International Labour Organization

ILO brief

Social Protection Spotlight

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Securing access to long-term care without hardship as an integral part of universal social protection systems[1]

Key points

- Access to long-term care (LTC) should be provided through a rights-based approach. It is an enabling right for older persons who experience functional impairments insofar that it helps them towards their enjoyment of other human rights.
- Regarding the regulation of LTC service provision, out of 179 countries, only 89 of them (representing half of older persons globally) have established statutory national LTC services for older persons. Such a weak legal basis affects the ways in which services are provided and regulated.
- Even within countries that have statutory provisions, models of care encompass very diverse realities. Ideally, there should be a continuum of care along family, home-based social and health care, and residential care provided in different types of institutions for older persons who are unable, or no longer wish, to stay in their home. In practice, however, this continuum is not always a reality.
- The principles of broad risk pooling and solidarity and sustainability in financing, enshrined in international social security standards, are more relevant than ever when it comes to LTC. Countries, in their efforts to extend social protection coverage for LTC, have adopted different financing strategies and institutional arrangements; these include:

  (i) the creation of dedicated LTC schemes; (ii) the provision of "top-up" pension benefits or expansion of the scope of disability benefits; (iii) embedding LTC provision within social health protection benefit packages; or (iv) a combination of these strategies.
- Defining an appropriate package of benefits is critical as the scope of what is needed and what is covered in LTC is broad and a mix of benefits in cash and in kind is often required.
- Next in terms of importance is specifying the level of financial protection to be granted. In this respect, international social security standards (ISSS) on social health protection provide clear guidance on the avoidance of copayments, or at least on their limited use, so as not to create hardship. Most LTC programmes include some level of copayment. The absence of entitlements to LTC without hardship can lead to high out-of-pocket payments (OOPs) and impoverishment and ultimately to the erosion of old-age pensions, which are often at a level that is insufficient to cover LTC costs.
- A number of knowledge gaps need to be addressed in order to foster evidence-based policies geared towards such objectives. Most of the available evidence and data collection on LTC concern high-income countries. Context is important and therefore more evidence is needed in order to extrapolate lessons that are applicable to low- and middle-income countries.
- Ensure universal health coverage and take urgent measures for the extension of social health protection coverage to all, throughout the life cycle, with a focus on the groups most impacted by climate change that are not yet covered.

[1] This brief presents the role of universal social protection in securing access to long-term care (LTC) without hardship building on the working paper: "Long-term care in the context of population ageing: a rights-based approach to universal coverage" (Tessier et al. 2022).

Introduction

The demographic context is changing and societies will need to adapt. While population ageing is more advanced in certain countries, the transition will affect all countries, and the future pace of this demographic transition is projected to be faster in those countries whose populations are currently relatively younger and where resources are also comparatively scarcer. In many cases, these are low- and middle-income countries that lack universal social protection systems.

In view of such an evolving demographic trend, the ILO Centenary Declaration for the Future of Work, 2019, recognizes the importance of investment in the care economy as a means of achieving gender equality at work. In June 2021, the International Labour Conference (ILC) called on Member States and the International Labour Organization (ILO) to consider LTC as an integral part of social protection systems and to invest in the care economy and to support workers with care responsibilities (ILO 2021a). The role of social protection in LTC in the context of population ageing is more recently discussed in the ILC Report on Decent Work and the Care Economy (ILO 2024) and it will figure on the agenda of the 112th Session of the International Labour Conference in June 2024.

Defining long-term care (LTC)

There is a growing body of literature discussing LTC, yet definitions of its scope can vary greatly. Thus, some authors equate it to social care (Roland et al. 2022) while others include in its definition healthcare and social care services provided to all age groups in need of care or support to conduct activities of daily living (Addati et al. 2022). While activities of daily living are considered a core element, some authors and agencies put the emphasis on ability to live independently or to enjoy fundamental human rights and freedoms (Love and Lynch 2018). The World Health Organization (WHO) defines LTC systems' objectives as being to "enable older people, who experience significant declines in capacity, to receive the care and support that allow them to live a life consistent with their basic rights, fundamental freedoms and human dignity" (WHO 2021a). The variety of definitions reflects the range of different perspectives. From a needs-based perspective on who receives care, definitions can include persons in need of prolonged care across all age groups owing to disability or illness. Other definitions reflect the type of services provided (medical care, assistance with activities of daily living and so on), the place where they are provided (that is, institutions such as LTC facilities and nursing homes, clinical settings, communities or the home of the recipient) or the type of worker providing the service (specialized health personnel, personal care workers, domestic workers or unpaid family members) and whether or not they are licensed to do so (informal care and formal care) (GHWA and WHO 2014; ILO 2020b; UNECE 2019). Local social and cultural contexts vary greatly and may emphasize different aspects of LTC depending on what fits them best.

While fully acknowledging that LTC needs are present across all age groups, this brief focuses on LTC in the context of ageing. This brief uses available statistics that take the threshold for old age as being either 60 years, 65 years or the official national retirement age and endeavours to highlight the practical challenges of threshold definition in the context of social protection policies.[2] Focusing on LTC in the context of ageing, one of the objectives of social protection policies should be to ensure that efforts are made to prevent the need for LTC across the life cycle while also ensuring that all older persons in need of LTC can access it without suffering hardship and that those who provide it can enjoy continuous social protection coverage.[3] This brief focuses specifically on the need to access LTC services without suffering financial hardship.

The need for LTC in the context of ageing

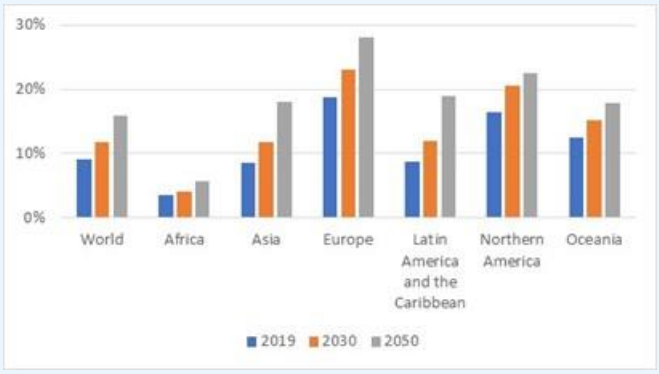
The need for LTC in older persons is determined by both their demographic and health status. The demand for LTC services is further influenced by the availability of LTC service providers and the aspiration to equal opportunity

[2] It is also necessary to appreciate that there is no universal age threshold for when a person is considered "old". Social and cultural perceptions of age vary widely across regions, countries and even localities. The UN has decided to monitor the Decade on Healthy Ageing by looking at adults above 60 years of age, while keeping in mind that policies at national level need to be tailored to local realities. In many countries, pension system reforms around retirement age have also shown that such thresholds can be relative and they do not always correspond with individual perceptions of them or sufficiently take into account people's capacities.

[3] As per ILO Convention No. 156, those who provide unpaid care and need to balance it with economic activity can do so without discrimination as part of their right to equal opportunity and treatment in employment and occupation.

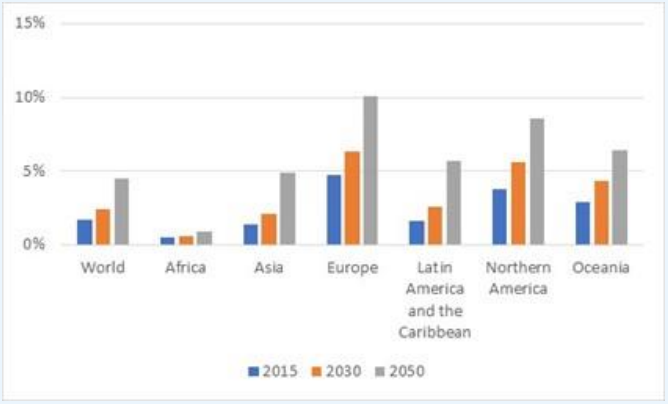
and treatment at work of unpaid family workers. While there is ample data on the demographic aspect and its correlation with ageing (see figures 1 and 2), the situation is very different when it comes to obtaining evidence on the health status, functional abilities and intrinsic capacities of older persons worldwide. The data is both scarce and difficult to compare or corroborate[4]. However, the WHO has been able to estimate, based on countries for which data is available, that worldwide 142 million persons older than 60 years of age (a fifth of older persons globally) currently lack the functional ability to meet their own basic needs to dress, take medication and independently manage money (WHO 2021a). This situation is compounded by the inability of many older persons to meet other basic needs such as nutrition and housing as they are disproportionally represented among the world's poor (Randel et al. 2017).

▶ **Figure 1: Percentage of the total population aged 65 years or over in 2019 and projections for 2030 and 2050**



Source: UN, 2019.

▶ **Figure 2: Percentage of the total population aged 80 years or over in 2015 and projections for 2030 and 2050**



Source: UN, 2015.

A clear pattern of increase in loss of intrinsic capacities with age emerges, especially beyond the age of 80 (WHO 2021a). Therefore, as longevity increases, so will the probability that people require LTC. This trend masks considerable variations, some of which are largely determined by socio-economic and other inequalities. The pattern of impairment of intrinsic capacities with age is more pronounced for women than for men, with a gap that widens with age (WHO 2021a). Thus, estimates in China forecast that while disability will be multiplied by a factor of 1.5 among the older population in general in the coming decades, it will double in older women (Cui 2019).

Similarly, there is evidence from a number of countries where data is available to show that older persons at the lowest end of the wealth distribution spectrum and with the least educational attainment tend to have higher LTC needs. For example, it has been found that older persons who have not completed high school are three times more likely to have severe needs than ones with a university degree (Johnson 2019).

This situation has two important implications. Firstly, it means that at the individual level the need for LTC, both in term of timing and magnitude, cannot be anticipated with any certainty. The uncertainty of the risk and its inequitable distribution make a strong case to treat this as a whole-of-society matter that calls for solidarity and collective action. Secondly, there are levers that can help prevent some of the need for LTC. There is evidence that

[4] According to WHO, 2020, three quarters of the world's countries have limited or no comparative data on healthy ageing or on older age groups.

diversity in functional abilities and intrinsic capacities in old age are often at least partially determined by the compounded impact of the disadvantages and deprivations people experience throughout their lives as by the adaptation of their direct environment (that is, their homes, the places where they shop or do leisure activities), thus calling for a life-cycle approach to healthy ageing and pointing to the need to address the social determinants of health, including through social protection benefits throughout the life course.

LTC, within the broader context of healthy ageing, needs a multi-sectoral response that puts older persons and their carers at the centre. This notion was embedded in the 2002 Madrid International Plan of Action on Ageing (MIPAA), adopted during the Second World Assembly on Ageing and likewise in the United Nations General Assembly's declaration of 2021–2030 as the Decade of Healthy Ageing.[5]

Given current trends, while the majority of older persons may not require LTC, a small proportion of them necessarily does and this proportion increases with age. With the absolute number of older people on the rise and longevity also increasing, the need for LTC is correspondingly mounting. This is a multi-faceted issue that goes well beyond the scope solely of social protection policies. Thus, social protection policies should aim to ensure that all those in need of LTC can access it without incurring hardship, while ensuring that the those persons who provide it can enjoy continuous social security coverage. While the modalities that each country will choose for the delivery of the requisite services and their financing may vary greatly, social protection policies will need to be flexible and to offer tailored solutions while keeping the aspirations of older persons in need of LTC and also those of their caregivers at the centre of coordinated policy responses.

Guidance from international social security standards (ISSS) provides a range of principles that can be employed in the design and implementation of social protection schemes, aimed at guaranteeing LTC without hardship and which satisfy the criteria of availability, accessibility, acceptability and quality with a view to supporting life in dignity. While ISSS have yet to identify LTC as a separate contingency, it is still possible to utilize their general principles as well as refer to other contingencies addressed by health and old-age benefits as guidance in drafting LTC policy. This brief sets out the principles that relate to different scheme design parameters along the dimensions of population coverage, benefit adequacy, sustainable financing, governance and administration.

Coverage of the population

Because the risk of needing LTC is uncertain and the determining factors are complex and difficult to anticipate, this is a risk best financed and managed collectively. Moreover, in many countries old age and disability are not evenly distributed across geographical locations and income levels, which calls for adopting an approach based on rights and broad risk sharing.

Access to LTC should adopt a rights-based approach because it constitutes an enabling right for older persons with functional impairments insofar that it helps them towards their enjoyment of other human rights. Their accessing of LTC services is necessary for ensuring their continued meaningful participation in public and family life and for maximizing the contribution they can make to society. With this principle in mind, a number of countries, such as Sweden, have enshrined in their legal framework the right to LTC benefits based on needs rather than means (Schön and Heap 2018). There is limited data on legal coverage for LTC entitlements and the available evidence highlights important coverage gaps, suggesting that as little as 5.6 per cent of the global population over 65 years of age lives in countries that provide universal legal entitlements to free or affordable LTC (Scheil-Adlung 2015).

Today, the majority of countries that have recognized the public provision of LTC services in national legislation have done so with conditions of resources for beneficiaries (that is, with some form of means test). Out of 60 countries, 55 have targeted or means-tested provisions (Addati et al. 2022). The rationale behind this policy choice is often to contain public expenditure on LTC (ILO 2017). The scalability of this approach and its desirability are limited, however, by a number of factors:

- Firstly, while means testing for the provision of LTC services ensures a level of solidarity between the poor and higher-income groups, it fails to share the risk of needing LTC services among all members of society and therefore tends to favour the development of a

[5] United Nations General Assembly Resolution A/RES/75/131. United Nations Decade of Healthy Ageing (2021–2030). Available at: https://undocs.org/en/A/RES/75/131

two-tiered system. In such a system, public provision often ends-up catering to the poorest, who generally have less of a say in policy processes owing to lack of adequate representation and such service provision is therefore more susceptible to budget cuts and deterioration of quality over time. Furthermore, it is not a gender-neutral choice, in light of the fact that women live longer and that globally older women are over-represented at the lower end of the income spectrum (Kidd and Whitehouse 2009; OECD 2019). For instance, a review of the means-tested LTC voucher scheme in Nanjing, China, revealed that the conditions of eligibility for the scheme were too narrow to render it effective in responding to needs and that the level of the benefit was too low in comparison to the average costs of accessing LTC (Yang et al. 2016).

- Secondly, there are well-documented issues with the implementation of means tests, in particular with proxy means tests, which are used in countries where access to reliable information on household income is limited. In those countries, exclusion errors have been shown to be rampant and to negatively impact the effective coverage of health services and social assistance (Devereux et al. 2015; Kidd et al. 2017). Therefore, one may question the feasibility and desirability of adopting a similar approach for LTC guarantees.
- Lastly, there is a well-documented shortage of health and personal care workers in the LTC sector. Therefore, creating different risk pools for LTC runs the risk of generating or perpetuating large inequities in access and quality of the benefits provided, with the wealthiest pools being able to attract most of the available supply. This is an issue at the country level but also has a global dimension since the labour market for health and care workers is globalized (Thompson et al. 2022). This, in turn, has implications for the unpaid, often female, family carers who have to fill the gap when professional care remains out of reach.

Attaining universal coverage of the population and ensuring that everyone can access quality LTC services while being protected against the associated costs when they need such services require a broader effort to close social protection coverage gaps in many countries. When it comes to extending social protection coverage in the areas of health and old-age pension benefits, universal protection has still to be achieved (ILO 2021c).

Against this backdrop, building LTC schemes runs several risks:

- Firstly, if LTC systems are built on the basis of existing health and pension schemes, then given the path dependency in social protection/social security systems they risk replicating similar population coverage gaps. For instance, when the city of Shanghai decided to include some LTC benefits, it did so by expanding the benefit packages of the then three different social health insurance (SHI) schemes, which meant that the LTC scheme also suffered from the coverage gaps and inequities inherited from a fragmented social health insurance landscape (Yang et al. 2016).
- Secondly, if it is created without a substantial coverage extension of all three guarantees (LTC, healthcare, pensions), then it runs the risk of creating a game of cost shifting. For instance, where healthcare benefits are accessible to all, but LTC benefits are means-tested, a tendency towards later discharge owing to the unavailability of social care services may still prevail. Similarly, if LTC schemes are created where health and pension benefits are not available, this can create an increased demand on the scheme. Therefore, it is important to address the coverage gaps of pension and health benefits alongside the design of solutions to cover LTC costs. This is of particular importance for low- and middle-income countries, where ageing is happening at a faster pace than in other countries, yet health and pension coverage are lower.

It is also worth mentioning that when LTC services are needed by younger population groups, such as persons of working age living with disabilities, the social protection coverage gaps for people with disabilities also exacerbate the lack of adequate LTC services. The latest ILO estimates of effective coverage show that only 33.5 per cent of people with severe disabilities worldwide receive a disability benefit (ILO 2021c).

Adequacy of benefits

Though international social security standards (ISSS) clearly provide a legal basis for social protection systems to support access to LTC without hardship, they do not yet provide a benchmark when it comes to determining adequacy of LTC benefits as they do with other contingencies. It is important to consider for LTC the issue of adequacy along the dimensions that ISSS consider for health and income support benefits. Hence, an entitlement is materialized though a clear definition of: i) the contingency covered; ii) a package of benefits corresponding to the contingency, principally the range of

LTC services that are made accessible; iii) the level of financial protection provided to cover the costs of the benefit package; and iv) a dedicated network of service providers in charge of service delivery (that is, a network from which services can be availed and which meet certain quality criteria). The adequacy of benefits is largely contingent on the design of these four parameters, which will be explored in this part of the brief.

Contingency, eligibility, assessment and periodic review

The contingency that LTC benefits should aim at covering can be summarized as being foremost a significant decline in a person's capacity requiring extended care and support in order to live a life consistent with human rights and dignity. In practice, countries have defined various criteria and rules governing eligibility for LTC benefits. These rules provide concrete interpretations of contingency. The ability to perform activities of daily living (ADLs) – eating, bathing, dressing, toileting, mobility and continence – is generally used as a key indicator for assessing the need for both care and social services (ISSA 2022b). There are several ways that loss of function can be assessed, and in most countries with LTC benefits, loss of function is commonly understood as the inability to perform activities of daily living. For example, in Singapore, the assessment of loss of function is carried out by an assessor accredited by the Ministry of Health and LTC benefits under the ElderShield social insurance programme are granted to older persons and persons with severe disabilities who require the physical assistance of another person to perform at least three of the following activities of daily living: washing, feeding, dressing, toileting, mobility and transferring (that is, the ability to move from bed to an upright chair or wheelchair) (ILO 2021b). While the inability to perform one or several ADL alone is commonly used across existing LTC provisions, it is important to note that care needs may go beyond those (see **box 1)**.

▶ Box 1: Incidence of difficulties in the performance of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) among older adults in Malaysia

The National Health Morbidity Survey (NHMS) of Malaysia is a periodic survey conducted by the Ministry of Health every four years. In 2018, its survey focused on the health of older adults and recorded their functional limitations in performing both their activities of daily living (ADLs) and instrumental activities of daily living (IADLs). While ADL measurement was based on the self-care activities of grooming, using the toilet, feeding, bathing, transfer, mobility, dressing and climbing, IADLs included activities that are integral to independent living, such as using the telephone, shopping, preparing food, housekeeping, doing laundry, using transportation, medication self-management and handling finances. Interestingly, while only 17 per cent of older adult respondents reported some level of functional limitation in ADLs, over 40 per cent reported being dependent for IADLs.

Source: Yunus et al., 2022.

If the goal of an LTC social protection guarantee is to support life in dignity, a broad consideration of functional loss is needed, as well as of the crucial matter of a person's aspiration to independent living. With regard to the latter, support may be needed to perform activities such as preparing food, doing laundry, buying food or going out to participate in community activities. The UN Decade on Healthy Ageing has specified three important dimensions to articulate the aspirations of older persons (see **box 2**). These provide a useful framework to refer to when defining LTC as a life contingency and determining which objectives might be addressed by social protection policies and social security systems.

▶ Box 2: Defining the contingency for LTC: the three dimensions of healthy ageing activities of daily living (IADLs) among older adults in Malaysia

The UN Decade on Healthy Ageing considers three important dimensions: functional ability, intrinsic capacity and environment. Functional ability "enables people to be and to do what they have reason to value". It refers to several domains, including people's abilities to:

- "meet their basic needs to ensure an adequate standard of living (such as being able to afford an adequate diet, clothing, suitable housing, and healthcare and long term care services, including medications);
- learn, grow and make decisions (to strengthen the person's autonomy, dignity, integrity, freedom and independence);
- be mobile (for completing daily tasks and participating in activities);
- build and maintain relationships (with children and family, intimate partners, neighbours and others); and
- contribute to society (such as by assisting friends, mentoring younger people, caring for family members, volunteering, pursuing cultural activities and working)."

Intrinsic capacity comprises "all the physical and mental capacities that a person can draw on", including locomotor capacity (physical movement); sensory capacity (such as vision and hearing); vitality (energy and balance); cognition; and psychological capacity.

Similarly, living environments (including home, community and society at large) shape what people with a certain level of intrinsic capacity can effectively do. In particular, the following can be considered: products, equipment and technology (with the potential to facilitate – or even impede – movement, sight, memory and daily functioning); the built environment; access to emotional support, assistance and relationships; individual and societal attitudes – and more broadly, services, systems and policies.

Source: WHO, 2021a.

In the case of countries with limited resources, it is important to consider solutions for assessment of loss of function that will be implementable within the context of existing health and social care structures. In this respect, much can be learned from the work on disability benefits, and especially with respect to measuring functional impairment, such as the question sets developed by the Washington Group. For instance, in Cambodia, community workers have been trained to determine the social and environmental dimensions for use in classifying disability into three different levels (Boros 2022). In the Dominican Republic, the national census has been used to create a social registry that includes the identification of persons with disabilities according to the six domains of communication, mobility, ability to bathe, recall/concentration, hearing and vision (Lizardo 2022).

In order for it to be fit for purpose, the assessment of eligibility for LTC benefits requires flexibility and periodic reassessment to reflect individuals' changing needs and circumstances. LTC schemes must depend on eligibility criteria that take into account the trend in increasing functional loss that accompanies ageing, as well as patterns of degenerative conditions. In Japan, under Article 28 of the Long-Term Care Insurance Act, the Ministry of Health, Labour and Welfare recommends that the periodicity of reassessment be every 12 months. However, municipalities can flexibly adjust this periodicity within a range of 3 to 48 months (Japan 2021).

Package of benefits

Deciding on the package of benefits that needs to be provided to adequately secure access to LTC without hardship is arguably one of the most central elements in the design and establishment of social protection guarantees in LTC. Defining them appropriately is therefore critical as the scope of what is needed and what is covered in LTC is wide and a variety of benefits are often required. Indeed, a mix of benefits in cash and in kind may be needed. Similarly, responsiveness to actual needs entails access to a range of services, encompassing healthcare and social care services provided in the home, in the community or in institutions, as well as access to house equipment/adaptations and assistive medical devices.

- Benefits in kind are typically health and personal care services needed to preserve health, prevent further loss of function, conduct activities of daily living, support independent living and foster participation in social activities.
- Cash benefits can take different forms, such as cash to the person in need of LTC to cover the costs of accessing goods and services not directly provided in

kind, direct payment to care takers or subsidy for home accessibility improvements.

Work on the definition of a basic LTC package applicable for all in need is still ongoing. Preliminary work has highlighted the mixed nature of the benefits to be provided, as well as the urgent need to assure that the provision of them meets the intertwined objectives of universal health coverage and universal social protection (Perracini et al. 2022) (see **box 3**).

▶ **Box 3: Defining a benefit package for LTC**

As per ISSS, there is no one-size-fits-all and each Member State needs to tailor its social protection benefits to its national circumstances, including for example to the epidemiological profile of its population when it comes to healthcare benefits. The standards offer an approach based on reaching a desired objective (effective protection against a defined contingency) through possibly a diversity of modalities respecting a number of common key principles (such as solidarity in financing, risk pooling, non-discrimination and the like). Such an approach can guide the definition of benefit packages for LTC at national level.

At a minimum, such a package would need to ensure that persons in need of LTC can effectively access a range of services of good quality and without hardship. The relevant services should support them in living their life in dignity, as well as contribute to maintaining or improving their physical health to the extent possible, support their activities of daily living and realize their desire for independent living, while giving them scope for autonomy and inclusion. Such an aspiration is likely to require the definition of a package of benefits provided in kind, but also in cash in some circumstances. The package is likely to consist of a combination of health and other services, provided in a variety of settings across an integrated continuum of care.

Working on the basis of a WHO consensus study conducted among a globally selected body of specialists and stakeholders, an expert panel has been able to achieve consensus on 50 interventions across six categories ranging from training and support to care workers to palliative care to formulate a package of LTC services focused on healthy ageing (Perracini et al. 2022).

Today, benefit packages in practice vary considerably from country to country. Thus, in some countries different types of benefits are provided via different schemes. Considering the example of three Asian countries, Japan, the Republic of Korea and Singapore, it can be seen that diverse approaches have been adopted. Thus, in Japan, health and social care can be accessed through services that are facility-, home- or community-based, as can preventative LTC services depending on the level of care needed (Yamada and Arai 2020). In Singapore, the long-term care social insurance (LTCI) programme, ElderShield, provides benefits in cash in the form of monthly payments (Singapore, n.d.). In contrast, the Republic of Korea provides benefits both in-kind and cash benefits. With regard to the LTCI programme in Singapore, this offers a unique benefit package, defined positively and including home care services, such as bathing, day and night care, nursing for older family members. It likewise makes available assistance with household services, institutional care and in exceptional cases, cash benefits (Lee 2015). In the Republic of Korea, a family member who supports beneficiaries can receive supportive cash benefits from the National Health Insurance Service (NHIS). LTCI in the Republic of Korea also gives financial support in the purchase of equipment required to provide assistance with the daily and physical activities of persons who have difficulties carrying out their daily routines owing to physical or cognitive decline (National Health Insurance Service 2020). Similarly, cash benefits are provided on a case-by-case basis to older persons living in remote areas with no access to in-kind benefits (Choi 2015). The differences in the form taken by LTC benefits across countries also reflect to some extent differences in the models of care chosen by countries and their national circumstances.

When designing LTC benefits, countries often need to take into consideration which health services may already be included under existing health and social care programmes and it may not always be necessary to create a new dedicated programme. Nevertheless, it is crucial to map existing gaps and find adequate solutions to bridge them. This requires inter-sectoral coordination among the different line ministries and responsible agencies.

Financial protection

Once the benefits and services to be covered have been determined, it is next important to specify the level of financial protection to be granted. In this respect, ISSS on

social health protection provide clear guidance on the avoidance of copayments or limited use of them so as not to create hardship (ILO 2020a). There is evidence that out-of-pocket payments (OOPs) for LTC services are high globally and in many countries, they are the main funding mechanism for such services (see **box 4**). Only 29 countries have set up a universal and free LTC service scheme enshrined in national legislation (Addati et al. 2022).

▶ Box 4: Impoverishing out-of-pocket payments (OOPs) from households on LTC

In many countries, owing to the lack of legal entitlements to LTC benefits without hardship, most of the LTC costs are borne by households via OOPs. Even in countries with some legal entitlements, financial protection can be limited by high copayments and user fees. For instance, available data from OECD countries on OOP related to LTC show overall high levels of OOP in comparison to income and large discrepancies across countries, including countries in similar income groups.

Even older persons with low needs can suffer impoverishing spending. For example, the OECD estimates that OOP on home-based LTC for people with relatively low needs represents 44 per cent of the median disposable income in old age in Latvia while it represents only 5 per cent in Japan (OECD 2021).[6] This figure goes up to 223 per cent and 32 per cent respectively when it comes to home-based LTC for severe needs, while the difference between the two countries virtually disappears when it comes to institutional care, with OOP ranging from 34 to 36 per cent of median disposable income in old age. In all instances, while no threshold is internationally recognized when it comes to OOP on LTC, it is important to consider that for healthcare, households incurring OOPs representing either over 10 per cent or over 25 per cent of their total income/consumption are deemed to be experiencing catastrophic spending. For many older persons living on low incomes such thresholds may already be set too high (ILO 2017).

More importantly, many older persons are not even incurring OOP spending on LTC simply because they cannot access LTC services in the first place. Indeed, large shortages in the LTC workforce make access to services extremely difficult for the majority of the world's older persons, especially in low- and middle-income countries and in remote areas (ILO 2017).

The lack of LTC services and their cost, when they exist, are barriers that account for why at present most of the care provision is shouldered by households themselves, especially by working-age women. The economic value of this unpaid work is estimated to exceed OOP and public spending on LTC in the United States, for example (Utz 2022).

[6] Source: OECD analyses based on the OECD Long-Term Care Social Protection questionnaire and the OECD Income (IDD) and Wealth (WDD) Distribution Databases.

Most LTC programmes include some level of copayment. The absence of entitlements to LTC without hardship can lead to high OOPs and impoverishment and to the erosion of old-age pensions, which are often at a level that is insufficient to cover high OOPs on LTC. A study in Malaysia compared the monthly cost of private nursing homes (public ones are only available subject to means testing and other narrow eligibility criteria[7]) with the mean income of older adults and found it to be two to three times higher.

Network of service providers, contracting modalities and service delivery models

Once the range of benefits to be provided and their level of financial protection are defined, a network of service providers must be identified that are able to deliver services meeting the criteria of availability, acceptability, accessibility and quality of care, so that beneficiaries can effectively avail themselves of such benefits. In accordance with the type of scheme, benefits can take various forms, with some countries providing only cash benefits that beneficiaries are free to use in care markets (which can be regulated to varying degrees depending on the country context), while other countries may organize and sometimes provide LTC services eligible for coverage exclusively through public services. When considering the typically mixed nature of the benefit package needed by people experiencing functional impairments, it can be seen that identifying service providers and delimiting the profile of their remit while also guaranteeing service quality are a complex matter. Services are often associated with specific sectors such as healthcare, social care and domestic work. The regulation of the private provision of care also varies greatly across countries, ranging from very stringent through to an absence of regulation thus making contracting difficult. The existence of weak legal frameworks in some countries along with a broad diversity of actors providing LTC are complicating factors in the identification and contracting of LTC services by social protection schemes, and are compounded by the issue of scarcity of supply (Bannenberg et al. 2019).

Constraints for contracting LTC service providers can be groupped in three main themes:

- Lack of regulatory frameworks;
- Wide diversity of providers;
- Insufficient evidence on provider payment methods.

Regulation in LTC service provision

Out of 179 countries, only 89 of them (representing half of the older persons globally) have established statutory national LTC services for older persons. In 69 countries in-home personal care services are mandated and 87 countries alone mandate statutory provision of residential LTC services. Similarly, 70 countries have laws obliging families to care for older relatives (Addati et al. 2022). Such a weak legal basis as the foregoing affects the ways in which services are provided and regulated. Regulation encompasses authorization, licensing, control and oversight of service providers and is often weak in the LTC sector (Mor et al. 2014). In turn, lack of regulation makes it difficult for public authorities to contract providers and hence at a broader level hinders the provision of quality care that meets the criteria of availability, acceptability and accessibility.

Collaboration among healthcare, social care and social protection/social security systems is needed to ensure quality, especially with care models that are pluralistic (that is, comprising a mix of public and private provision). It is the responsibility of the State to ensure regulation and oversight geared towards quality care so as to avoid negligence and malpractices

The establishment of harmonized quality standards for LTC service providers is an important step forward for monitoring the dimensions of availability, acceptability, accessibility and quality of care and in determining which care providers to contract. However, such harmonization is seldom present at national level and monitoring is weak, particularly for home care services. A recent regional study conducted across 14 Latin American countries found overall low levels of registration and licensing requirements, compliance and controls of care providers and care workers, even though the majority of countries have established minimum quality criteria at the national level (Aranco et al. 2022).

[7] In Malaysia only 0.4 per cent of the population was living below the national poverty line in 2020 according to the Department of Statistics of Malaysia (Malaysia 2020)

Diversity of providers along the continuum of care

Even within countries that have statutory provisions, models of care encompass very diverse realities. Ideally, there should be a continuum of care along family, home-based social and healthcare and residential care provided in different types of institutions for older persons who are unable, or no longer wish, to stay in their home. In practice, this continuum is not always a reality and coordination across it is not necessarily well organized (WHO 2021b). Choosing the network of providers of LTC services is therefore complex, country-specific and highly strategic. It requires strong coordination between the health and social care sectors and a good understanding of the diversity of care models.

Contracting modalities need to be adapted according to each type of provider and intervention and their diversity adds complexity to the process of administering care. Moreover, the provision of health and social care in the home is not always well regulated, which creates issues in the contracting of such services. Accordingly, some countries have explored simplified procedures for the formalization of care work with the aim of making contracting possible. Provider payments mechanisms also need to be aligned with the objectives of access and quality.

The diversity of LTC providers encompasses differences in the type of settings (medical institutions, community institutions, home-based) as well as in the type of ownership (public and centralized, public and decentralized, private for profit and private not-for-profits). In view of the largely informal nature and status of care work in many settings, a number of countries have made efforts to support the structuration and integration of care providers into registered not-for-profit organizations that are also anchored in the community, such as associations, mutual benefit societies or cooperatives (ILO 2022).

Some countries have explored the use of community volunteers, though this has been accomplished with varying degrees of success and has been conditional on the way that a volunteer's role has been defined and supported. Ultimately, many countries have acknowledged that the role of the unpaid family caregiver needs to be recognized and have adapted the social protection system to ensure that unpaid family caregivers can receive an income for the care they dispense. Social protection coverage of caregivers is explored in the last section of this paper, 'Decent working conditions and extension of social security coverage to paid health and care workers' .

Provider payment methods

The diversity of provider payment methods currently used reflects the diversity of care models, providers and legal entitlements to LTC without hardship. Often various payment methods exist side by side in a country depending on the type of services (home-based, institutional care), the type of provider (public, private, voluntary sector) and, if several are in place, the scheme securing the entitlements (LTC social insurance, national healthcare system, social assistance scheme, etc., which may be under the oversight of different ministries). In China, for example, several LTC programmes have been implemented in different localities using different provider payment mechanisms. Thus, while in Shanghai institutional LTC was covered by the social health insurance schemes using fee for service, in Qingdao the LTC nursing insurance was able to negotiate with institutional providers a price schedule based on per diem and with home-based care providers based on daily rates (Yang et al. 2016).

While little systematic compilation of data or comparison across countries in the low- and middle-income groups is available when it comes to provider payment methods for LTC, many of the caveats of strategic purchasing for healthcare apply, in particular to institutional care. At the same time, the pressure to contain costs in higher-income countries (HICs) has motivated a number of the reforms aimed at shifting the burden of LTC onto the social care system through home-based care, viewed as a cheaper option for older persons at the lower end of the dependency spectrum. Nevertheless, the cost containment motivation tends to affect the method and level of provider payments, which in turn impacts on working conditions and remuneration of care workers.

A greater effort is needed to document in a systematic manner the various provision and contracting modalities of LTC, especially in low- and middle-income countries, so that the strengths and weaknesses of these modalities can be identified.

Governance and administration

Participation

It is paramount to build person-centred LTC systems. The principle of participation of the persons concerned and effective social dialogue in social security governance are at the forefront of international social security standards and should apply. Engaging with social partners will be key in building systems that are both responsive to needs and financially sustainable. The participation of the representatives of persons concerned by LTC benefits can be a tremendous asset in the design and implementation of LTC schemes.

The elements of responsiveness to needs at both the design and implementation stages are seen as crucial for monitoring the effectiveness of LTC schemes (Allen et al. 2011). While the reality of this is acknowledged, much less research has been devoted in this respect to the concrete modalities for continuous and meaningful social dialogue within the settings of various countries. This is all the more pertinent in view of the fact that social partners have a role to play not only in the governance of social security mechanisms for LTC but are also key actors in shaping the LTC provision labour market and working conditions.

Coordination

Coordination with the various actors across the continuum of care

With the increasing incidence of LTC needs, more people are experiencing the need to access and receive different kinds of health and social services, which can sometimes result in very complex situations. As management and coordination tasks need to be accomplished by different organizations, professions and family carers, a more horizontal coordination and integration of social and healthcare is crucial in order to reduce the pressure on health systems and enhance the quality of LTC. Care can be provided by a combination of family, civil society, the public sector and the private sector. Nevertheless, governments should take overall responsibility and assume the coordinating role for mobilizing resources and ensuring the proper functioning of the system (WHO 2021b).

Ensuring coordination contributes to enhancing the quality of care, patient experience and prevention opportunities. For example, to reduce the risk of rehospitalization for people aged over 75 and to prevent the loss of autonomy, the French national health insurance agency, *Caisse nationale de l'assurance maladie* (CNAM), offers older people who are still independent specific support from the moment they are discharged from hospital for a period of 30 to 90 days (National Sickness Insurance Fund 2016). This support aims to optimize a smooth transition between hospital and home and to organize the health pathway around multi-professional teams (physician, nurse, pharmacist) and social services (meal delivery, household help).

To enhance the services offered to older people requiring home care, a range of initiatives has emerged. The move to professionalize services aimed specifically at older people goes hand in hand with providing technical solutions to support the work of everyone involved in an individual's care. The Social Insurance Fund of Costa Rica, for example, has devised a mobile application, the Single Digital Health Record (*Expediente Digital Único en Salud – EDUS*), that enables home-based care providers to access a patient's medical history and profile via an integrated mobile family record system, thus facilitating the delivery of coordinated care (Social Insurance Fund of Costa Rica 2020).

Coordination across social security branches and with the health sector

The role of social security institutions is to administer the rights and obligations of their members and beneficiaries and this function has become even more critical amidst growing threats to health security. The challenges and risks associated with population ageing and changing healthcare and LTC needs have been on the social security agenda for many years (ISSA 2022b; 2021a). More recently, concerns about ageing unequally and lack of access to LTC services and benefits have received considerable attention. Dynamic social security systems, then, need to anticipate new risks and develop tailored strategies to support confronting urgent LTC challenges in coordination with other actors.

When designing new LTC schemes, countries need to take stock of the currently provided healthcare, social care and old-age pension benefits. Making use of installed capacities in the provision as well as in the management of entitlements will be paramount in avoiding duplication of efforts and multiplication of administration costs. In this perspective, a pragmatic approach consists in involving social security institutions that have expertise

firstly in managing/contracting complex service delivery systems (such as national health insurance schemes) and secondly in administering benefits that are financed through a mix of revenues from social security contributions and a range of tax revenues.

Overall, the role of social security is evolving from 'payer to player', as social security institutions come to acknowledge the need for them to act across a range of domains in taking advantage of the opportunities that ageing offers by supporting health, employment and empowerment of older persons. Greater coordination among different branches of social security is essential (that is, across disability, unemployment, health and retirement systems) with a view to responding to the needs of older persons in a holistic manner.

This needs to go hand in hand with an increased focus on primary healthcare, in particular on promotion and prevention activities, an investment called upon by many Ministries of Health and that social security systems should support.

Financing

Financing arrangements are not neutral. The principles enshrined in ISSS of broad risk pooling and solidarity and sustainability in financing are more relevant than ever when it comes to LTC.

Public financing is needed for several reasons. A principal reason is that the absence or insufficiency of public financing for LTC affects the adequacy of pension benefits, which are rendered too low to cover both living expenses and LTC. The financial sustainability of health benefits is also undermined owing to the absence of public financing of LTC, as some of the its costs are shifted towards the health system. To reduce gaps in care and excessive hospitalizations, many countries are seeking to coordinate health and social care provision, enabling individuals to remain at home for as long as possible. For instance, in the United Kingdom, the National Health Service (NHS) of Great Britain and Northern Ireland did not initially finance most LTC or social care services and in turn, deficiencies in public financing of those services and poor coordination incurred costs to the NHS. In 2016, the NHS estimated that the use of over 60,000 hospital bed days per month resulted from delayed discharges from hospital attributable to failures in social care (Smith 2018). However, the implementation of an effective system of LTC can relieve the pressure on such healthcare services and resources. Thus, according to research[8] conducted in Catalonia, Spain, a monthly LTC benefit equivalent to 214 euros was able to reduce avoidable hospitalizations by 60 per cent and numbers of unscheduled "walk-in" patient visits by a half (Serrano-Alarcón et al. 2021).

Another reason for public financing of LTC is that leaving it to be financed by OOP and unpaid family caregivers is regressive, inequitable for those who do not have family members who can provide this care and entails a significant opportunity cost for unpaid caregivers. In this respect, solidarity-based financing mechanisms are most appropriate to ensure families and older persons themselves do not have to bear individually the burden of loss of function. This type of financing mechanism can further foster social inclusion and contribute to renewing the social contract that binds people in societies (Razavi et al. 2020).

In their attempt to extend social protection coverage for LTC, countries have adopted different strategies and institutional arrangements. In terms of schemes, countries have: (i) created dedicated LTC schemes, such as Japan and the Republic of Korea whose approaches are illustrated at the end of this section; (ii) provided "top-up" pension benefits or expanded the scope of disability benefits; (iii) embedded LTC provision within social health protection benefit packages as in Northern Ireland[9] (Roland et al. 2022). In practice, many countries employ a blend of the above arrangements. For example, the Netherlands has a LTC insurance scheme that initially financed nursing care. In 2015 the scheme was reformed and it was decided that nursing care in the context of LTC would go back to being financed by social health insurance with a view to not only reducing costs but also to providing "incentives for coordination between primary care, hospital care, rehabilitation and community nursing for the frail elderly"(Alders and Schut 2019). Uruguay has created a scheme for home-based care that covers LTC needs across all age groups while residential care is covered by a programme within the national social security fund (Matus-López and Terra 2021). Yet another example comes from South Africa, where the Department

[8] Data set combining administrative data from a representative sample of LTC benefits claimants from Catalonia, Spain, linked with primary and secondary healthcare data for the period 2009-2014.

[9] The Department of Health is responsible for financing LTC through five health and social care trusts.

of Social Development is in charge of both administering old-age social pensions and financing publicly provided residential, community and home-based care while geriatric care is integrated into the national health service under the Department of Health (WHO 2017).

While strategies differ, it needs to be emphasized that the provision of additional benefits requires complementary sources of sustainable financing, regardless of the institutional arrangements to deliver the said benefits (ISSA 2022a). As outlined above, shifting the costs of LTC from the individual (and family) onto society can be promising as a gender-transformative investment in equity and for offering the possibility of dignified and active ageing. This nonetheless requires identifying equitable and sustainable sources of public financing (Allen et al. 2011; Joshua 2017; Walker and Wyse 2021). Singapore has adopted a strategy of raising additional revenues through further social security contributions mandatory from the age of 40 onwards. Similarly, in 2013, France created a new earmarked tax[10] to remedy the lack of funding of LTC services (Doty et al. 2015).

Systematically collecting data and information on the cost and financing of the modalities of social protection LTC benefits would also allow the monitoring of trends over time and for lessons to be garnered from studying country demographic and health trajectories. The political economy around LTC systems and their financing is a complex one, in part due to the diversity of architectures outlined in the above section. For example, in countries where LTC benefits provided as part of social protection schemes are merged into social health protection schemes or bundled with old-age benefits, the analysis of related costs is made difficult. Likewise, monitoring is rendered complex when different elements of LTC are subsumed under multiple sources of financing without necessarily clear earmarking (OECD 2020).

Ways forward

The global situation of increased ageing calls for profound changes. Many countries face a growing demand for LTC linked to fundamental demographic and epidemiologic changes combined with shifts in traditional care structures, thus making it urgent for social protection systems to develop tailored responses rapidly.

There is no one-size-fits all solution, but countries should:

- Consider the core principles of ISSS in the design of their LTC policis and schemes;
- Take stock of existing schemes providing health and old-age pension benefits and aim at complementing them rather than creating any duplication;
- Support a stronger and more enabling regulatory framework for LTC service provision;
- Secure adequate and sustainable financing.

A number of knowledge gaps also need to be addressed in order to develop and foster evidence-based policies geared towards such objectives. Most of the available evidence and data collection on LTC and on the health impacts of social protection policies concern high-income countries. While there is a growing body of evidence in this respect, as highlighted above, context is important and therefore more evidence is needed to extrapolate lessons that are applicable to low- and middle-income countries. Of specific interest are successful examples of practice in the coordination of social protection, health and social care policies and social security institutions, particularly with regard to delivery and financing of a guaranteed package of services and products. Such a package should extend across several sectors and include rehabilitation effectively. Similarly, contracting modalities and provider payment methods for LTC providers, especially in low- and middle-income countries, require both documentation and analysis, including of their possible impact on the working conditions of care workers and women's labour market participation.

Moreover, there is a significant gap in the monitoring and systematic documentation of LTC programmes outside OECD countries. While some ad hoc reviews of existing legal frameworks in selected countries and some documentation of practices, often by region, are available, there is a need for comprehensive monitoring that might render more visible the progression of legal and effective coverage over time, and thus contribute to policy formulation and implementation with better results. Similarly, actuarial modelling for LTC is identified as an important area of knowledge and tools development since it has potential as a means for dynamically anticipating demographic changes and other megatrends in LTC guarantees. Such improvements in the documentation of LTC scheme design, monitoring of legal and effective

[10] The *Contribution additionnelle de solidarité pour l'autonomie (CASA).*

coverage and evidence generation on outcomes and the broader health outcomes of social protection policies would be indispensable in ensuring adequate protection for people in need of LTC and their caregivers.

The design of social protection/social security systems must be informed by considerations of the need for LTC and what their specific role should be in facilitating this. One pragmatic approach that can avoid the duplication of efforts is the mapping of existing healthcare, social care and old-age pension entitlements while assessing needs and in the process of doing these identify where gaps lie.

In implementing policy responses, due consideration should be given to existing institutional capacities in both the provision of health and social care services and the management of social security entitlements that involve complexity in both financing mix and provider contracting modalities. Closing the knowledge gaps highlighted above is central to the provision of further practical guidance on the design and implementation of LTC schemes adaptable to a wide range of country contexts.

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