long-term care workforce, with the number of professionals involved in long-term care provision remaining at the same levels or declining over the years (54).

Across high-, middle- and low-income countries, there is a wide group of paid carers who are poorly trained and receive low pay, a great number of whom are domestic workers in households. Informality, long working hours and non-standard forms of employment are common issues related to paid work in these countries. The migration of women from low- and middle-income countries, or even within countries from less resourced settings to more wealthy settings, might result in migrant women who are care workers needing to employ other internal or international migrants or count on relatives to provide care to their own children (56).

Understanding the existing workforce

Effective workforce planning needs to begin with gaining an understanding of the existing health and social care workforce involved in long-term care in each context (for example, quantity, ratio of care workers to carers, distribution, skills mix, education, regulation, inflow and outflow, working conditions and remuneration). No "one-size-fits-all" model of the workforce or service provision team exists, given the variable cultural context and needs of the persons receiving the services. Ideally, long-term care teams should be interdisciplinary, including both the health and social care sectors. However, when assessing the availability and distribution of the workforce, it is important to take a needs-based approach and recognize that each country context influences how multidisciplinary teams of health and social workers are organized.

Particularly in countries where facility-based care is common, there should be an accurate picture of the number of care workers and carers involved and a minimum staff ratio should be established in policies and legislation to ensure care quality and safety, as well as workforce satisfaction and retention (34). This ratio could be based on the number of older people in need of long-term care at the facility and the level of such needs, with a higher number of skilled staff for those with higher levels of needs.

Capacity-building and professionalization of the workforce

Having a well trained, well equipped and sufficient long-term care workforce is key to ensuring that the needs of older people and their carers are met. To achieve that aim, countries need to implement actions for capacity-building and professionalization of individuals involved in long-term care provision.

Care workers should have training in the provision of long-term care and should receive regular training and evaluation (including specialization, yearly training and retraining courses). Capacity-building initiatives should be based on an evidence-based curriculum and should be widespread to avoid differences in the quality of care provided across different geographical regions. Training should be based on the key needs of the older people being cared for and on the knowledge gaps identified in institutional evaluations. Countries should also seek to establish professionalization of the long-term care role by implementing policies and procedures to deliver (and to require) long-term care certification and accreditation, particularly for licensed practitioners and care workers in home care and care facilities.

Individuals who are employed as carers (see glossary) represent about 70% of the paid long-term care workforce in OECD countries and up to 90% in other settings, such as Estonia, Israel, Republic of Korea, Sweden and Switzerland (54). However, in many countries, these carers do not have their role officially recognized by law, which prevents them from having professional rights and an established curriculum. These individuals are often hired as “domestic employees”; typically have low levels of education; are mostly untrained to provide long-term care and receive low wages; and are likely to experience discrimination. It is urgent that countries officialize care workers as professionals, supported by implementation and regulation of terms and conditions of employment so that their role, skills and employment rights can be defined and secured as part of the professional long-term care workforce.

Staff turnover and retention

High workforce turnover in the long-term care sector is a common challenge, and countries may need to make macro-level decisions to incentivize those working in the sector through formalizing roles, providing ways to increase pay, and other means (34). Ideally, the professional long-term care workforce should be paid at least the minimum standard established by their professional councils (such as the nursing council) and efforts should be made to ensure workforce satisfaction by providing qualifications, incentives and other benefits. This could also help mitigate negative stereotypes related to care for older people. Specific skills should be promoted according to the role, following standardized core competencies for each long-term care setting (for example, care facilities may require different professional skills compared to respite or home care). Establishing, monitoring and evaluating key quality assurance and improvement indicators are also essential.

Support for family carers

Carers provide the bulk of long-term care (46). It is therefore essential that long-term care system planning include measures to secure training and support for carers, and that the system can effectively meet their physical, emotional and financial needs. To adequately support carers, every individual who is willing to provide care to a family member, friend or neighbour should receive a regular (for example, yearly) needs and capacity assessment, as well as training on long-term care and support for self-care (such as support groups, psychological support and financial support).

Carer training should go beyond the physical needs of the older person (such as control of blood pressure or hygiene) to include the development of ethical and compassionate care skills and self-care strategies, for example. Training is important not only for the quality of care to be secured, but also to prevent anxiety and lack of confidence among carers. Training should be provided in line with the existing needs of carers and the older people being cared for, and should also be provided preventatively to prepare carers for future and unexpected care needs.

Every carer should be able to meet their mental and physical needs through respite, community day centres, temporary home support or online support (for example, WHO iSupport and mDementia). Such services should be used as a means of preventing the occurrence of or alleviating the mental and physical burden of carers. It is important that carers are not taken to their limit before any action can be taken to mitigate the impact on their health. Support strategies should also be provided in an integrated way, including all health, social, economic and environmental aspects to facilitate carer navigation within the various existing systems (for example, through each carer having a reference care manager). Countries should secure flexible working arrangements for carers within their work legislation and should provide incentives to carer-friendly employers. Support should go beyond the death of the older person in order to support the carer during bereavement and their return to the labour market, for example.

It is essential that long-term care system planning include measures to secure training and support for carers, and that the system can effectively meet their physical, emotional and financial needs.

Key aspects to consider for the long-term care workforce

Box 8 presents the key aspects that should be considered for the long-term care workforce, while Box 9 presents a country example.

BOX 8. WORKFORCE: KEY ASPECTS

Key aspects that should be considered for the long-term care workforce are as follows:

- ✔ Identify and regularly update the number of carers (family members, friends, volunteers, paid and unpaid), their profiles and needs.
- ✔ Identify and regularly update the turnover rates of the long-term care workforce according to each setting (home, community-based centre, long-term care facility).
- ✔ Formulate policies and legislation on registration, requirements, curriculum standards, core competencies and certification for carers and care workers in each long-term care setting (including home care services, long-term care facilities).
- ✔ Regulate annual pedagogic inspection, in-training requirements, and pedagogic supervision regularly assured by an accredited supervisory body for staff in each long-term care setting.
- ✔ Formulate evaluation mechanisms for current workforce capacity (specialization, training and retraining courses) and monitoring (for example, skills, satisfaction).
- ✔ Formulate and set up mechanisms to ensure gender equity in care provision (for example, flexible working and learning opportunities for women who are or were carers, benefits, and entitlements for returning to work).
- ✔ Formulate and set up mechanisms to ensure staff retention and minimum staff ratio (for example, flexible working arrangements, minimum established salaries, target-based awards, career development and promotion).
- ✔ Set up strategies to measure the availability of workforce capacity-building initiatives that are responsive to population needs.
- ✔ Formulate policies to support carers and promote their mental and physical well-being (for example, respite, day centres, home support, who iSupport and mDementia).

BOX 9. WORKFORCE: COUNTRY EXAMPLE

Brazil

The city of Belo Horizonte in Brazil has established a scheme to develop and support care skills for community-based long-term care in poor neighbourhoods through municipality funding (61). Care support workers are recruited from local communities and provided an initial customized training programme. Paid a minimum wage, care support workers work closely with a small number of families, providing each between 10 and 40 hours of care support a week. Care support workers are jointly supervised by staff from health and social assistance centres, and this has strengthened coordination across these agencies, including monthly joint case reviews. Care support workers are not expected to fully take over family care responsibility: instead, they offer families some respite from round-the-clock caring for dependent relatives. Also, they work with carers to build their own care skills and competencies, and, together with the older person, care support workers and families agree on personalized care plans. When problems occur, care support workers report back to the interagency case reviews. They continue to support older people when they are hospitalized, to ensure a smooth and timely discharge.

Evaluations show that, on a modest budget, the Belo Horizonte scheme has improved care outcomes for dependent older people, eased carer burdens and reduced the unplanned use of health services (62). This shows the value of embedding appropriate forms of capacity-building within an institutional structure that links families, support workers and different agencies. The scheme has been operating for over a decade and now has support from the Federal Ministry of Health, which is looking to help other cities to establish similar interventions.

Element 5. Service delivery

In many countries, health care and social care services are not integrated, creating difficulties for older people who need both types of services. Deeply rooted differences generate a series of functional divisions, such as different eligibility criteria and timing, geographical boundaries, legal frameworks, staff training and comprehensiveness of coverage. Separate budgets and a fragmented patchwork of funding sources contribute to insufficient care coordination. Moreover, professionals from social and health care usually have different values and cultures and are unfamiliar with each other's ways of working, creating additional barriers to integration (63).

There needs to be a concerted effort to realize a continuum of care with integration of essential long-term care services, whether they be health or social. To do this, contributory factors to fragmentation, such as aspects of fragmented governance, disjointed funding sources, and parallel workforce training, should be analysed and revised according to each country's geographical, political, social and cultural situation (64).

Long-term care systems should clearly define the types of services that are included, as well as the settings where such services are provided. Service delivery should be based on needs assessment and there should be an established quality management plan in place to ensure good-quality service provision to all those who need it, when they need it (promoting choice and person-centeredness), and where they need it (promoting ageing in place), while ensuring access to and coverage of equitable, evidence-based and sustainable long-term care.

Minimal services defined

When defining the types of services, Member States need to consider the continuum of care (preventive, promotive, rehabilitative, curative, palliative, bereavement), the specific types of care (personal assistance, medical or clinical, support with self-management, social support), and the target audience for each of them (consider for example older people with various degrees of functional ability and their choices, those who live alone versus those who are accompanied, and carer needs – working

versus retired carers, older versus younger carers, cohabiting versus long-distance carers). Services should be provided in line with the needs, choices and preferences of each older person and their carers (for example via co-designed individual care plans). Services should also respond in a timely manner to rapid changes in intrinsic capacity, which could be facilitated by introducing some degree of flexibility along the various care pathways.

Settings for long-term care provision

Long-term care can be provided in several settings. Older people should be able to choose where they wish to live, and this place should allow them to age with well-being. The various settings where long-term care is provided need to be mapped out and defined, and both rural and urban areas should benefit from long-term care services to enable universal coverage. Equal distribution of services should be targeted in large cities where normally there is a concentration of services around the city centre or in more wealthy areas. City outskirts are commonly not covered by a range of services, resulting in poor service provision and unmet needs. Transportation should be provided to services that cannot be delivered at home or near home. Home- and community-based services, such as outreach programmes, day care services, and support services in primary care facilities, are often useful for older people who have chosen to live at home and who are at any point of their trajectory of functional capacity. Community-based services and assisted living facilities, in particular, are more suitable for those whose intrinsic capacities are more preserved. Long-term care facilities (care homes, nursing homes, hospices) can be an option in cases where the older person's intrinsic capacity has severely deteriorated and these are their preferred choice, or when there are no family members nearby for support, or when carers are no longer able or willing to provide care and support at home.

Additionally, countries should ensure progressive but sustainable availability of adequate infrastructure to support community-delivered long-term care aiming at supporting safe and effective care delivery

Countries should ensure progressive but sustainable availability of adequate infrastructure to support community-delivered long-term care aiming at supporting safe and effective care delivery in the community.

in the community (physical space, transport, telecommunications, access to assistive devices). The physical infrastructure of many health and social care settings is far from prepared to attend to older people's needs – there is often a lack of adequate community care centres, no universal design (such as provision of accessible toilets in buildings), physical barriers to access, and communication barriers resulting from a lack of accessible information for people with hearing loss and visual impairment. Poor home accessibility, lack of services for home modification, difficult access to assistive products, and violent neighbourhoods can significantly impact the care provided by care workers and carers. In addition, there is a shortage of affordable transportation, particularly for those living in rural areas where the concentration of services is further reduced. This is compounded by a lack of coordinated referral systems (63) and transition of care services that link acute care to long-term care services when needed. Multisectoral action to strengthen environmental infrastructure will contribute to ageing in place as well as enhancing the quality of life for all, as environments play a fundamental role in the maintenance of functional ability.

Integrated care and person-centred care pathways

Regardless of where long-term care is provided, strong coordination and integration should exist among the different services and sectors to enable the promotion of intrinsic capacity and functional ability whilst optimizing resources. This could be done via integrated care pathways (integration of health and personal care and social support, and standardized clinical guidelines and protocols) (14) and via robust data and information systems integrating information from the various services and sectors (including private, not-for-profit and public sectors). Integrated care pathways can be guaranteed via intersectoral legislation, shared fiscal and information systems, and accountability mechanisms.

Eligibility criteria defined

Long-term care plans or policies should clearly specify when and who should be entitled to which type of service (based on disability, type of needs, care dependency status and socioeconomic status). This is also applicable to entitlements and specification criteria for receiving benefits. A needs assessment protocol should be used to measure the needs of both older people (for example using validated measures of functional ability, intrinsic capacity and levels of social support) and carers (using validated measures of self-care, burden and

psychological well-being). These criteria need to be, to the extent possible, harmonized across the country to allow comparison between locations and adequate allocation of resources. Once older people or carers are qualified for any service, the process of initiating the service should be timely and transparent for both service providers and users. In addition, less emphasis should be given to pharmacological treatment and greater emphasis placed on non-pharmacological interventions and care.

Quality assurance

To ensure good quality long-term care, quality standards should be established across different settings. The quality of and access to long-term care can be monitored via similar criteria to WHO's proposed indicators for quality and efficiency of health systems (20):

- **effective:** needs-based, evidence-based care leads to improved health outcomes and benefits older people and their carers;
- **efficient:** delivery of care maximizes outcomes per resource and infrastructure used and avoids waste;
- **accessible:** geographically reasonable care is provided in a setting where skills, information and resources are appropriate to individual needs;
- **timely:** care is responsive to individual needs in a timely manner, without delay in receiving the appropriate care when there is a need for it;
- **patient-centred:** care is delivered with empathy and respect and considers the values, preferences, aspirations and culture of each individual, including the provision of information about treatment alternatives and involvement in the decision-making of their own care;
- **acceptable:** interventions are accepted by stakeholders and older people and their carers;
- **safe:** care processes avoid, prevent and ameliorate adverse outcomes or injuries that stem from the care provided itself, including abuse of and discrimination against older people;
- **equitable:** the quality of the care delivered does not vary because of personal characteristics such as gender, race, ethnicity, geographical location or socioeconomic status.

There are several means by which such criteria can be assessed, for example by accreditation mechanisms, hospitalization rates, unintended injuries or harm (for example, pressure injuries or falls), level of satisfaction, length of time waiting for service or procedures, or medication-related incidents (such as overmedication or medication errors). Member States should also have procedures for enforcing measures of quality assurance (for example, quality

assurance by independent institutions, inspection and public reporting). Minimum quality assurance and improvement processes should be implemented for long-term care services provided by the private, public and not-for-profit sectors. This could be done by identifying critical areas of service delivery

where quality assurance is needed; by selecting appropriate tools; by developing processes for use of quality outcome data to improve services; and by expanding system-level quality measures to include person-centred and provider outcomes across services (13, 65–68).

Key aspects to consider for long-term care service delivery

Box 10 presents the key aspects that should be considered for long-term care service delivery, while Box 11 presents a country example.

BOX 10. SERVICE DELIVERY: KEY ASPECTS

Key aspects that should be considered for long-term care service delivery are as follows:

- ✔ Set up a strategy formulation process for quality assurance.
- ✔ Define a strategy for quality-related measures and establish a body with responsibility for quality control.
- ✔ Set up assessments of perceived quality by users and providers in the services provided.
- ✔ Plan service provision based on accurate data on the number of home care provisions, community-based centres and long-term care facilities.
- ✔ Set up standardized person-centred assessment protocols, including degrees or levels of dependency categories, health criteria assessment to qualify for services, preferences, and older adult and carer needs.
- ✔ Formulate control mechanisms to ensure that providers (public, private non-profit or commercial) are respecting (minimum) standards conducted by independent institutions, inspections and public reporting.
- ✔ Define evidence-based care pathways based on clinical guidelines, systematic reviews and best-practice recommendations from recognized organizations.
- ✔ Define clear quality standards for provision of long-term care across different settings based on fundamental rights, evaluation of needs-oriented care and preferences (for example, accreditation mechanisms, hospitalization rates, unintended injuries or harm such as pressure ulcers and falls, levels of satisfaction, and medication-related incidents such as overmedication and medication errors).
- ✔ Define clear processes and procedures to create integrated and person-centred care pathways (transition policies, case prioritization, case and care management).
- ✔ Provide timely integrated and person-centred services inclusive of all aspects of the continuum of care (preventive, promotive, rehabilitative, curative, palliative, assistive, social and carer support).
- ✔ Set up strategies for coordination and communication systems between services providers, health care workers, care receivers and carers, including sharing information between clinicians about patient care.

BOX 11. SERVICE DELIVERY: COUNTRY EXAMPLE

Qatar

In line with the national priorities of Qatar, the Geriatric and Long-Term Care Department in Hamad Medical Corporation has implemented diversified services to ensure comprehensive care delivery for older adults with long-term care needs in a timely, person-centred, fully integrated, affordable and equitable manner. The long-term care system facilitates the proactive identification and assessment of patients with ongoing care needs, patient transitions to appropriate settings, and coordination of care delivery services across Qatar.

To provide person-centred care in a home setting, nationally coordinated integrated home care and mobile health care services were established, thereby ensuring centralized referral management and a unified approach to managing the complex needs of older people through greater utilization of available resources and with suitable involvement of social services. Various long-term peripheral services are available, in collaboration with primary health care centres.

Long-term inpatient care services are designed and equipped to accommodate patients with complex needs who require prolonged nursing and medical care. A specialized on-site team delivers comprehensive care based on daily assessments to continuously help patients to reduce dependency on supportive devices and regain as much functional independence as possible.

Several services were set up to ensure continuity of access to services during the COVID-19 pandemic, including geriatric telephone guidance and telemedicine, telepharmacy to help older people to continue their medications, and a helpline for people living with dementia and their carers, recognizing that supportive services are critical for older people requiring long-term care.

Specialized care centres for older people offer patient-centred medical care while supporting patients in regaining or maintaining optimal levels of functioning. Unlike a traditional hospital environment, such centres adopt a person-centred, care-based approach, including a focus on compassionate patient-provider interactions, access to information, family and patient involvement and the physical environment of care.

Community-based residential care services help older people transition from long-stay acute care to the home environment by helping them to learn ways to overcome the effects of their injury or illness through compensatory strategies. In addition, a number of activities are in place for the engagement of residents via social activities, group therapy, and family engagement programmes that further prepare them for reintegration into the community in the long term.

Element 6. Innovation and research

Innovation and research should drive the development and expansion of long-term care services towards the provision of equitable, sustainable and effective care. Research and innovation should be based on the priorities of stakeholders, including older people themselves, and innovative solutions should be provided equitably among the various population groups to avoid widening health disparities among older people. Assistive technology, in particular, has the potential to help compensate for loss in intrinsic capacity and to restore functional ability.

Research is also vital to generate answers to key questions, such as advancing knowledge on person-centredness, optimizing functional ability, and what works and what does not work in terms of long-term care in different contexts. Each country should have a strategy to encourage the development and adoption of new technological solutions for assistive care to meet older people's needs.

Strategy to encourage technological innovation

Countries are encouraged to have their own strategy to foster the development and adoption of emerging technologies considering their cultural preferences, levels of digital literacy, and key needs for advanced digital solutions. Partnerships with industry, other private sector entities and civil society are encouraged both to reduce costs and to optimize uptake. Such a strategy can also include innovating for workforce communication and service user-provider communication.

Digital health

The use of digital technology and solutions is still low among older people, particularly among older people living in low-resourced settings and from underrepresented racial and ethnic groups (69, 70). Ageism can also be an important barrier that prevents older people from using technology (71, 72). However, technological solutions have the potential to facilitate access to information, to be easily scalable, to facilitate communication between service providers and service users, to offer good value for money, to have greater reach among isolated populations, and to be easily updated and tailored to needs. Digital technology and solutions can help older people's self-management of health care needs, management of medication, cognitive and social stimulation, and carer training and support. Internet and equipment could be provided via incentives to industry or via intergenerational

activities, including in schools. Efforts should be made to facilitate digital health capacity-building in older people and their carers, including improving digital literacy, particularly among those from low-resourced and underrepresented groups.

Assistive products

Assistive technology is "the application of organized knowledge and skills related to assistive products, including systems and services", and is considered a subset of health technology. Assistive products are "any external product (including devices, equipment, instruments or software), especially produced or generally available, the primary purpose of which is to maintain or improve an individual's functioning and independence, and thereby promote their well-being". Assistive products are also used to prevent impairments and secondary health conditions (73). A comprehensive list of assistive products can be found in the Priority Assistive Products List published by WHO, the United States Agency for International Development and the International Disability Alliance (73).

Assistive products can enable older people to live healthy, productive, independent and dignified lives and to participate in education, the labour market and civic life. They can help reduce the need for health and support services and carers' time. Such products can have socioeconomic benefits through reducing direct health and welfare costs (such as hospital admissions or State benefits) (73).

Assistive products should be used with the aim of promoting intrinsic capacity, compensating for loss of functional ability, and fostering independence and agency. They should be provided equitably among the population with long-term care needs. Ideally, needs for assistive technology should be assessed for every individual. Furthermore, such an assessment should consider each older person's and carer's goals for using assistive products. It is important to recognize that without a thorough assessment of need and the potential for training and follow-up, a significant proportion of assistive products might end up not being effectively used.

Research priorities defined

Research priorities for long-term care should be defined based on data on the current state of long-term care in each setting, within the context of the local and international agenda for long-term care. The identification of research priorities should involve the views of researchers, policy-makers, and health and social care providers, as well as older people and their carers. Adequate funding should be allocated to achieve the research goals, and these should be regularly re-evaluated.

Key aspects to consider for long-term care innovation and research

Box 12 presents the key aspects that should be considered for long-term care innovation and research, while Box 13 presents country examples.

BOX 12. INNOVATION AND RESEARCH: KEY ASPECTS

Key aspects that should be considered for long-term care innovation and research are as follows:

- ✓ Encourage high-quality research and set up, in collaboration with national and regional research agencies, specific research grant schemes dedicated to long-term care.
- ✓ Formulate an innovation and research plan and revise it periodically in line with current national and subnational policies.
- ✓ Create an expert advisory commission for the long-term care research agenda that includes researchers and key stakeholders, as well as older people and carers.
- ✓ Identify partner organizations to fund or co-fund specific projects that are perceived as high-priority research.
- ✓ Establish annual funding investment in long-term care innovation and research.
- ✓ Encourage subnational research initiatives that provide regional policy-makers with information on cost-effective policies, developing databases to support analysis of subnational variations.
- ✓ Foster a continued dialogue between researchers and end users (older people, carers, staff in long-term care facilities, home care providers) to identify and address information and quality gaps at the micro level (needs of older people and carers), meso level (care service delivery), and macro level (policies, strategy, legislation).
- ✓ Promote improvement in the quality of education and capacity-building of human resources by encouraging postgraduate student programmes and young researchers.
- ✓ Generate indicators to measure the level of implementation of innovation and research on long-term care practice.
- ✓ Facilitate and encourage technological and policy innovation, leveraging national and regional agencies and hubs to build on long-term care.
- ✓ Promote the adoption and uptake of innovation by engaging in partnerships (universities, research institutes, networks and business associates).
- ✓ Create mechanisms to accelerate innovation in the sector by supporting the implementation of well validated strategies and programmes in long-term care practice.
- ✓ Showcase innovation experiences and success stories in adopting long-term care solutions and innovative ways of delivering interventions.
- ✓ Value the expertise of long-term care staff and carers by implementing staff- and carer-driven innovation programmes.
- ✓ Foster the development of digital information technologies to facilitate communication and information exchange among sectors and stakeholders.

BOX 13. INNOVATION AND RESEARCH: COUNTRY EXAMPLES

The Netherlands

The Dutch Government, with the leadership of the Ministry of Health, Welfare and Sport, has consistently invested in collaboration with universities and other independent organizations towards developing a knowledge infrastructure dedicated to long-term care. Organizations involved include the Netherlands Institute for Health Services Research (Nivel), the Centre of Expertise for Long-Term Care (Vilans), and the Living Lab in Ageing and Long-Term Care (with a total of six units distributed across the country).

Vilans is an example of an independent national knowledge organization that carries out assignments at the government's request using innovation and research to develop and disseminate information and implement best practices. Vilans works in collaboration with clients, relatives, health care professionals and other policy partners and focuses on three main areas: person-oriented work, quality care and effectiveness, and digital transformation. Several innovative projects are being undertaken by Vilans, such as POSTHCARD (PersOnalized SimulaTion Helping Caregivers to Cope with AlzheimE Disease) and GUARDIAN, a care robot that serves as a companion and interacts with older people in their own homes.

The Living Lab in Ageing and Long-Term Care (74) was founded in 1998 at Maastricht University. It is currently a network composed of senior researchers that coordinate scientific research and teaching activities, a multidisciplinary working group of long-term care professionals, and staff and older people to assist in the identification of gaps in current practice that need further investigation. The Living Lab drives scientific research in long-term care in co-creation with end users to address problems identified by people living and working in long-term care. Several research projects resulted in positive impacts on national policy development through changes in legislation and policy. For example, research conducted by the Living Lab and other stakeholders about the reduction of restraints and involuntary treatment served as input for the new Dutch Care and Coercion Act (January 2020).

Singapore

Kampung Admiralty is Singapore's first public housing innovation that integrates housing for seniors with a wide range of social, health care, communal, commercial and retail facilities under one roof. Completed in May 2017, the 11-storey vertical "kampung" (a Malay word meaning village) features studio apartments fitted with older people-friendly features, a medical centre, an active ageing hub, a childcare centre, dining and shopping facilities, a community plaza, community park and community garden.

With this wide range of amenities in close proximity to where seniors live, Kampung Admiralty is designed to enable seniors to age in place by encouraging them to lead active and healthy lifestyles and by promoting intergenerational bonding. For example, the active ageing hub offers active ageing programmes (such as life skills courses for seniors) and preventive health programmes (such as health checks and fall risk screenings) to help keep seniors in the community healthy and safe. A community nurse is on site to check the seniors' vital signs and advise seniors, referring them to specialized care if necessary. The active ageing hub is located beside a childcare centre, which makes it easy to hold activities that promote bonding across generations.

Singapore

In line with the move to transform Singapore's health care delivery system from one that is built around the hospital to one that is centred in the community, the medical centre at Kampung Admiralty offers selected specialist outpatient services, day surgery, endoscopies, rehabilitation and diagnostic services. An in-house diabetes centre provides care for complex diabetes patients. On the preventive health front, the medical centre provides a range of community health education and chronic disease management programmes. Hence, the medical centre offers increased convenience for seniors to access specialist care without having to go to a hospital. Other features of Kampung Admiralty are illustrated in Figure 6 (75).

Figure 6. Features of Kampung Admiralty integrated development



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Annex 1. Checklist of key action points for strengthening long-term care systems

Using the checklist

As we embark on the United Nations Decade of Healthy Ageing, WHO's role will be to support countries in establishing sustainable and equitable long-term care systems and providing technical advice to achieve provision of long-term care to meet the needs of older people. The framework for countries to achieve an integrated continuum of long-term care can guide countries in assessing system-level components to implement sustainable and equitable long-term care actions.

By applying this checklist, countries can begin to shape their long-term care systems as a prerequisite for universal health coverage and promote investment in the long-term care health workforce, including carers. The checklist will help countries to visit their existing systems, identify potential gaps and ultimately help in planning for next steps.

The checklist is primarily intended to be used by governments and policy-makers, both national and subnational, to assist countries in fulfilling their goal of establishing effective and sustainable long-term care provision (care workers and carers). In addition, many of the actions are relevant for other stakeholders at the country level, such as nongovernmental organizations, the private sector, health care providers and development partners. Those in academic institutions may also find this

document useful for identifying areas requiring further research.

The checklist should be:

- used as a general reference tool for assessing the country long-term care situation at a macro level in conjunction with other more in-depth harmonized normative products on long-term care by WHO;
- adapted to national and local contexts by taking account of a country's policies, guidance, local risks, requirements, standards and practices;
- used periodically to monitor the progress of country preparedness to provide an integrated continuum of long-term care services.

For each of the key items described below, choose one of the following options:

- **Not available:** indicate that the action was not initiated yet.
- **Partially functional, initiated, implemented or covered:** indicate that current action has been initiated but is only partially created or implemented.
- **Fully functional, implemented and covered:** indicate that current action is fully implemented and is being continuously refined and improved.




1. GOVERNANCE

Rating



1. Include long-term care within the portfolio of national and regional or municipal governments with the designation of a dedicated focal coordinating body aiming at reaching leadership and engaging community representatives and other relevant stakeholders.
2. Formulate legislation for long-term care that includes a mandate for governance structure, financing mechanism, service provision with a defined target population, and monitoring of quality care and performance.
3. Formulate legislation to ensure protection of rights and entitlements of both older people and carers.
4. Establish an overarching national (and relevant regional) plan, strategy or framework that sets the directions and outcomes to achieve an organized and sustainable long-term care system operationalized at subnational level with a specified target population.
5. Map key stakeholders in the development of policy and strategy for long-term care.
6. Formulate an explicit long-term care policy document developed as a stand-alone national document, usually including a multistage stakeholder process, led or supported by the focal governmental entity dedicated for long-term care.
7. Steer roles of national, regional and municipal government in the assurance, financing, regulation and provision of long-term care services, including the roles of public and private providers and nongovernmental organizations.
8. Establish a detailed action agenda with essential implementation strategies.
9. Create and support a regular decision-making body for integrating all levels of the long-term care sector, including collaboration of health and social workforce organizations, aiming at fostering dialogue and formulating processes, norms, standards and regulations.
10. Define strategies and actions to facilitate leadership, foster collaboration between health and social systems, and enable alliances to promote more integrated models of long-term care.
11. Define how public funds will be allocated and distributed for the implementation of the national or subnational plan in a sustainable manner.
12. Allocate and coordinate budgets across multiple levels of governance to implement an integrated long-term care system.
13. Promote intersectoral collaboration (health and other government sectors, as well as representatives from private, voluntary and non-profit groups) to build on common goals and to allocate resources.
14. Establish mechanisms to review and share progress towards the national long-term care policy goals as defined in the plan or framework.
15. Establish and constantly refine the measures to track and monitor the long-term care national plan to ascertain whether it is implemented as intended and strategies are met.
16. Configure audit activities to measure performance and transparency of responsible bodies.
17. Monitor performance of long-term care services in terms of their effectiveness, efficiency, economy, compliance with laws and regulations, contract requirements, grant requirements, and organizational policies and procedures.
18. Develop labour policies, including labour protection policies, to clarify the rights, entitlements and obligations of parties to the employment relationship, including a context of non-discrimination and protection from violence.

	Rating
19. Set out labour standards, procedures and regulations for carers and care workers, such as working conditions, wages, working time arrangements, compensation mechanisms and strategies to overcome informality.	○ ○ ○
20. Promote the recognition of the long-term care workforce and the observance of workplace health and safety standards.	○ ○ ○
21. Provide an ongoing training programme for carers (whether unpaid or paid) and formulate legislation for training and certification requirements to accredit people's caregiving expertise.	○ ○ ○
22. Partner with national, subnational and local stakeholders and groups to identify and strengthen mechanisms to engage and empower communities in the processes of governance.	○ ○ ○
23. Formulate and regulate quality standards for long-term care services, whether provided by public, private or non-profit organizations, by setting minimum quality standards for providers through licensing and certification and carrying out periodic inspections to ensure their compliance and monitor their performance on quality.	○ ○ ○

 2. SUSTAINABLE FINANCING	Rating
	● ○ ●
24. Establish a public long-term care financing system with a defined set of eligibility criteria that is used to determine access to and entitlement for a publicly funded range of services that should be available for people, as well as the responsibilities for long-term care, recognizing that this does not need to be a stand-alone financing system, but a predictable financing system for long-term care that is well integrated with other health and social systems.	○ ○ ○
25. Ensure that public revenues are allocated and pooled for redistributive purposes to support equitable access to long-term care, and allocate a sustainable budget to fund long-term care and related aspects (for example, long-term care information systems).	○ ○ ○
26. Establish financing mechanisms to ensure equitable use and universal coverage of long-term care and to support integrated care for older people (for example, outcomes-based financing, pay for performance and bundled payments).	○ ○ ○
27. Ensure that public financial management systems are based on key local population needs and are able to allocate, distribute, execute and account for funds.	○ ○ ○
28. Implement mechanisms to ensure that those who are not able to contribute to the social insurance system (such as those not formally employed) are still covered if needed.	○ ○ ○
29. Set up accurate measurement tools for current expenditure on long-term care as a proportion of other expenditures (for example, total health expenditure or GDP) as part of a national health accounts methodology.	○ ○ ○
30. Ensure that financing is based on accurate data related to costs (see element 3).	○ ○ ○
31. Set up measures and subsidies for reducing costs experienced by informal carers (for example, cash allowance, paid leave, respite services or informal care leave).	○ ○ ○



3. INFORMATION, MONITORING AND EVALUATION SYSTEMS

Rating



- | | |
|--|---|
| 32. Identify current and forecasted life expectancy (for example, median age, life expectancy), population growth (for example, fertility rate, migration trends), and old-age dependency ratio (working age population relative to older people). |    |
| 33. Survey populations, underlying chronic health conditions and risk factors for the decline and loss of intrinsic capacity and functional ability to estimate and anticipate needs. |    |
| 34. Monitor and evaluate the levels of care and support needs among older people and carers. |    |
| 35. Integrate and link long-term care information systems with health information systems to ensure person-centred approaches. |    |
| 36. Track and monitor long-term care performance based on a broad and updated range of data sources, including facility-based information systems, public health surveillance systems and population-based surveys. |    |
| 37. Survey socioeconomic status of older people (family size, place of residence, household income status, poverty rates). |    |
| 38. Survey disability trends (for example, disability-adjusted life-year, leading cause of disability). |    |
| 39. Set up measures of well-being (for example, life satisfaction, health-related quality of life) and health status of older people and carers. |    |
| 40. Create integrated minimum data sets (clinical outcomes, integrated service targets, composite quality measures) used routinely to support the sharing of and improve the quality of information between all stakeholders. |    |
| 41. Determine intersectoral indicators of care distribution, quality and equity (for example, provision of home modifications, transportation and food and nutrition security). |    |
| 42. Identify the number and geographical distribution of community social centres and the number of people using these services. |    |
| 43. Audit the number of long-term care facilities, their geographical distribution, complexity levels, number of beds and number of care workers per number of beds. |    |
| 44. Map the number of health practitioners delivering long-term care services (for example, generalist medical practitioners, nurses, social workers, psychologists, geriatricians, physiotherapists, occupational therapists, gerontologists, community nurses and carers). |    |
| 45. Map the number of practitioners working at the interfaces or transitions of care (for example, medical liaisons, social protection worker care managers, nurse discharge managers). |    |
| 46. Audit the number and characteristics of older people receiving long-term care and their carers. |    |
| 47. Formulate measures for quality assessment (such as rates of avoidable hospital admission, service integration, clinical outcomes, user satisfaction, waiting time). |    |
| 48. Map and generate reports of the characteristics of the services provided (type, private versus public, size, quantity, geographical and quality distribution), including home-based services (outreach programmes, day care services, support services in primary care facilities), community-based centres (day care centres and services, respite care, support services in primary care facilities), and long-term care facilities (nursing homes, assisted living facilities, residential care homes, hospices). |    |
| 49. Generate detailed data on financing (for example, out-of-pocket expenditures for long-term care, coverage based on eligibility, number of people who are entitled to long-term care who have received a needs assessment in the past year, proportions of each type of long-term care services provided and by which sector, funding from health care systems versus dedicated funding for long-term care, proportion of care provided by informal carers and its costs). |    |



4. WORKFORCE

Rating



- | | | | |
|---|-----------------------|-----------------------|-----------------------|
| 50. Identify and regularly update the number of carers (family members, friends, volunteers, paid and unpaid), their profiles and needs. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 51. Identify and regularly update the turnover rates of the long-term care workforce according to each setting (home, community-based centre, long-term care facility). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 52. Formulate policies and legislation on registration, requirements, curriculum standards, core competencies and certification for carers and care workers in each long-term care setting (including home care services, long-term care facilities). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 53. Regulate annual pedagogic inspection, in-training requirements, and pedagogic supervision regularly assured by an accredited supervisory body for staff in each long-term care setting. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 54. Formulate evaluation mechanisms for current workforce capacity (specialization, training and retraining courses) and monitoring (for example, skills, satisfaction). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 55. Formulate and set up mechanisms to ensure gender equity in care provision (for example, flexible working and learning opportunities for women who are or were carers, benefits, and entitlements for returning to work). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 56. Formulate and set up mechanisms to ensure staff retention and minimum staff ratio (for example, flexible working arrangements, minimum established salaries, target-based awards, career development and promotion). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 57. Set up strategies to measure the availability of workforce capacity-building initiatives that are responsive to population needs. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 58. Formulate policies to support carers and promote their mental and physical well-being (for example, respite, day centres, home support, WHO iSupport and mDementia). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |




5. SERVICE DELIVERY

Rating



- | | | | |
|---|-----------------------|-----------------------|-----------------------|
| 59. Set up a strategy formulation process for quality assurance. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 60. Define a strategy for quality-related measures and establish a body with responsibility for quality control. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 61. Set up assessments of perceived quality by users and providers in the services provided. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 62. Plan service provision based on accurate data on the number of home care provisions, community-based centres and long-term care facilities. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 63. Set up standardized person-centred assessment protocols, including degrees or levels of dependency categories, health criteria assessment to qualify for services, preferences, and older adult and carer needs. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 64. Formulate control mechanisms to ensure that providers (public, private non-profit or commercial) are respecting (minimum) standards conducted by independent institutions, inspections and public reporting. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 65. Define evidence-based care pathways based on clinical guidelines, systematic reviews and best-practice recommendations from recognized organizations. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| 66. Define clear quality standards for provision of long-term care across different settings based on fundamental rights, evaluation of needs-oriented care and preferences (for example, accreditation mechanisms, hospitalization rates, unintended injuries or harm such as pressure ulcers and falls, levels of satisfaction, and medication-related incidents such as overmedication and medication errors). | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

	Rating
67. Define clear processes and procedures to create integrated and person-centred care pathways (transition policies, case prioritization, case and care management).	<input type="radio"/> <input type="radio"/> <input type="radio"/>
68. Provide timely integrated and person-centred services inclusive of all aspects of the continuum of care (preventive, promotive, rehabilitative, curative, palliative, assistive, social and carer support).	<input type="radio"/> <input type="radio"/> <input type="radio"/>
69. Set up strategies for coordination and communication systems between services providers, health care workers, care receivers and carers, including sharing information between clinicians about patient care.	<input type="radio"/> <input type="radio"/> <input type="radio"/>

 6. INNOVATION AND RESEARCH	Rating
	<input checked="" type="radio"/> <input type="radio"/> <input type="radio"/>
70. Encourage high-quality research and set up, in collaboration with national and regional research agencies, specific research grant schemes dedicated to long-term care.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
71. Formulate an innovation and research plan and revise it periodically in line with current national and subnational policies.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
72. Create an expert advisory commission for the long-term care research agenda that includes researchers and key stakeholders, as well as older people and carers.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
73. Identify partner organizations to fund or co-fund specific projects that are perceived as high-priority research.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
74. Establish annual funding investment in long-term care innovation and research.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
75. Encourage subnational research initiatives that provide regional policy-makers with information on cost-effective policies, developing databases to support analysis of state variation.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
76. Foster a continued dialogue between researchers and end users (older people, carers, staff in long-term care facilities, home care providers) to identify and address information and quality gaps at the micro level (needs of older people and carers), meso level (care service delivery), and macro level (policies, strategy, legislation).	<input type="radio"/> <input type="radio"/> <input type="radio"/>
77. Promote improvement in the quality of education and capacity-building of human resources by encouraging postgraduate student programmes and young researchers.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
78. Generate indicators to measure the level of implementation of innovation and research on long-term care practice.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
79. Facilitate and encourage technological and policy innovation, leveraging national and regional agencies and hubs to build on long-term care.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
80. Promote the adoption and uptake of innovation by engaging in partnerships (universities, research institutes, networks and business associates).	<input type="radio"/> <input type="radio"/> <input type="radio"/>
81. Create mechanisms to accelerate innovation in the sector by supporting the implementation of well validated strategies and programmes in long-term care practice.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
82. Showcase innovation experiences and success stories in adopting long-term care solutions and innovative ways of delivering interventions.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
83. Value the expertise of long-term care staff and carers by implementing staff- and carer-driven innovation programmes.	<input type="radio"/> <input type="radio"/> <input type="radio"/>
84. Foster the development of digital information technologies to facilitate communication and information exchange among sectors and stakeholders.	<input type="radio"/> <input type="radio"/> <input type="radio"/>

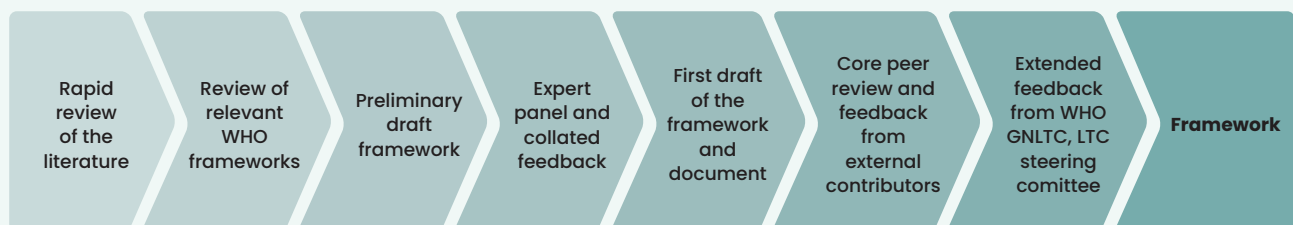
Annex 2. Methodology for development of the framework

The framework components have been developed to be consistent with the objectives of the Global Strategy and Action Plan on Ageing and Health. They reflect the framework presented in the *World report on ageing and health* (1), and further developed in Pot et al. (2). They also build on the integrated care for older people (ICOPE) framework (3), the WHO Operational Framework for Primary Health Care (4), the European Quality Framework for long-term care services (WeDO project) (5), the WHO Regional Office for Europe country assessment framework for the integrated delivery of long-term care (6), the OECD report on providing and paying for long-term care (7), the WHO handbook on strategizing national health in the 21st century (8), the work of the Global Dementia Observatory (9), and the WHO handbook

on health systems building blocks (10). The framework has also been informed by discussions held with the members of the Global Network on Long-Term Care (GNLTC) and long-term care steering committee, as well as by academic literature on the performance of long-term care systems and on the definition and measurement of particular aspects of long-term care. Where possible, the same wording and definitions have been used to ensure transferability and consistency across the various policies.

The process between the creation of the framework concept note up to publication of its final version was based on a reflexive, collaborative and iterative process, as shown in Figure A2.1.

Figure A2.1 Approach used for drafting the framework document



References: Annex 2

1. World report on ageing and health. Geneva: World Health Organization; 2015 (https://apps.who.int/iris/bitstream/handle/10665/186463/9789240694811_eng.pdf;jsessionid=220E0C1396B0150A25FAF88C341D3357?sequence=1, accessed 7 August 2021).
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Annex 3. Rapid review: macro and meso levels of long-term care

Aim

The aim of the rapid review was twofold: first, to look at the extent and nature of the available literature; and second, to understand what data have emerged from studies in terms of the barriers and facilitators in implementing long-term care at the macro and meso levels, and any lessons that have been learned across from high-income to low-income countries.

Method

An adapted rapid review methodology was used to reflect the limited resources and time available for the review. Acknowledging the wealth of material already produced by WHO, but also by previous reviewers, we concentrated on literature published since 2016 in order to capture the latest evidence from research and policy development. Only reviews and systematic reviews were sought, partly given the time constraint but also since there was an impetus to cover as much of the literature as possible at the same time as being able to reflect upon the diversity of the material and draw out the main thrusts for policy-makers.

The following databases were searched in April and May 2020: Cochrane Database of Systematic Reviews; PubMed; Medline; NHS Evidence; Database of Abstracts of Reviews of Effects (DARE); Campbell Collaboration; Web of Knowledge (for Science Citation Index and Social Sciences Citation Index); SCOPUS; RePEc; ERIC; and Google Scholar. Reviews were included if they explored either long-term care or integrated care at a macro (national system) level or meso (subnational service) level. Studies that only covered interventions at the micro (front-line, service delivery) level were not included, and this exclusion covered those focusing on service delivery or integration of specific services or specific care packages. Nonetheless, this did not preclude studies or reviews that encompassed interventions at different levels.

The searches were limited to reviews since 2016, using Medical Subject Headings terms where applicable and specific key words relevant to long-term care and integrated care. Care was taken in this rapid review to include a range of search terms to ensure good coverage: health systems, health systems organization, models of care, long-term care, social care, social services, integrated care, health integration, patient-focused care, person-centred care, health care organization, older people, formal/informal care, dependency, transferability, health policy, health policy implementation, systems enablers, policy context/development, health transformation, intersectoral collaboration, delivery of care.

Relevant references listed within the literature searched were also sourced. The final selection comprised a total of 29 reviews. Despite the focus being on the macro and meso levels, a number of articles selected for inclusion were primarily based at the micro level, since the emerging analysis had wider implications.

Findings

Scope of the literature

Long-term care is a rapidly growing area of study with a reported eightfold increase in publications between 1991 and 2018, due to an increase in ageing populations at the same time as the decreasing ability of family support networks to support those in need. Nonetheless, there is very limited evidence of long-term care strategies within low- and middle-income countries, though there is acknowledgement that transporting models from high-income countries to low- and middle-income countries is inappropriate. Despite ample evidence to justify transformation of the health and social care system at the national or policy level there is a notable lack of data to support such macro-level change and, thus, limited evidence for strategies to achieve it.

This is also the case at the subnational or meso level. Further, there remains no consensus in the literature on the actions that need to be taken at either of these levels. On the other hand, at the micro level there is a disproportionate amount of evidence, concentrating predominantly on integrated care.

Nature of evidence

Assessment of integrated care models remains at a local rather than a national level, reporting on either specific care services or conditions. Indicators measuring care and non-clinical outcomes remain scarce, however, and most do not meet standards of high methodological quality. It has proved challenging to evaluate programmes and frameworks for integrated care, given their varied objectives and the lack of consistency in the terminologies and definitions used. Such difficulties in evaluation may be compounded by inadequate or inaccurately reported data and information, which are critical to identify success factors of an integrated care programme and its impacts on service delivery. Further, despite an abundance of structural, process and outcome measures for evaluation of social and health care integration at the micro level, there is neither a set core of measures nor guidance on how it should be measured.

At the meso level, the few studies where the emphasis was on understanding the wider process and implementation of organizational change were seen to be lacking in adequate evidence and mixed in their results. For instance, it remained unclear which structural changes in local health care delivery were the most effective in terms of delivering improvements in health care. Evidence was also considered lacking in determining appropriate factors enabling successful implementation of integration across health and social care, though there was a reported need for long-term commitment from respective organizations. Reviewers of studies have argued that as integrated care is a dynamic process, the long-term effects need to be monitored to draw lessons, not least because governance structures, developing appropriate leadership with clear goals, workforce requirements and financing mechanisms all take time to build and sustain. In the same way, a broader systems perspective has to be taken into account in developing models of care for both target populations or services in order that a greater understanding can develop of the interdependence of elements in the implementation of integration and how they interact.

Shift of emphasis

In recent years there has been a shift in the literature, with a greater emphasis on the process and appraisal of approaches rather than on effectiveness and outcomes. In addition, greater attention has been given to provision and supply of care as opposed to a concentration on the demand side. Recently integrated care frameworks have tended to adopt a population–health approach instead of a disease-based focus at the same time as a call for a more thorough understanding of person-centeredness as a way of shaping and improving interactions with patients and carers. This appears to have been driven not simply by the need to understand more fully chronic care but equally to evaluate the individual more holistically, acknowledging the role that non-disease components play.

Gaps

There is a growing call for evidence of multilevel initiatives over time for sustainable outcomes. Importantly, there is a need for frameworks and models of care to be inclusive of those with needs that require long-term management such as multimorbidity, thus including younger age groups as well as those who may be older and frail. More critically, there is room for a broader understanding of the contextual factors and mechanisms that drive success and their interdependence within a whole systems perspective.

In terms of integrated care, there is a need for a more accurate definition of population target groups and profiling needs, with greater attention paid to wider contextual factors, including those that will drive success. Further, given that most studies tend to concentrate solely on defining the elements of integrated care, it will be important to explore structures and possible strategies to support the actual process of any implementation of long-term care services.

At the meso level, too, there is a strong call for studies over time with a greater emphasis on components of local service organizational delivery covering both horizontal and vertical integration within health care and across organizational boundaries. These studies may focus on the role of providers, trusting multidisciplinary relationships or collaboration. At the macro level, policy, governance, finance and most importantly multisectoral coordination will all play an integral part in contributing to implementation of long-term care. Such developments may, in turn, define a need for a greater focus on the role of values at all three levels. Different values may be relevant at different levels, that is, from the individual to the team, organization, and system level.

At the macro level, the process of concretizing implementation of long-term care might include a consensus on desirable goals, governance principles or decision-making processes, while at the meso level, it might include guiding multidisciplinary care professionals in their relationships with colleagues and patients or in co-production. At all levels, the process of implementing long-term care will necessitate adaptive leadership styles. The clear need to articulate a core set of context-specific outcomes for long-term care has to be accompanied by the need to clarify definitions as well as target populations and cohorts so that it will be possible to evaluate health impacts within a broader and more holistic patient-centred context.

Conclusion: the need for a long-term care framework

A response is needed to the demand for a long-term care framework, which dictates a broad system change instead of piecemeal, isolated interventions. This has to be accompanied by longitudinal data on the health impact of long-term care services integrated within health systems. This will, in turn, necessitate a greater understanding of the interdependence and interaction of factors at the macro, meso and micro levels as well as, importantly, the role and value of more adaptive processes, particularly in leadership or professional and clinical cultures. Any guidance designed for policy-makers has to be aligned with evidence that is appropriate and detailed, but which is also context specific. Above all, frameworks are needed that assess the readiness for change, shifting the focus from the “why” and the “what” to the “how to”.

Glossary

Activities of daily living. The basic activities necessary for daily life, such as bathing or showering, dressing, eating, getting in or out of bed or chairs, using the toilet, and getting around inside the home (1).

Assistive care. Assistance provided to help a person perform a particular task to maintain functional ability and preserve independence (for example, caregiving).

Care coordination. A proactive approach that brings care professionals and providers together around the needs of service users to ensure that people receive integrated and person-focused care across various settings (2).

Carer, caregiver. Individuals who provide care for a member or members of their family, friends or community, usually informally. They may provide regular, occasional or routine care or be involved in organizing care delivered by others. Carers or caregivers are distinct from providers associated with a formal service delivery system, and most often provide unpaid care (1, 2).

Care worker. Care provider associated with formal service delivery systems of long-term care. Examples include professional, formal caregivers and carers, social workers and nurses (1, 2).

Case management. A targeted, community-based and proactive approach to care that involves case finding, assessment, care planning and care coordination to integrate services around the needs of people with a high level of risk requiring complex care (often from multiple providers or locations), people who are vulnerable, or people who have complex social and health needs. The case manager coordinates patient care throughout the entire continuum of care (2).

Continuity of information. Continuity of information is best achieved by a single information system, or by shared access to medical and social care records and highly effective communication – for example, a continuous flow of information when a person is discharged from acute care back to the community (in the form of effective discharge planning).

Digital health. An overarching term that comprises eHealth (which includes mHealth), and emerging areas, such as the use of computing sciences in the fields of artificial intelligence, big data and genomics (1).

Digital health intervention. A digital health intervention is defined here as a discrete functionality of digital technology that is applied to achieve health objectives. The range of digital health interventions is broad, and the software and technologies – digital applications – that make it possible to deliver these digital interventions continue to evolve within the inherently dynamic nature of the field (1).

Functional ability. The health-related attributes that enable people to be and to do what they have reason to value (1).

- **To build and maintain relationships.** Building and maintaining relationships is often identified by older people as central to their well-being, and as people age, they may give increasing priority to this ability. A broad range of relationships is important to older people, including their relationships with children and other family members, intimate relationships, and informal social relationships with friends, neighbours, colleagues and acquaintances, as well as more formal relationships with community service providers (1, 3).
- **To contribute.** The ability to contribute covers a myriad of contributions that older people make to their families and communities – such as assisting friends and neighbours, mentoring peers and younger people, and caring for family members and the wider community. The ability to contribute is closely associated with engagement in social and cultural activities (1, 3).
- **To learn, grow and make decisions.** The ability to learn, grow and make decisions includes efforts to continue to learn and apply knowledge, engage in problem solving, continue personal development, and be able to make choices (1, 3).
- **To meet basic needs.** The ability of older people to manage and meet their immediate and future needs to ensure an adequate standard of living as defined in Article 25 of the United Nations Universal Declaration of Human Rights. This ability includes older people being able to afford an adequate diet, clothing, suitable housing, and health care and long-term care services. It also extends to having support to minimize the impact of economic shocks that may come with illness, disability, losing a spouse or the means of livelihood (4, 5).

- **To be mobile.** The ability to be mobile is important for healthy ageing. It refers to movement in all its forms, whether powered by the body (with or without an assistive device) or a vehicle. Mobility is necessary for doing things around the house, accessing shops, services and facilities in the community, and participating in social, economic and cultural activities (3, 6).

Institutional care setting. Institutions in which long-term care is provided; these may include community centres, assisted living facilities, nursing homes, hospitals and other health facilities. Institutional care settings are not defined only by their size (1).

Instrumental activities of daily living. Activities that facilitate independent living, such as using the telephone, taking medications, managing money, shopping for groceries, preparing meals and using a map (1).

Intrinsic capacity. The composite of all the physical and mental capacities that an individual can draw on (1).

Long-term care facilities. Long-term care facilities may vary by country. Nursing homes, skilled nursing facilities, assisted living facilities, residential facilities and residential long-term care facilities are collectively known as long-term care facilities. They provide a variety of services, including medical and assistive care, to people who are unable to live independently in the community. The use of the term “long-term care facilities” does not include home-based long-term care, community centres, adult day care facilities or respite care (7).

Multidisciplinary or interdisciplinary team. An interdisciplinary team consists of members who work together interdependently to develop goals and a common care plan, although they maintain distinct professional responsibilities and individual assignments. Leadership functions are shared. A multidisciplinary team consists of members

of different disciplines, sometimes from one or more organizations, involved in the same task (assessing people, setting goals and making care recommendations), working alongside each other but functioning independently.

Palliative care. An approach that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (3, 6).

Person-centred assessment and care planning. Assessment and care planning that consciously adopts the perspective of individuals, families and communities, and sees them as participants in as well as beneficiaries of health care and long-term care systems that respond to their needs and preferences in humane and holistic ways. Person-centred care also requires that people have the education and support they need to make decisions and participate in their own care (2).

Provider continuity. Seeing the same professional each time, with the opportunity to establish a therapeutic, trusting relationship (a role often filled by the primary care physician, a care worker, or case manager).

Responsive referral protocols or pathways. Protocols or guidelines that outline clear indications for referrals and responsibilities of each professional and department involved.

Self-care. Activities carried out by individuals to promote, maintain, treat and care for themselves, as well as to engage in making decisions about their health (1).

Social network. An individual's web of kinship, friendship and community ties (1).

References: glossary

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