Healthy Ageing and the need for a Long-term-care system

Anne Margriet Pot & Andrew M Briggs, John R Beard

Global consultation on integrated care for older people (ICOPE)– the path to universal health coverage

23–25 October 2017

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# Table of Contents

1. Why do we need a system of long-term care? ................................................................. 2
2. What might a system of long-term care look like? .......................................................... 3
3. The establishment of a sustainable and equitable system of long-term care ................. 5
4. Moving Forward .................................................................................................................. 6
References ................................................................................................................................ 7
Glossary ...................................................................................................................................... 7
In 2016, WHO’s Member States unanimously adopted the *Global strategy and action plan on ageing and health*. The Strategy calls for every country to put in place a sustainable and equitable “system of long-term care”. But why is such a system needed? What might it look like? How might countries, particularly less developed countries, start to lay the foundations for it?

1. Why do we need a system of long-term care?

In many people’s lives there will come a stage when they experience a significant loss of mental or physical capacity, particularly in older age. Indeed, because populations around the world are rapidly ageing, the number of older people with significant ongoing losses is increasing rapidly. These people continue to have a right to the best attainable health, and WHO’s concept of *Healthy Ageing* provides a starting point for how to understand and meet their needs (Figure 1).¹

WHO considers *Healthy Ageing* from the perspective of an individual’s functional ability to be, and to do, the things they value. This functional ability is determined not just by an individual’s capacities, but also by the environments they inhabit and the care and support that is available to them. For people with significant losses of capacity, these support mechanisms are crucial and can help an older person maintain a level of ability, and live a life of meaning and dignity, despite these losses.

![Figure 1. Healthy Ageing model showing the target group for long-term care: people with a significant loss of capacity, or at risk of such a loss](image)

Many terms have been used to describe the care and support for people with significant losses of intrinsic capacity. This document seeks to clarify the purpose, approach and terminology used to describe these actions, and uses the term “long-term care” to describe the full range of these efforts, which are all directed towards a common endpoint – to ensure the best possible trajectories of an individual’s capacity and functional ability over time.
Long-term care can take many forms and be provided by many people. It may take the form of direct assistance from a caregiver for basic activities such as bathing or shopping. It might take the form of engaging with the recipient in a meaningful and respectful relationship. Or it may involve supporting them to maintain their capacities through physical activity or good nutrition.

This support can be provided by organised services such as primary health care, a community nurse or an occupational therapist. Sometimes it is provided in an institution, for example a care home, but most often it is provided in an older person’s home or community. It may be provided by a paid but untrained caregiver, by a friend, volunteer or community organization or by health care professionals. Traditionally, it is provided by a person’s family.

The reciprocal provision of care and support between generations has many benefits. For example, it may help to foster social cohesion and help families avoid poverty and catastrophic care expenditures. It can help frail older people maintain a role and a sense of purpose. But as the number of older people in need of care and support is increasing, the proportion of younger people who might be able to provide this care is falling. Moreover, women, the traditional caregivers within many families, are often aspiring to other social and economic roles. As a result, the assumption that families alone can meet the needs of older people with significant losses of capacity is outdated and neither sustainable nor equitable. Changing family structures, social roles and places of residence underline the need for a long-term-care system to support healthy ageing in the current world.

The Global strategy therefore calls on every country to start to build a system of long-term care. Just as configurations of universal health coverage will vary across countries, long-term-care systems would look different in every setting, depending on local culture, capacity and resources. It should build on the strengths of family care but comprise a partnership with government and other health and social care service providers. Importantly, this “social” care, support and assistance need to be much better integrated with health services so that all of the older person’s needs can be met in a coordinated way.

2. What might a system of long-term care look like?

WHO defines long-term care as “all activities undertaken by others to ensure that people with, or at risk of, a significant ongoing loss of capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity”

<table>
<thead>
<tr>
<th>Long-Term Care is:</th>
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<tr>
<td>✓ For whom? People with, or at a risk of a significant ongoing loss in capacity</td>
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<tr>
<td>✓ What? All activities of others to maintain people’s functional ability, for example social care and health services, aligned and in accordance with the person’s unique needs</td>
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<tr>
<td>✓ Why? To enable people to continue to live lives of meaning and dignity regardless of their level of physical or mental capacity</td>
</tr>
<tr>
<td>✓ Where? In all settings: at home, in the community or in nursing homes</td>
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Long-Term Care is NOT:

- For people who are expected to recover with no need for care and support anymore
- Nursing home care or family care only
- Poor quality care to the detriment of people’s functional ability and well-being
- Care services provided in silo’s
- Adaptations to the physical environment

A long-term-care system should coordinate all efforts to ensure the best possible trajectories of an individual’s capacity and functional ability over time. It should deliver services at the right time, in the best place, with good quality and tailor these services for people with different levels of capacity and different personal circumstances and aspirations. It should seamlessly link health and social services and care, and, above all, it should be person-centred.

The components of a Long-term-care system are described in further detail below. A Long-term-care system should:

1. **Focus on the person’s needs**
   Fundamentally, long-term addresses a person’s unique needs. This means that the components and sequencing of care needs to be aligned to the person, not the configurations of a service system or provider. While implementation of care services is important, they need to be focused on optimizing the trajectories of the person’s intrinsic capacity and functional ability, also for those with a significant ongoing loss in capacity.

2. **Focus on the individual as a person**
   Long-term care is a holistic approach to re-enable people despite their loss in intrinsic capacity. Long-term care is not focused on disease or capacity, but on the person as a whole. Person-centred care should aim to maintain the core abilities important to an older person, including older people’s abilities to move around; to build and maintain relationships; to learn, grow and decide; and to contribute to their communities.

3. **Focus on building upon the strengths of a person to foster self-management and control**
   Long-term care is meant to enable people to do as much as possible for themselves. This is important for an optimal trajectory of functional ability and well-being over time. Long-term care is not meant to take over activities that a person still can do, either independently or with some support. For example, a person with dementia might not be able to dress or undertake household chores independently, but explaining step by step how to dress or undertake tasks might be enough to let this person do the rest of the dressing or household tasks by him/herself. Removing the functional ability of a person to actively participate in physical and mental tasks will reduce intrinsic capacity in these domains and lead to deterioration of the person’s functional ability and well-being over time.
4. Focus on consistency with the person’s values, choices, and preferences
Irrespective of the care or support provided, there must be alignment with the person’s values, choices, and preferences. Every person is different, and will have unique values of what is important to him or her.

“Long-Term Care is about people, not about services”
Jing Xiao (79) does not succeed to do the shopping anymore. For the last two weeks, home help has been provide to do the shopping for her. However, is this the long-term care that she needs? She needs someone who can enable her to continue to do the shopping herself. Maybe she needs medical care, or a walker, or someone to drive her to the shopping centre because she has difficulty walking. Maybe making a shopping list together is enough for her to continue to do her own shopping. Assessment, care planning and the right person-centred care, support or assistance are key to help her perform her own shopping – instead of immediately taking over - to improve her functional ability and well-being.

3. The establishment of a sustainable and equitable system of long-term care

The Global strategy and action plan on ageing and health calls for every country to develop a sustainable and equitable system of long-term care, emphasising the importance of enabling older people to age in a place that is right for them. The form this system takes will vary among countries depending on specific contexts, available resources, existing infrastructure, cultural preferences and choices about how care resources should be distributed.

Integration and coordination of health and social care services will be important if optimal health and economic outcomes are to be achieved, so the approach used will also need to take account of existing health system structures, responsibilities and financing. This will require significant reorientation since the historic focus of most health systems has been to meet acute care needs, for example through centralised hospital services. Such systems are not well aligned with the needs of the increasing population of older people who tend to experience more chronic conditions and multi-morbidities.

An effective system of long-term care will also ensure that all caregivers are adequately trained and supported. Educational curricula need to be tailored to ensure graduates have the skills and understanding necessary to fill their role, and continuing professional development will be important if professional caregivers are to maintain them. Many paid caregivers have received little training and an effective system of long-term care can ensure general standards in the paid workforce and might establish accreditation mechanisms to ensure staff and care providers develop and maintain appropriate competencies. Moreover, since most care is provided by family caregivers, a core element of any system must be to ensure they receive adequate training, are supplemented where necessary with professional support and have access to services such as respite care. This can
not only ensure that the care recipients needs are understood and met, but also to ease the burden on caregivers who may be confronted with challenging situations without the understanding or tools that might help them deal with them.

While there is no generic model for how to achieve fairer, more supportive and more sustainable systems, many WHO Member States, particularly in resource-constrained settings, are looking for guidance on how to establish an effective, sustainable, and equitable system that will meet the needs of frail and care-dependent older people.

4. Moving Forward

WHO (2017) has identified three global actions that can facilitate the development of long-term-care systems:

a. Building understanding and commitment to developing long-term-care systems. One way of achieving this is through global, regional and local policy dialogues to catalyse change. The global consultation meeting in Berlin on Integrated Care for Older People – The path to Universal Health Coverage will provide an opportunity for concrete discussions about how health systems need to respond to the care needs of older people and strategies to provide long-term care and support.

b. Mapping the current situation in long-term-care provision in countries to inform country action and serve as a baseline with regard to the need, unmet need, type and quality of existing services, legislation, human resources and financing mechanisms.

c. Providing guidance, tools and technical assistance for countries at all levels of socioeconomic development, on building sustainable and equitable systems to meet the needs of older adults with significant losses of capacity. Guidance may draw from systematic reviews, case study analysis and expert meetings to inform strategies to overcome fragmentation of service provision and to ensure better outcomes for older care recipients and their caregivers.

These actions will catalyse and support countries to develop effective, sustainable and equitable systems and services that improve care for older people with significant losses in intrinsic capacity and reduce the burden on caregivers.

Some of the actions that have been taken in the three key areas of action are the following:

- To build understanding and commitment two initial regional policy dialogues on Long-Term Care have taken place (sub-Saharan Africa, 6-9 Dec. 2016, http://www.aphrc.org/iagg/, and West Pacific Region, 10-12 July 2017). Additional policy dialogues are planned, including one in East Asia in 2018.
- A short film on the importance of having a Long-term-care system in place is in progress.
- A framework for country self-assessment, policy making and monitoring are currently under development.
• At the end of 2017 the WHO Long-Term Care series to guide – especially low- and middle income - countries in laying the foundations of Long-Term-Care systems will be launched by publication of the first report ‘Towards Long-Term-Care systems in sub-Saharan Africa’.
• A tool for scaling up family support, an online self-help training and support program, is under development.

References


Glossary

Long-term care is defined as all activities undertaken by others to ensure that people with, or at risk of, a significant ongoing loss of capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity.

A long-term-care system is aimed at the delivery and coordination of all care, support and assistance to ensure the best possible trajectories of an individual’s capacity and functional ability over time for people with, or at risk of, a significant ongoing loss of capacity.