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## Working Paper Long-term care in the context of population ageing: A rights-based approach to universal coverage

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# Abstract

With the acceleration of population ageing, the achieving of healthy ageing is becoming a global imperative and social protection policies and social security systems have an important role to play in this endeavour. Through a life-cycle approach, social protection systems can support the prevention of disability in old age (i.e. by addressing social determinants of health), effective access to long term-care without hardship for those in need of it and decent work in the care economy. In order to make this contribution effectively, the adoption of a gender-transformative approach will be required; for, women are disproportionately represented among both older persons and long-term care (LTC) providers in all their diversity. Furthermore, to adequately contribute to the achieving of healthy ageing and effective access to LTC without hardship as a rights-based entitlement, social protection systems will need to build strong coordination among health care, social care and other social and employment policies. This paper highlights the key entry points for social protection systems to contribute to the Decade on Healthy Ageing, building on a rights-based approach achored in human rights and international social security standards.

This working paper draws from the article "Long-term care in the context of population ageing: What role for social protection policies?" by the same authors published in the special edition of the International Social Security Review "The human right to long-term care for the elderly: Extending the role of social security programmes (Tessier et al., 2022).

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# Foreword

This working paper was developed jointly by staff of the International Labour Organization and the International Social Security Association to address current debates on the role of social protection policies and social security systems when it comes to long-term care in a context of population ageing. It sets the scene for maximizing the contribution of social protection policies to the United Nations Decade of Healthy Ageing, highlighting the opportunities and challenges at stake.

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 without universal social protection. The ILO Social Protection Department and the ISSA decided it was timely to explore the role that social protection/social security systems might play in supporting countries' anticipated needs and in adapting to the new demographic context, in line with the guidance provided by international social security standards.

This working paper sets out the demographic, financial, institutional, regulatory, administrative and labour market challenges and opportunities for all societies in adequately meeting the needs of ageing populations. More specifically, this paper explores the role that comprehensive social protection/social security systems can play in realizing three core objectives, namely: i) fostering healthy ageing through a life- cycle approach; ii) ensuring that older persons in need of long-term care can access it without hardship; and iii) extending adequate social security coverage to all caregivers and care workers. The paper moreover underlines existing knowledge gaps and areas for the development of future research and systematic information collection with a view to informing policy and practice. It likewise summarizes the conceptual basis for establishing healthy ageing within the framework of the human right to social security.

We hope that this paper will be a useful contribution to the United Nations Decade of Healthy Ageing as well as a basis to further support the operational objectives of ILO constituents and ISSA member organizations.

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## Introduction

The world's population is ageing at a time when an increasing number of countries are going through a demographic transition. Thus, fertility rates are decreasing while in many countries mortality rates are declining or stagnating (Wang et al., 2020). In 2019, half of the world's countries and territories had below-replacement fertility, meaning that the policy challenges associated with ageing populations are becoming extremely acute for many countries. This phenomenon is emerging more rapidly in low- and middle-income countries than in high-income countries. Thus, today two out of three older persons live in low- and middle-income countries and it is projected that by 2050 this proportion will increase to four out of five older persons (UN, 2019). These changes are occurring in a context of economic and institutional development that tends to be less favourable than what it was when high-income countries began their demographic transition.

Against this backdrop, the COVID-19 public health crisis has starkly revealed how ill-prepared countries are to secure healthy ageing and adequately respond to the needs of older persons experiencing loss in their functional abilities. This crisis has further prompted greater global recognition of the need to improve working conditions in the care economy as part of comprehensive care policy packages to meet the demographic challenges ahead.

#### Box 1: What is the UN Decade of Healthy Ageing?

The UN Decade of Healthy Ageing is a global initiative adopted by the UN General Assembly (UNGA) through its Resolution A/RES/75/131. It brings together diverse stakeholders such as governments, civil society, international organizations, professionals, academic institutions, the media and the private sector to improve the lives of older people, their families and their communities. Four strongly interconnected action areas constitute the focus of the Decade, namely: "changing how we think, feel and act towards age and ageing; developing communities in ways that foster the abilities of older people; delivering person-centered integrated care and primary health services responsive to older people; and providing older people who need it with access to long-term care."

Activities conducted within the Decade come under four action areas and include tackling "the current challenges that older people face, while anticipating the future for those who will journey into older age" and focusing "on older adults, while recognizing that the environments in which we are born, grow, work and live strongly influence the opportunities available to each of us as we age."

#### Source: Decade of healthy aging, n.d.

The COVID-19 crisis is a wake-up call for countries to take urgent action and develop appropriate policies. In December 2020, the United Nations General Assembly adopted the UN Decade of Healthy Ageing through Resolution A/RES/75/131 (see box 1). The Resolution calls on Member States to take "action to prevent, monitor and address the disproportionate effects of the COVID-19 pandemic on older persons, including the particular risks that they face in accessing social protection and health services". It further recognizes the role of social security in ensuring the full realization of all human rights and fundamental freedoms for older persons (see box 2). In June 2021, the International Labour Conference (ILC) called on Member States and the International Labour Organization (ILO) to consider long-term care as an integral part of social protection systems, to invest in the care economy and support workers with care responsibilities (ILO, 2021a). Responding to this call, the present paper aims to reflect on the role that international social security standards (ISSS) and national social protection policies and systems can play when it comes to LTC in the context of population ageing and the formulation of appropriate policies.

#### Box 2: How are social protection and social security defined?

Social protection, or social security, is a human right. It is defined as the set of policies and programmes designed to reduce and prevent poverty, vulnerability and social exclusion throughout the life cycle. It includes nine main areas: health care, child and family benefits, maternity protection, unemployment support, employment injury benefits, sickness benefits, invalidity/disability benefits, old-age benefits and survivors' benefits. Social protection/social security systems address all these policy areas through a mix of contributory schemes (social insurance) and non-contributory tax-financed benefits (including social assistance).

As a human right, social protection, or social security, is enshrined as such in the Universal Declaration of Human Rights (1948), the International Covenant on Economic, Social and Cultural Rights (1966) and other major United Nations human rights instruments. States have a legal obligation to protect and promote human rights, including the right to social protection, or social security, and to ensure that people can realize their rights without discrimination.

The overall responsibility of the State includes guaranteeing the due provision of benefits according to clear and transparent eligibility criteria and entitlements and the proper administration of the concerned institutions and services. Where benefits and services are not provided directly by public institutions, then the effective enforcement of the legislative framework is particularly important for ensuring the provision of benefits and services.

"Social protection" as a term in this current context is used to refer to "social security" and generally the two terms are used interchangeably. It is to be noted, however, that the term "social protection" is sometimes used to cover a broader range of services than "social security", and includes protection provided to members of the family or members of a local community; on other occasions, it can also be used with a narrower meaning, where it is understood as comprising only measures addressed to the poorest, most vulnerable or excluded members of society. In the majority of contexts, however, the two terms, "social security" and "social protection" are largely interchangeable, and the ILO and other United Nations institutions use both in discourse with their constituents and in the provision of relevant advice to them.

Source: ILO, 2021b.

## Defining long-term care (LTC)

There is a growing body of literature discussing long-term care (LTC) yet definitions of the scope of LTC can vary greatly. Thus, some authors equate it to social care (Roland et al., 2022) while others include in its definition health care 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, etc.), the place where they are provided (i.e. 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 (i.e. specialized health personnel, personal care workers, domestic workers or unpaid family members) and whether or not they are licensed to do so (i.e. informal care and formal care) (GHWA and WHO, 2014; ILO, 2020a; UNECE, 2019). Local social and cultural contexts vary greatly and may put emphasis on different aspects of LTC, depending on what fits them best.

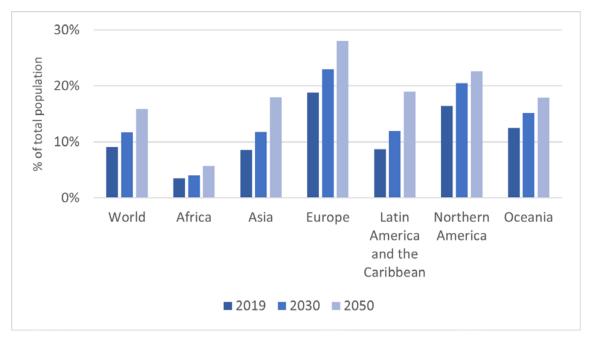
While fully acknowledging that LTC needs are present across all age groups, this paper will focus on LTC in the context of ageing. It is also necessary to appreciate that there is no universal age threshold for when a person is considered "old". Social and cultural perceptions of age vary widely across regions, countries and even localities. The UN has decided to monitor the Decade of 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. This paper 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. Focusing on LTC in the context of ageing, this paper postulates that 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.<sup>1</sup>

## 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 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<sup>2</sup>. 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 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 amongst the world's poor (Randel et al., 2017).

<sup>&</sup>lt;sup>1</sup> 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.

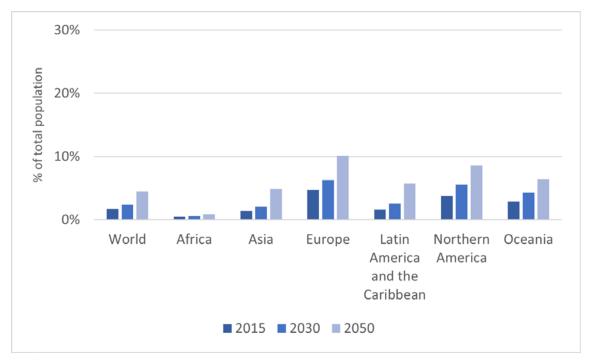
<sup>&</sup>lt;sup>2</sup> According to WHO, 2020, three quarters of the world's countries have limited or no comparative data on healthy ageing or on older age groups.



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

Source: UN, 2019.





Source: UN, 2015.

Available data suggests that overall around a fifth of older persons are adversely affected by impaired functional ability to perform and meet their basic personal need to dress, take medication and manage money independently. A clear pattern emerges of increase in loss of intrinsic capacities with age, 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 terms 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 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 (i.e. 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.

These two elements highlight the complexity of the issue at hand, which is the great diversity of individual, family and country contexts to which any policy aiming at addressing the issue will need to respond. Given this high level of complexity, there is a global consensus recognizing that 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.<sup>3</sup> While there is consensus that social protection policies have an important role to play in fostering healthy ageing and responding to the demographic challenges ahead, there is much less clarity when it comes to defining the actual contours that such policies should take. More precisely, while countries are increasingly adopting LTC policies,<sup>4</sup> their scope and the extent of their linkages with social protection policies vary greatly (Scheil-Adlung, 2015; WHO, 2021a).

## An integrated gender-transformative response is urgently needed

LTC also has a noteworthy gender dimension. Women constitute the majority of LTC users as well as care providers (both paid and unpaid), thus making the gender dimension a priority issue in building LTC systems that are rights-based, inclusive and financially and socially sustainable (ILO, 2018).

Women are more likely to need LTC as they tend to live longer than men – often in poor health – and face higher rates of disability or chronic health problems. The proportion of women increases with age and globally older women constitute almost two thirds of those aged 80 years or over (UN Women, 2022). Being more likely to have a lower average income, older women tend to be more marginalized and disadvantaged than older men, with higher rates of poverty present among older women in both developed and developing countries. At the same time, older women are more likely to live alone (higher life expectancy means they are more often widows) and not to be able to rely on support from other household members.

<sup>&</sup>lt;sup>3</sup> 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

<sup>&</sup>lt;sup>4</sup> Early research conducted by the ILO in 2013 on countries accounting for 80 per cent of the population above 65 years old showed that 32 countries had a policy, while in 2018 the WHO counted 80 countries with such policies and 96 in 2020, all pointing to an upward trend.

Much of the burden of unpaid care is disproportionately borne by women – globally, 76.2 per cent of unpaid care work is undertaken by women (ILO, 2018). Calculations suggest that if the market-based rate were applied for unpaid care, it would represent "9 per cent of global GDP, which corresponds to US\$11 trillion PPP (purchasing power parity 2011) in 2016" (ILO, 2018). Unpaid carers providing many hours of care per week are less likely to engage in employment and more likely to suffer from mental health problems, with women disproportionally affected. When unpaid carers have a job, it is more likely that it is part-time as combining care and paid work makes a full participation in the labour market difficult, leading to fewer opportunities for promotion and to lower salaries. This illustrates that LTC always comes with costs, even if it is provided by family members on an unpaid basis. It is therefore paramount to find ways to share these costs more equitably across society (UN Women, 2017).

Similarly, the paid care workforce is predominantly made up of women. Around three quarters of people working in health and social care in OECD countries are women, often working in lower-paid jobs (OECD, 2020a). In the European Union, almost 90 per cent of the LTC workforce are women (European Commission, 2021a). In the United States of America, of approximately 1.5 million people employed in the LTC sector, 90 per cent were middle-aged and female and 20 per cent were foreign-born (UN Women, 2017).

Working conditions and low pay in LTC provision are common, a factor which contributes to gender gaps in pay and pensions later in life. Hence, addressing the challenges of the LTC workforce would help to tackle gender inequalities in the broader labour force. How LTC is financed and provided has a major impact on women's ability to live a dignified life while sustaining their participation in the labour force, by helping to reconcile paid employment with unpaid care responsibilities and meeting the rising demand for care. It is therefore crucial that social protection systems adopt a gender-transformative approach in the area of healthy ageing and LTC.

## Social protection, healthy ageing and LTC

Social protection systems have an important role to play in providing support to healthy ageing and LTC policies and this role may take different forms depending on the country context. International social security standards (ISSS) rooted in the principles of universality, solidarity, and non-discrimination can provide guidance in developing such policy frameworks. Universal social protection that is characterized by a rights-based approach to universal population coverage and by comprehensive and adequate protection offers a solid basis for this.

This paper postulates that the role of social protection policies in supporting healthy ageing be geared towards three objectives. Thus, social protection policies can firstly support the social determinants of health that influence the loss of functional abilities and intrinsic capacities of older persons by adopting a life-cycle approach. Secondly, social protection policies can contribute to enabling access to LTC without hardship for those older persons who need such support. Lastly, social protection policies need to be inclusive of caregivers in all their diversity and in a way that is conducive to the promotion of equal opportunities for women and men and that is supportive of workers with family responsibilities. International social security standards (ISSS) and principles can guide social protection policy in responding to these three objectives. This paper will accordingly explore the role of social protection systems in fostering healthy ageing, supporting access to LTC without hardship and securing coverage of caregivers as a core component of decent work in the care economy.

# 1 The role of universal social protection in fostering healthy ageing through a life-cycle approach

Leading causes of disability<sup>5</sup> in populations above 50 years of age include cancer, chronic kidney conditions, hearing impairment, dementia and falls (Vos et al., 2020). Likewise, non-communicable diseases (NCDs)<sup>6</sup> are on the rise globally. Their prevalence increases with age and they have major consequences for the loss of functional abilities and intrinsic capacities in old age. They also impact the balance between disability<sup>7</sup> and death within the global burden of diseases; for, disability accounts for a greater share of the global disease burden and requires a larger allocation of health expenditure than in the past. The implication of this is that people tend to suffer less from early death but more from long-term conditions. The incidence of multiple comorbidities in older adults is often higher than for other population groups, which affects their functional abilities and often requires chronic disease management. Moreover, the effects of NCDs on older adults make them particularly vulnerable to certain impacts of climate change, such as rising temperatures and the increased frequency and intensity of adverse weather events (McDermott-Levy et al., 2019).

A large proportion of NCDs can be prevented or limited through early detection and appropriate management. Leading risk factors can be mitigated through a healthy diet, physical exercise and avoidance of smoking and drinking, all of which are closely associated with socio-economic conditions (Murray et al., 2020). For example, physical exercise reduces the risk of falls for older persons – falls that are often responsible for rapid degradation of health status, resulting in earlier dependency and hence increased needs for LTC. Furthermore, the long-term impacts on health of many conditions can be contained through early detection and rehabilitation. Supporting people throughout their lives to prevent illness and disability in old age is therefore contingent upon addressing the factors likely to stand in the way of them adopting desirably healthy behaviours, maintaining their health and getting the professional support they need to monitor it (Heikkinen, 2003). It is in this area that social protection policies can, and should, make an important contribution.

The ILO Social Protection Floors Recommendation, 2012 (No. 202) calls for the urgent establishment of national social protection floors accessible to all and guaranteeing that people have effective access to health care without hardship and income security through a life-cycle approach (see box 3). This approach is needed in order to comprehensively address some of the social determinants of health (Commission on Social Determinants of Health, 2008).

#### **Box 3: Universal social protection throughout the life cycle**

Universal social protection (USP) is firmly grounded in the international human rights framework and international social security standards (ISSS) and is encompassed by the Universal Declaration of Human Rights; the International Covenant on Economic, Social, and Cultural Rights; the Social Security (Minimum Standards) Convention, 1952 (No. 102) and the Social Protection Floors Recommendation,

<sup>&</sup>lt;sup>5</sup> Within the framework of the global burden of disease, years of healthy life lost owing to disability is a time-based measure that represents years of life lost as a result of time lived in states of less than full health.

<sup>&</sup>lt;sup>6</sup> According to the WHO, "Noncommunicable diseases (NCDs), also known as chronic diseases, tend to be of long duration and are the result of a combination of genetic, physiological, environmental and behavioural factors. The main types of NCD are cardiovascular diseases (such as heart attacks and stroke), cancers, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma) and diabetes. NCDs disproportionately affect people in low- and middle-income countries where more than three quarters of global NCD deaths – 31.4 million – occur." (Allen et al., 2017).

<sup>&</sup>lt;sup>7</sup> Understood in the context of the global burden of diseases as time lived in states of less than full health.

2012 (No. 202). USP refers to comprehensive, sustainable and adequate protection throughout the whole duration of the life cycle and comprises three core dimensions:

- Universal coverage as applicable to persons protected All should have effective access to social protection throughout the life cycle, if and when needed.
- Comprehensive protection with regard to the social risks and contingencies that are covered

   This includes access to health care and income security. Thus, the Social Security (Minimum Standards) Convention, 1952 (No. 102) sets out nine contingencies that every person may face over the course of life. These are the need for medical care; and the need for benefits in the event of sickness, unemployment, old age, employment injury, family responsibilities, maternity, invalidity and survivorship (where the death of a breadwinner results in surviving dependants). This comprehensive protection also includes protection against new and emerging risks, such as needs related to LTC.
- Adequate protection Benefits provided need to be set at a level that effectively prevents poverty, vulnerability and social exclusion, maintains decent standards of living and allows people to lead healthy and dignified lives.

Source: ILO, 2021a.

# Access to health care without hardship, including rehabilitation, as a key contributor to maintaining and restoring health

In accordance with the objective of universal health coverage (UHC), social protection systems are expected to guarantee access to health care without hardship by satisfying the criteria of availability, accessibility, acceptability and quality. In removing financial barriers to accessing a comprehensive range of quality health interventions, social health protection contributes to improving continuous access to health care throughout the life cycle. ILO Recommendations and Conventions on social health protection, in particular, the Medical Care Recommendation, 1944 (No. 69), the Social Security (Minimum Standards) Convention, 1952 (No. 102), the Medical Care and Sickness Benefits Convention, 1969 (No. 130), and the Medical Care and Sickness Benefits Recommendation, 1969 (No. 134) require that such health services be comprehensive and emphasize the need to include prevention, screening, which is crucial for early detection, and support to behavioural changes over the life course. In this regard, they are strongly aligned with the approach promoted by the Alma Ata Declaration on Primary Health Care (Bayarsaikhan et al., 2022).

Securing effective access to health care without hardship across a wide range of services comprising health promotion, prevention, rehabilitation and early detection throughout the life cycle makes a crucial contribution to fostering healthy ageing and addressing the determinants of poor health in old age through a life-cycle approach. It ensures that people have access to health and care services early on in order to prevent severe health outcomes. For example, access to early rehabilitation treatment by patients while they are in intensive care units reduces the risk to them of severe health outcomes and helps them to regain independence sooner (Anekwe et al., 2020). Access to a wide range of inter-disciplinary services as well as assistive products is needed. It is recommended that social health protection schemes include such services and products to increase access and utilization and tackle impoverishment, in line with ILO Conventions No. 102 and 130. Indeed, there is evidence that people with disability, who are more likely to require rehabilitation services, are also significantly more likely to experience catastrophic health expenditures (Mitra et al., 2017). Covering the costs of rehabilitation services and products should be seen as an investment. This may allow patients to return to work after an episode of accident or illness instead of having to rely on a temporary invalidity pension for instance. However, in some contexts very little attention is given to these preventive strategies, which ultimately might influence the need for LTC in older age and the overall costs incurred to the social protection system (see box 4).

#### Box 4: Rehabilitation: a priority

Rehabilitation has been defined by the WHO as "a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions (such as disease, disorder, injury or trauma, pregnancy, ageing, stress, congenital anomaly, or genetic predisposition) in interaction with their living and working environment." There is evidence that access to rehabilitation can improve quality of life, though globally there is a conspicuous lack of a robust monitoring system for the availability of rehabilitation services.

Access to a wide range of inter-disciplinary services as well as assistive products is needed. It is recommended that health insurance and other social health protection programmes include such services and products to increase access and utilization and tackle impoverishment, in line with ILO Conventions No. 102 and 130. Indeed, there is evidence that people with disability are more likely to require rehabilitation services and are also up to twice as likely as the general population to experience catastrophic health expenditure (Mitra et al., 2017). Covering the costs of rehabilitation services and products should be seen then as an investment since they are "associated with increased participation in labour markets and education, longer independent living and fewer or shorter hospital admissions".

Coordination between the ministry of health and other relevant sectors, such as social welfare, education and labour, is crucial for providing the kinds of rehabilitation services needed by the population in medical facilities as well as in the community and in the home.

#### Source: WHO, 2017a.

While international social security standards (ISSS) have long called for universality of coverage, significant social health protection coverage gaps persist. As illustrated by figure 3, while two thirds of the global population is protected by a social health protection scheme, this proportion is respectively only 16 and 34 per cent in low- and middle-income countries. This absence of social protection combined with insufficient public health expenditure more generally impacts on catastrophic out-of-pocket (OOP) spending by health by households, which is on the rise globally. Indeed, the number of people incurring catastrophic OOP health spending (classified as expenditure exceeding 10 per cent of their household consumption or income) rose from 940 million to 996 million per year between 2015 and 2017 (WHO and World Bank, 2021).

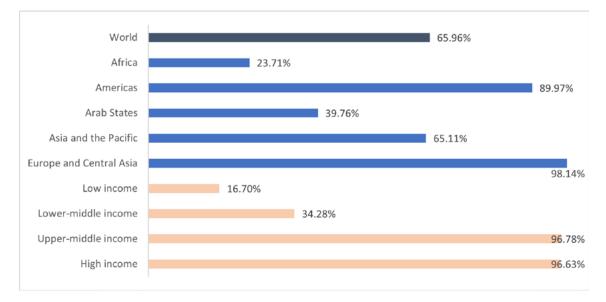


Figure 3: Percentage of the population protected by a social health protection scheme (protected persons), by region, subregion and income level, 2020 or latest available year

Source: ILO, 2021c.

While ILO social security standards stipulate that the range of services covered should be comprehensive (see box 5), in practice, specific services are often excluded from benefits packages, such as dental and optometry care. Thus, a recent review of social health protection in Asia and the Pacific revealed that these services were excluded from social health protection entitlements in Cambodia, China, Lao People's Democratic Republic and Viet Nam (ILO, 2021d). Such health care interventions can in fact be essential for enabling individuals to perform daily activities and demand for them tends to increase with age. They can moreover be crucial for the maintenance of general health; thus, poor dental health, for instance, can lead to malnutrition among older persons (Ástvaldsdóttir et al., 2018). Similarly, though rehabilitation is key to the prevention of long-term loss of functional capacities, it is given less prominence than other services in the design of many social health protection schemes (Stucki et al., 2019).

#### **Box 5: ILO social security standards on social health protection (SHP)**

ILO Convention No. 102 calls on States to provide social protection to cover those health care interventions needed to "maintain, restore or improve" the health of the protected persons and their ability to work and to attend to their personal needs. Moreover, it is stated in Medical Care Recommendation, 1944 (No. 69) that the range of services covered should be comprehensive. The scope of a health care package should be determined and defined through a national dialogue process, with due regard accorded to the principles of availability, accessibility, acceptability and quality and the package should be regularly assessed to ensure that it remains sufficient to ensure a life with dignity.

In an ILO report on social health protection in the Asia and Pacific regions to boost Universal Health Coverage, it is observed that "States should also seek to provide higher levels of protection as soon as possible using guidance provided by Convention No. 102 and more advanced standards, notably Convention No. 130. Convention No. 102 provides guidance regarding a minimum package of health care, which should include general practioners' services and provide a basic package of PHC (primary health care). Moreover, it should include reproductive, maternal new born and child health (RMNCH) services, including antenatal care, confinement, postnatal care and hospitalization if required, specialist and hospital care and essential prescription pharmaceuticals, to be complemented by dental care and medical rehabilitation (including prosthetic and orthopaedic devices). The responsibility of national authorities is not only to regulate such entitlements, but also ensure that provided services meet the criteria of availability, adaptability, acceptability and quality.

ILO standards stipulate that institutions responsible for SHP shall make a proactive effort to encourage protected populations to utilize population health interventions and more generally promotion and prevention services. This is in line with the vision promoted by the WHO on service delivery. Indeed, PHC was early on identified as a central function and a fundamental approach to the delivery of health care."

When it comes to financial protection, ILO standards allow cost-sharing within limits – "the rules concerning such cost sharing shall be so designed as to avoid hardship" (Convention No.130) – though not for maternity care.

#### Source: ILO, 2020c.

Even when SHP entitlements are comprehensive, further barriers persist to the effective access and utilization sought in the indicators under SDG target 3.8 on achieving universal health coverage (WHO and World Bank, 2021). These obstacles take the form of informal payments, geographical distances, gaps in service availability and quality. More particularly, recent analysis shows that access and utilization of health interventions – measured by the UHC service coverage index – increased between 2000 and 2019, but noncommunicable disease (NCD)-related interventions showed lower gains than other sub-indexes (WHO and World Bank, 2021).

# Income security throughout the life cycle as a policy lever to address social determinants of health

As per ILO Recommendation No 202, social protection systems should ensure income security throughout the life cycle, from pregnancy, childhood, and working age to old age. In particular, Convention No. 102 identifies eight contingencies in addition to access to health care that all individuals may face over their life course: sickness, unemployment, old age, employment injury, family responsibilities, maternity, invalidity and survivorship (where a breadwinner dies leaving dependants). Effective access to a range of benefits can specifically contribute to supporting healthy ageing and shaping its determinants along the life cycle through three main entry points: an adequate standard of living, resilience to contingencies and shocks and a smooth transition between work and retirement.

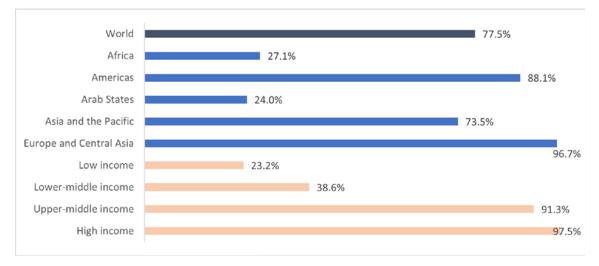
## Adequate standard of living, including in old age

Having income security impacts positively on households' financial ability to adopt a healthy diet, maintain appropriate housing, access education and partake in social and physical activities that are crucial to staying healthy. Child benefits, benefits in active age and old-age pensions, if set at an adequate level, can all contribute as key enablers in this respect. For instance, there is evidence that adequately designed child benefits can have an impact on nutrition and early childhood development (Alderman, 2015; ILO and UNICEF, 2019). Moreover, such positive impact on nutrition has also been identified with well-designed oldage pensions (Duflo, 2003; Ko, 2019; Zheng et al., 2020). Similarly, access to social protection is identified as being closely related to good self-reported health in Europe, underlining the mutually reinforcing relationship between them (WHO, 2019a).

Regrettably, income security along the life cycle is not yet a universal reality. Less than half of the world's population is effectively covered by at least one social protection cash benefit along the life cycle, with large disparities across and within countries (ILO, 2021c). Only 38.6 per cent and 23.2 per cent of older persons in low- and middle-income countries respectively, enjoy effective pension coverage as indicated by figure 4. Furthermore, the majority of the labour force is not contributing to a social insurance scheme to accumulate rights to an old-age pension in the future. This can be because such schemes are not in place or because narrow eligibility criteria and poor enforcement preclude their extension.

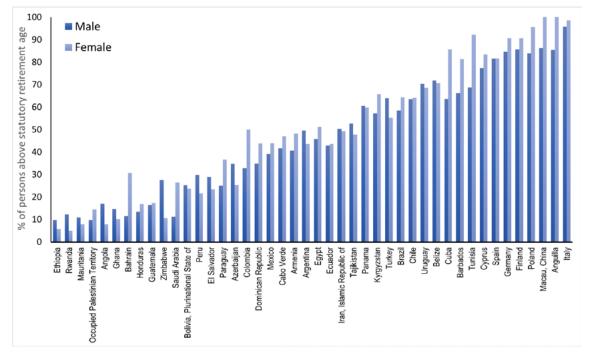
Adequate protection in old age remains a challenge for many workers, such as women, people in low-paid jobs, those in precarious employment situations, people working in agriculture and on digital platforms, as well as migrants. Of particular importance when it comes to LTC, is the fact that pension coverage gaps do not affect men and women equally. Globally, less than half of the women in the labour force today are legally protected by a mandatory social insurance scheme or a non-contributory scheme for their old-age pension (see figures 5 and 6). This is compounded by important differentials in pension adequacy, with pension levels reflecting the gender pay gap in many regions as well as unequal labour market participation. Indeed, because they have to shoulder most of the care responsibilities in the home, women experience more interruptions in their careers and tend to have less access to decent work opportunities and to be disproportionately represented in the informal economy (European Commission, 2021b; ILO, 2021e). This means that while women live longer than men, they are also less likely to have income security in old age, which in turn affects their ability to stay healthy longer.

Figure 4: Proportion of older persons receiving a pension: the ratio of persons above statutory retirement age receiving an old-age pension (including contributory and non-contributory) to persons above statutory retirement age, 2020 or latest available year



Source: ILO, 2021c.

Figure 5: Effective coverage for old-age protection by sex: percentage of labour force aged 15+ years covered by pension schemes (active contributors), selected countries, 2020 or latest available year



Source: ILO, 2021b.

## **Resilience to shocks**

At its 109<sup>th</sup> Session in 2021, the International Labour Conference (ILC) recalled that the role of social protection is to bolster resilience of individuals, families and societies alike (ILO, 2021a); for, having access to social protection impacts people's ability to face shocks and contingencies throughout their lives. Moreover, being assured of the security to be able to meet basic needs in a crisis situation has implications for preserving a person's mental health and meeting immediate physical needs (Cappelletti et al., 2015). Crisis situations at the individual and collective levels can be triggered by covariate and idiosyncratic risks. Demographic and epidemiological trends influence both and interact with other megatrends such as climate change. The latter is expected to bring about more adverse weather events and natural disasters, as well as to influence the apparition of new diseases (Romanello et al., 2021; Watts et al., 2015). Looking ahead it is expected that people are likely to be confronted with such adverse events more often and possibly with greater intensity.

In this context, there is strong evidence that social protection contributes to cushioning the socio-economic impact of a crisis, such as that induced by the COVID-19 pandemic (ILO, 2020b). Timely adaptation of administrative processes can make the response of social protection systems more effective in some contexts (World Bank, 2020). For example, to improve the support given to families in difficulty during the COVID-19 crisis, Poland's Social Insurance Institution (*Zaklad Ubezpieczen Spolecznych* - ZUS) has implemented exceptional services that are also intended for older persons as part of an "anti-crisis shield" (ACS) policy (Social Insurance Institution, 2022).<sup>8</sup>

More generally, the ability to have the time to recuperate properly from periods of maternity, illness or injury without loss of income contributes to ensuring that people do not experience preventable adverse health impacts in the long run. Having income security guaranteed during maternity, sickness, recovery and rehabilitation (including after occupational injuries) is therefore a crucial element in making individuals more resilient and restoring and preserving their health. In this respect, some countries, such as Sweden, have adopted a universal social insurance approach to sickness benefits to ensure that people have income security and can afford to take the time they need to recover from illness (ILO, 2021b). While a rights-based approach to rehabilitation has been adopted in some, mostly high-income, countries, health and social protection systems in low- and middle-income countries still need to accord greater attention to it (Bernhardt et al., 2020; Bright et al., 2018; Garg et al., 2020) and thus secure the financial sustainability of such benefits as those for sickness, maternity and disability.

## Smooth transitions between different phases of life

Coordination between social protection and employment policies to ensure a smooth transition into retirement can make an important contribution to healthy ageing. Indeed, it is crucial not only for people who can no longer perform a professional activity to be able to retire from working and enjoy a pension, but also that people who can and wish to continue working, possibly under more flexible modalities, be enabled to do so. There is evidence that the continued pursuit of a level of professional activity by older persons who have the capacity and desire to do so can have positive effects on health outcomes (WHO, 2021a). At an early stage, international social security standards (ISSS) made provisions to ensure that social security systems could be adapted to give due regard to the working ability of older persons in each country (ILO Convention No. 128, article 15). This consideration may also impact the aggregate demand for old-age pensions and their financial sustainability.

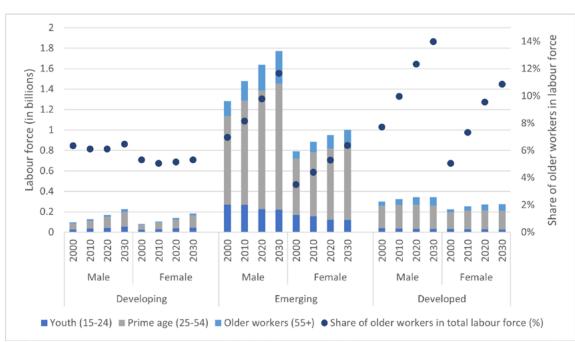
In this vein, some countries have reformed their pension systems with a view to ensuring greater equity in access to an old-age pension, while simultaneously ensuring that people who start working earlier or who perform hazardous or physically demanding work can retire sooner, and others who are still able to work and wish to do are enabled to stay longer in full or partial activity (ILO, 2013a). Thus, in Viet Nam, although the pensionable age is 60, early retirement five to ten years earlier is allowed by the social insurance system for certain categories of workers, including workers who have been employed in hazardous activities for more than 15 years (Nguyen et al., 2021). Similarly, in many European countries reforms that push back, or delay, the retirement age uniformly have eventually been adapted. Some countries are tending to opt for flexible measures that give scope for the specificities of workers' occupations and their physical capacities. In 2018, for example, Belgium extended the flexi-job status to pensioners; Greece has lowered from 70 per cent to just 30 per cent the pension reduction that was applied to pensioners who maintain professional activity (European Commission, 2021b). Similarly, there have been various initiatives by social security institutions to provide additional services for assisting older persons to plan for the transition to retirement

The ACS consists of automation of processes, rapid assistance, support instruments and new forms of contact with beneficiaries.

in a smoother fashion. Such an example of this, is the retirement planning tool (*Uttagsplaneraren*) devised by the Swedish Pensions Agency (SPA) that citizens can use to assess the impact of decisions concerning their choice of retirement age on their pension income (Swedish Pensions Agency, 2022).

Some countries have implemented policies to meet the needs of older people while helping them to remain independent. For example, in Azerbaijan, the Agency for Sustainable and Operational Social Security (DOST) operates a policy that aims to support isolated older people with the activities of daily living. The Agency has developed initiatives to enhance the provision of social security for older persons, including helping to improve their quality of life and promote their active participation in society, such as through offering volunteering opportunities to give peer support at DOST service centres (Agency for Sustainable and Operational Social Security (DOST), 2022).

Pension systems will also need to closely coordinate and align with wider employment policies. Indeed, globally, the proportion of older workers aged 55 to 64 years in the total labour force has been increasing and is expected to continue to rise significantly and extend beyond the age of 65. This trend will be particularly marked in emerging and developed countries, where it is expected that between 2000 and 2030, the share of older workers in the labour force will have increased by 76 per cent in developed economies and by 80 per cent in emerging countries, as illustrated by figure 6. To enable the continued participation in the labour force of older workers who are both able and wish to go on working, workplaces will need to adapt in terms of occupational safety and health, working hours and work organization. International Labour Standards, in particular ILO Older Workers are not prey to discrimination and that workplaces and working conditions are adapted (Articles 3, 6 and 11). Active policies to sustain the employability of older workers will be needed, in particular targeted retraining, reskilling and upskilling (Harasty and Ostermeier, 2020).



# Figure 6: Composition of the labour force (in billions) and share of older workers, by sex and income group, 2000–2030

Source: calculations based on ILO LFEP database, July 2019 update (Harasty and Ostermeier, 2020).

Social protection policies therefore have an important role to play in countries' efforts to foster healthy ageing. In this respect, countries should view universal social protection as an essential investment for countering current trends of disease and disability in old age, at a time when people are living longer but may fall sick earlier or more frequently in life. Ensuring healthy ageing responds to the aspirations of older persons and their families and is integral to avoiding escalating health and LTC costs, as well as the overall societal costs of unhealthy ageing patterns.

# 2 The role of universal social protection in securing access to LTC without hardship

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. Social protection policies should aim to ensure that all those in need of LTC can access it without suffering 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. International social security standards (ISSS) provide 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 long-term care 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 section of the paper 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 who experience functional impairments to be able to enjoy 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 (i.e. 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, 2017a). 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 amongst all members of society and therefore tends to favour the development of a two-tiered system; for, 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. This phenomenon is apparent in a number of countries when it comes to health care benefits (ILO, 2021d). 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). In such a scenario, the rest of the population buys LTC services from markets that in many countries tend to remain poorly regulated, hence largely resulting in segmentation and cream-skimming<sup>9</sup>. 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). Such suboptimal coverage amounts to a missed opportunity to strengthen solidarity and the social contract among different generations.

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). More broadly, extending the scope of coverage to all in need of LTC redistributes care, giving professional LTC providers a stronger role and reducing the reliance on family for LTC. 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, as highlighted in the Resolution concerning the second recurrent discussion on social protection (social security).<sup>10</sup>

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, particularly with regard to health and old-age pension benefits. Indeed, while marked progress has been made over the past decades, 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, 2021b).

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 (at the time) 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, health care, pensions), then it runs the risk of creating a game of cost shifting. For instance, where health care 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 (see figures 3 and 4 in the previous section).

In economics, cream-skimming designates a business strategy by which a company decides to focus on customer segments that are seen as most profitable. For example, this is a strategy that a for-profit private health insurer may adopt to maximize profits and lower risks, agreeing to insure only those who can afford a certain level of premium and subjecting them to health checks to include only the healthiest.

<sup>&</sup>lt;sup>10</sup> "Invest in the care economy to facilitate access to affordable and quality childcare and long-term care services as an integral part of social protection systems, in a manner that is supportive of the workforce participation of workers with care-giving responsibilities and an equal sharing of care work between women and men." (Paragraph 13 clause (g)).

While older persons are a principal focus of discussion in this paper, 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 and with large regional variations; thus, while coverage in Eastern Europe appears to be almost universal, estimates for Southern Asia and sub-Saharan Africa show an effective coverage rate of below 7 per cent. Coverage in higher-income countries (HICs) is 85.6 per cent, compared with 11.3 per cent in low- and middle-income countries and 8.6 per cent in low-income countries (LICs) (ILO, 2021b).

While securing universal access to LTC services without hardship should become a clear objective of social protection systems in a context of rapid ageing, adopting a rights-based approach will also require that attention is devoted to considering the adequacy of LTC benefits.

## Adequacy

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 (i.e. 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 paper.

## 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, 2022a). 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 (i.e. the ability to move from bed to an upright chair or wheelchair) (ILO, 2021d). While the inability to perform one or several ADLs alone is commonly used across existing LTC provisions, it is important to note that care needs may go beyond those, as illustrated by box 6.

#### Box 6: 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.

An important aspect of assessing loss of function is to be able to effectively reflect the need for LTC. Thus, it is not only necessary to address physical impairment in LTC, but crucially also the impacts of mental illness, including dementia. Similarly, taking into account frequently overlooked environmental constraints can be central to making an adequate assessment of LTC needs (WHO, n.d.a). A shared understanding of disease, interventions and functioning in conjunction with a measuring framework at the global level can support such assessments. For instance, the WHO International Classification of Functioning, Disability and Health (ICF) (WHO, n.d.a) provides an internationally endorsed framework for measuring health and disability at both individual and population levels. The element of functioning is highlighted as a key component in fostering collaboration across different professions and in some cases even in setting up accurate provider payment systems (Hopfe et al., 2018, 2015). However, a recent review of LTC in Latin America suggests that only one country had a unified nationwide methodology to assess LTC needs (Natalia Aranco 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 of Healthy Ageing has specified three important dimensions to articulate the aspirations of older persons (see box 7). 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 7: Defining the contingency for LTC: the three dimensions of healthy ageing

The UN Decade of 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 health care 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)." (WHO, 2021a)

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.

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 the changing needs and circumstances of individuals. 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. Periodic reassessments can be undertaken to determine benefit eligibility or adjustments in the level of care needed. 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). The previously authorized maximum was 36 months, but it was decided in 2021 that if the level of care requested was unchanged, a reassessment every 48 months could be permitted in order to ease the administrative burden.

## 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 health care 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), as illustrated by box 8.

### **Box 8: Defining a benefit package for LTC**

As per international social security standards, 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 health care 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, etc.). 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.

Work is ongoing at the global level to try to define a minimum package of services that should be considered by countries as essential for LTC within the scope of their universal health coverage (UHC) strategies. 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). This preliminary endeavour highlights the wide range of services that may be needed and the varying degree of priority that may be assigned to an intervention in a given context.

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 (see the case studies at the end of this section). 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 and 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 (Jun 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, 2020c). 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 9). Only 29 countries have set up a universal and free LTC service scheme enshrined in national legislation (Addati et al., 2022). For example, in 2014 Sweden dedicated 2.9 per cent of GDP to its LTC system, 90 per cent of which was covered by county councils and municipalities and 5 per cent by the Government, leaving only 5 per cent to be borne by users (Schön and Heap, 2018). The example of Sweden illustrates that much as with health care, greater public spending on LTC is correlated with low reliance on OOPs (WHO, 2021b).

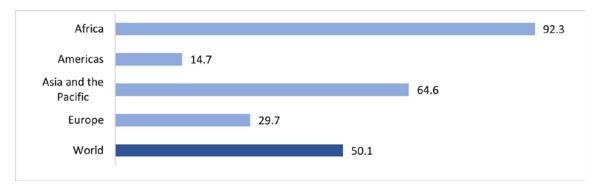
#### Box 9: Impoverishing out-of-pocket payments (OOPs) from households on LTC

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). 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 health care, 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, 2017a).

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 lowand middle-income countries and in remote areas (see figure 7) (ILO, 2017a).

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 of America, for example (Utz, 2022).



#### ▶ Figure 7: Percentage of population 65+ excluded from LTC owing to workforce shortages, by region, 2015

Source: Scheil-Adlung, 2015.

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 OOP 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<sup>11</sup>) with the mean income of older adults and found it to be two to three times higher. This situation

<sup>&</sup>lt;sup>11</sup> 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, available at: https://www.dosm.gov.my/v1/index.php?r=column/cthemeByCat&cat=493&bul\_id=VTNHRkdiZkF zenBNd1Y1dmg2UUIrZz09&menu\_id=amVoWU54UTI0a21NWmdhMjFMMWcyZz09

is compounded by the design of the pension system, which is based on individual accounts and therefore does not necessarily guarantee a monthly income in old age (Yunus et al., 2022).

# 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, 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 health care, 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).

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. The sub-sections below highlight the factors of LTC that need to be taken into account and further documented and analysed in future research.

## 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 health care, social care and social protection/social security systems is needed to ensure quality, especially with care models that are pluralistic (i.e. 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. In a number of countries in Western Europe and North America, scandals in LTC facilities have come to light in recent years (Armstrong et al., 2020). Analysis of quality of residential LTC facilities has revealed that quality of care and outcomes can be influenced by such factors as the ownership status of such facilities, regulation, public and market incentives and corporate strategies (Da Roit and Le Bihan, 2019; Harrington et al., 2017; Molinari and Pratt, 2021). This echoes a number of reports from other higher-income countries (HICs) such as Singapore, where issues concerning quality of care have been significantly associated with the working conditions and status of care workers for instance (Wong et al., 2014).

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 (Natalia Aranco et al., 2022).

### 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 health care, and residential care provided in different types of institutions for older persons who cannot 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, 2021c). 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.

LTC services can be delivered in the home (through family support, community-based mechanisms, health professionals or personal caregivers) or in various kinds of institutions associated with health- care or social care sectors. Home-based care services are deemed to be non-institutional services mainly provided in a recipient's home as are various congregate living arrangements (Agency for Health care Research and Quality, 2011). Conversely, typical LTC institutions are defined as "specifically designed nursing and residential care facilities that provide accommodation and care as a package, with the predominant service being care" (Dyer et al., 2020).

Some countries are more reliant on home-based and community-based care<sup>12</sup> than on institutional care, which may be viewed as a last resort. For example, in Myanmar, public and private institutional care facilities are designed for situations where home-based care normally expected to be provided by family members is not available. The Government supports 81 institutions and over 3,000 beneficiaries (Soe, 2017). A few public facilities alongside Buddhism-based charities offer such services. At the other end of the spectrum, the OECD estimates that Australia has one of the most developed institutional LTC systems and it is considered as a central channel for provide such services (Dyer et al., 2020). Coordination of services can relieve pressure on acute care in hospitals and reduce its associated financial costs. A number of hybrid supply structures have been established in the residential and semi-residential sector (short-term care, day care) including both medically trained staff and social care professionals (Becker and Reinhard, 2018).

New forms of care delivery making greater use of information and communication technology (ICT), such as eHealth and telemedicine, are also increasingly used. Investments in prevention provided via ICT have the potential to enhance the capacity of individuals to be empowered towards their own health. Making better use of ICT can not only improve the efficiency of LTC delivery, but also contribute towards safeguarding the resilience of services for older persons, even during a public health crisis (see box 10).

### Box 10: The use of technology in LTC service delivery

Some countries are trying to bridge shortages in the availability of LTC providers through the use of technology (Krick et al., 2019). For instance, in Uruguay, telecare services are used effectively with patients with chronic diseases (Cafagna et al., 2019). In Germany, online medical monitoring enables older persons to get support in the administering of their medication (European Commission, n.d.). Telecare allows health personnel to be contacted from the home. For example, the Japanese Ministry of Economy, Trade and Industry has developed strategies for the use of robotics in the care economy (ILO, 2018). Examples of efforts made to bring services to homes that would otherwise be unavailable owing to a limited supply of workers include the system for the home delivery of medicines set up by the Social Security Institute of Guatemala (Social Security Institute of Guatemala, 2020), the VIVA platform created by EsSALUD in Peru (EsSalud - Social Health Insurance Institute, 2020) and the virtual medical consultations offered by the Ecuadorian Institute of Social Security (IESS) (Ecuadorian Social Security Institute, 2020).

<sup>&</sup>lt;sup>12</sup> Care provided by a professional in the home or in the community as opposed to care provided in institutions.

In Belgium the Solidaris mutual insurance association has set up a multidimensional care system through the "Centrale de Services à Domicile" (Home Service Centres (HSC)), to provide home care though personalised services that are accessible 7 days a week, 24 hours a day (Solidaris, n.d.). Professionals (nurses, care assistants, physiotherapists, domestic helpers, etc.) work together to coordinate action and facilitate communication among all actors, aided by digital solutions, such as online medical monitoring.

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 (see box 15 in the next section). Provider payments mechanisms also need to be aligned with the objectives of access and quality (see the next section, 'Governance and administration').

The diversity of long-term care providers encompasses differences in the type of settings (medical institutions, community institutions, home-based, etc.) as well as in the type of ownership (public and centralized, public and decentralized, private for profit and private non-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. In some situations, carers provide equipment for home care or advise older people over most appropriate technical aids for them and on the design of their home to match their needs and abilities (ISSA, 2008). Therefore, in many settings public financing for LTC is geared towards contracted entities from the social and solidarity economy. Indeed, models of health care and social care based on solidarity can provide support to achieve sustainable and inclusive LTC service delivery, based on proximity, or within the reach of older persons (European Parliament, 2011). Overall, more research is needed on the potential for this model of provider organization and its contribution to the empowerment of care workers, their working conditions and the quality of care provided (ILO, 2022a).

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 (see the section below, 'Supporting volunteers'). 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'.

## Governance and administration

As the discussion in the preceding sections has suggested, securing access to LTC without hardship involves engaging with complex systems. In this respect, arrangements for governance and administration need to be focused on aiming towards excellence in social security administration; adequate participation and engagement of stakeholders - in particular social partners; provision of sufficient incentives to providers; and effective coordination with health and social care.

## Participation

It is paramount to build person-centred LTC systems where social protection schemes form a main component. This involves, as mentioned earlier, responding to the needs of older persons as well as to those of their families and caregivers. Accordingly, 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 (ISSS). 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. In particular, tripartite governance can secure a balanced monitoring over time that takes into account the experience of scheme beneficiaries.

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. Many of the available reviews concentrate on a few high-income countries (Joshua, 2017; Walker and Wyse, 2021). This is an area where further documentation of practices and analysis of lessons learned are crucially needed in order to inform policy. 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 as discussed in the following section.

## Coordination of 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 health care 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, while progressing towards systems of public LTC financing that mandate universal coverage and ensure entitlement and equitable access to quality services (WHO, 2021c).

LTC involves multiple stakeholders sharing responsibilities for regulation, funding and delivery of care under the aegis of multiple governance mechanisms. It can be decentralized and sometimes fragmented with regional or local levels of government playing a much greater role in financing or regulating the sector. Collaboration between health care professionals with LTC and social care professionals is often difficult because of non-compatible funding and different eligibility criteria (ISSA, 2021b). LTC provision should therefore be founded upon existing health and social care systems, making use of the health system infrastructure in place as a basis for formulating strategies and pooling synergies to establish sustainable and equitable LTC provision (WHO, 2021c).

Ensuring coordination contributes to enhancing the quality of care, patient experience and prevention opportunities. For example, to reduce the risk of rehospitalisation 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). Cuba has a community care plan (*Atención Comunitaria*), which ensures that dependent persons can receive in-home cross-disciplinary care. The country provides older people with a "*libreta de abastecimientos*" (supplies booklet), which permits them to receive pre-prepared meals or to have access to municipal canteens (ISSA, 2021c).

## 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 health care and LTC needs have been on the social security agenda for many years (ISSA, 2022b, 2021b). 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 supporting social security institutions in confronting urgent LTC challenges.

When designing new LTC schemes, countries need to take stock of the currently provided health care, 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 (i.e. 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 health care, in particular on promotion and prevention activities, an investment that social security systems should support as illustrated in the first section of this paper. Belgium, for example, has developed strategies to strengthen primary care and to stimulate the creation of integrated care settings informed by the principles of the "quadruple aim model", which consists of: i) improving the individual experience of care; ii) improving the health of the population; iii) reducing the per capita cost for populations; and iv) maintaining the well-being of health care providers (Goderis et al., 2020; Verhaeghe, 2021).

There is some overlap between health and LTC services covered by social security entitlements. The health branch of social security systems is the only other branch that deals with purchasing services on behalf of the protected population. In this respect, some functions could usefully be mutualized to facilitate the establishment of streamlined eligibility criteria and avoid the risk of people being overlooked or missing out. Much can be learned from health benefits management when it comes to provider payment methods.

## 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 health care 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 health care 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. There are indeed proven positive aspects of ageing, one being the desire of many older persons to be productive by continuing in gainful employment and there is also evidence to indicate that this contributes to them maintaining social engagement and participating in community activities, thus resulting in a better health status. 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. This is expanded upon in the next section of this paper.

## 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 of Great Britain and Northern Ireland, the National Health Service (NHS) 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 health care services and resources. Thus, according to research<sup>13</sup> 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, with the majority relating to social exclusion cases. The benefit was thus instrumental in containing the rising costs of health care (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. This latent kind of cost cannot be systematically taken into account, an example of it being the opportunity cost incurred by society when family members who would like to participate in the labour market cannot do so because of their care responsibilities. A further example is the costs incurred as a result of mental health issues that can arise for unpaid caregivers who receive little training, respite or psychosocial support (Utz, 2022). 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<sup>14</sup> (Roland et al., 2022). In practice, many countries employ a blend of the above arrangements. For example, the Netherlands has an 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).

<sup>&</sup>lt;sup>13</sup> Dataset combining administrative data from a representative sample of LTC benefits claimants from Catalonia, Spain, linked with primary and secondary health care data for the period 2009-2014.

<sup>&</sup>lt;sup>14</sup> The Department of Health is responsible for financing LTC through five health and social care trusts.

Yet another example comes from South Africa, where the Department 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, 2017b).

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 that will allow for the sustainability of such an investment over time without jeopardizing existing benefits. This has been identified as a challenge by many countries that have implemented LTC schemes (Allen et al., 2011; Joshua, 2017; Walker and Wyse, 2021).

Mobilizing fiscal space for social protection can be done through a number of ways, such as the following identified by Ortiz et al., 2019: extending social security coverage and contributory revenues; increasing tax revenues; eliminating illicit financial flows; improving efficiency and reallocating public expenditures; tapping into fiscal and foreign exchange reserves; managing debt; borrowing or restructuring sovereign debt; adopting a more accommodative macroeconomic framework; and increasing aid and transfers. In the case of LTC benefits, the systematic documentation and analysis of the costs and financing options chosen by countries across geographies, demographic profiles and income levels are needed. Most of the evidence is collected for HICs and few comparative analyses are available outside of OECD countries, while available documentations highlight the usage of a wide range of options. The examples at the end of this section of three Asian countries – Japan, the Republic of Korea and Singapore – that have developed LTC benefits over the past decades in a context of rapid population ageing (and as precursors in their region) provide an illustration of this funding diversity. To gain some idea of it, Singapore has had a strategy of raising additional revenues through further social security contributions mandatory from 40 years of age onward. In 2013, France created a new earmarked tax<sup>15</sup> to remedy the lack of funding of LTC services (Doty et al., 2015). Some countries raise taxes at different levels, for instance Finland, where municipalities are responsible for up to two thirds of public LTC funding and collect non-earmarked taxes (Anttonen and Karsio, 2016). In China, the LTC nursing insurance in Qingdao was financed by a mix of transfers from social health insurance schemes and revenues from lottery funds, subsequently transferred at city level (Yang et al., 2016). In order to avoid the pitfall of inequities across municipalities, many countries have maintained a balance between revenues collected and pooled nationally and locally (Ariaans et al., 2021; Francesca et al., 2011).

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 owing 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, 2020b). Efforts are under way to resolve some of those reporting issues in OECD countries, but they have yet to be considered in most countries. In taking stock of the increase in LTC spending in countries for which comparable data is available, it becomes apparent that the sustainable financing of social protection LTC schemes in a diversity of contexts requires further research. In particular, detailed analysis of financing flows and their evolution in a broader range of countries is needed in order to derive lessons on policy that can be usefully extended beyond the settings of high-income countries.

Just as with health care benefits, a balance needs to be struck between centralized and decentralized functions to ensure that the system adequately responds to people's needs in their particular context while ensuring that risk is pooled and that there is solidarity in financing (ILO, 2021d). This is an area where further

<sup>15</sup> The Contribution additionnelle de solidarité pour l'autonomie (CASA).

documentation and analysis are needed. When reflecting upon financing channels and decentralization of functions, countries need to be mindful of the need for portability of benefits. Geographically bound LTC entitlements can pose various obstacles to planning and coordination with other social protection benefits. For example, in order to clarify the rights to benefits for older persons with LTC needs who move to a EU country other than their country of origin, the European Union has since 2012 been working on changing the provisions on the coordination of social security systems towards introducing the new social risk of dependency (European Commission, 2021a). Differences in LTC entitlement across localities may further lead to disparities in benefits and to inequity in accessing needed care (AIM, 2018).

# Selected case studies of long-term care schemes in Asia

The three case studies of long-term care schemes below (from the Republic of Korea, Japan and Singapore) were drawn from original background research conducted for the ILO publication "Extending social health protection: Accelerating progress towards Universal Health Coverage in Asia and the Pacific" (ILO, 2021b). They are illustrative of the diversity of policy responses to growing LTC needs provided by social security systems in a context of rapid ageing.

# Long-term care insurance (LTCI) in the Republic of Korea

In the Republic of Korea, the long-term care insurance (LTCI) scheme, which was introduced in accordance with Article 1 of the Long-Term Care Insurance Act for senior citizens, is managed and regulated by the NHIS (National Health Insurance Service, 2019). The LTC Committee is placed under the oversight of the Minister of Health and Welfare. The Committee is comprised of 16 to 22 members, with the Chairperson appointed by the Minister of Health and Welfare. Other members include representatives of employees' and employers' associations, non-governmental organizations, LTC institutions and representatives of the academic community. The Committee makes decisions regarding LTC benefits and contributions, manages and assesses contributions and deals with all essential matters concerning the functioning of the scheme.

Uniquely, in the Republic of Korea, national health insurance and care insurance were integrated when the long-term care insurance system was introduced. The National Insurance Health Corporation (NHIC) administers both the National Health Insurance (NHI) and the LTC insurance. This architecture was endorsed with a view to reducing the cost of the establishment of new infrastructure (Chon, 2014). The idea was also to build further the purchasing power of the single payer system (Jeong and Niki, 2012).

The LTCI is funded by LTC social security contributions paid by active workers and employers along with Government subsidies (Park, 2015). The Government funds about 20 per cent of the annual budget for the scheme. The contribution rate is calculated as a share of the National Health Insurance (NHI) contribution and is paid together with contributions to the NHI. In 2019, LTCI comprised 8.5 per cent of NHI contributions.

Affiliation to the LTCI scheme is mandatory for individuals aged 65 or over and for persons aged below 65 with debilitating conditions (Kang et al., 2012). Thus, persons younger than 65 and suffering from illnesses such as dementia may also be affiliated (Park, 2015). Eligibility for LTCI is determined by a trained NHIS assessor. One of the main criteria for inclusion is the inability of the senior citizen to live on his or her own for longer than six months. An assessment of the person's physical and mental status is made irrespective of their financial status or family support, and eligibility is revaluated once a year (Park, 2015). Not all older people with care-related needs are covered by the scheme and central and local governments have introduced several smaller programmes for older people with a mild disability or who are living on their own (Jun Choi, 2015).

LTCI provides a unique benefit package, defined positively, which includes home care services, comprising bathing, day and night care, nursing older family members and providing assistance with household services institutional care and, in exceptional cases, cash benefits (Lee, 2015). A family member who supports beneficiaries can receive supportive cash benefits from the NHIS. LTCI also provides financial support to purchase necessary equipment that provides assistance in daily and physical activities for those who have difficulties carrying out their daily routines owing to physical or cognitive decline (National Health Insurance Service, 2020). Cash benefits are also provided on a case-by-case basis to older persons living in remote areas with no access to in-kind benefits (Jun Choi, 2015).

For the LTCI scheme, a purchaser-provider split is implemented. Each contracted service provider files a claim for reimbursement of costs incurred from the provision of benefits under the LTCI programme. When the NHIS receives a claim for reimbursement of costs of either home care or institutional care, it reviews the claim and proceeds with payment to the provider. The beneficiary's copayment is deducted from the

expenses.<sup>16</sup> Hospitals participating in the LTCI programme are paid based on per diem payments, differentiated by 17 disease categories (Kwon et al., 2015).

## Long-term care insurance (LTCI) (Kaigo Hoken) in Japan

The LTCI system in Japan is regulated by the Long-Term Care Insurance Act (Act No. 123 of 1997). LTCI is administered by municipalities, which set contribution levels, undertake contracting and coordinate service providers. The Health and Welfare Bureau for the Elderly under the Ministry of Health, Labour and Welfare (MHLW) oversees the implementation of the scheme by providing basic guidance and offering assistance related to planning, information collection and implementation (Sakamoto et al., 2018).

Around half of the LTCI budget is funded from tax revenues, and the remaining half is funded from social security contributions (Sakamoto et al., 2018). The contribution rate differs for each municipality and reflects its LTCI expenditures. Around two fifths of contributions are funded by contributions levied from persons aged 65 and over who reside in the municipality, and around three fifths is funded by the contributions from those aged 40–64, which is levied together with their social health insurance contributions. Contribution levels are revised every three years according to estimated expenditures, and the amount levied is allocated to the municipality's LTCI. Beneficiaries can benefit from a reduction of mandatory contributions under specific circumstances—for example, in cases where the insured person has experienced a sharp decrease in income compared to previous years (City of Sapporo, 2020). As for funding from taxes, 5 per cent of the total is allocated to municipalities that have a higher proportion of residents aged 75 and over and those that have a significant number of enrolees with low incomes. This allocation method is in place to ensure that factors that increase the contribution rate, such as age composition and income level, are adjusted, while at the same time placing fiscal responsibility on the municipality.

All persons with formal resident status aged 40 and over are eligible for LTCI coverage and must pay contributions alongside social health insurance contributions (JHPN, n.d.). Insured persons are divided into two categories: Category I is composed of those aged 65 and over who have unconditional rights to LTCI benefits, and category II is composed of those aged 40–64 experiencing age-related conditions such as stroke or Alzheimer's (JHPN, n.d.; Sakamoto et al., 2018).

The broad categories of benefits covered by LTCI are home care, day care, respite care, services at LTC facilities, equipment such as wheelchairs, assistive devices and home adaptation, such as with ramps, and maintenance rehabilitation services (Sakamoto et al., 2018). Community-based preventative services are also included. The monetary amount of benefits provided to a beneficiary is determined according to the results of an assessment that evaluates a person's physical capacity and cognitive status, following which, the applicant is assigned one of seven levels of assistance or else declared as ineligible (JHPN, n.d.; Sakamoto et al., 2018). The assessment is conducted using a standardized methodology that employs a questionnaire with 74 items to measure daily living activities and behaviours (Sakamoto et al., 2018) as well as further cognitive and behavioural questions. The results of the 74 assessment items are fed into a computer programme which classifies the applicant into one of the 7 levels of eligibility (or ineligibility). The results are reviewed by a Needs Assessment Review Committee established in each municipality, which reviews the statements made by the assessor and the opinion form completed by the attending doctor (Sakamoto et al., 2018). Those eligible then select a certified care manager, assigned by the insurer, who develops a care plan and coordinates service provision (JHPN, n.d.; Sakamoto et al., 2018). Reassessment is conducted every five years or following a request due to a change in circumstances (JHPN, n.d.).

There are ceilings on the amount of benefits that can be received from LTCI, determined by eligibility level (JHPN, n.d.). If the beneficiary wishes to purchase more services, they can do so by paying for them as an out-of-pocket expense. Should the monthly copayment exceed the amount set by their income level, the beneficiary may apply for reimbursement of the excess sum and copayment for health insurance may

<sup>&</sup>lt;sup>16</sup> Government of the Republic of Korea, National Health Insurance Law of 2011, available at: https://elaw.klri.re.kr/eng\_mobile/viewer. do?hseq=53994&type=new&key=

also be simultaneously taken into consideration. Low-income individuals are eligible to apply for additional exemptions (JHPN, n.d.).

## Long-term care insurance ElderShield Life and CareShield Life in Singapore

ElderShield was introduced in 2002 as a basic LTC insurance scheme and after an assessment conducted in 2018, the Government decided to enhance the scheme and replaced it with CareShield Life (Singapore, 2020). The CareShield Life and LTC Bill (Bill No. 24/2019) was further adopted in 2019.<sup>17</sup>

ElderShield was formerly managed by three private insurers appointed by the Ministry of Health (MOH) (Singapore, 2020). However, in 2019, MOH successfully reached an agreement with the ElderShield insurers for the Government to take over the administration of the scheme in 2021. This reform was made with the intention of boosting equity through a publicly managed scheme such that ElderShield members would be enabled to upgrade to CareShield Life more smoothly and have access to an expanded benefit package (Singapore, 2019).

Enrolment is automatic for all Singaporeans and permanent residents at the age of 40 unless they opt out of the scheme. The contribution term runs until the age of 65. By January 2019, there were 1.3 million ElderShield members (Singapore, 2019).

The scheme is contributory and the contribution rate is determined at the age of entry and does not increase with age (Singapore, 2020). Contribution rates vary according to sex, age cohort and the benefit package of choice. Females are required to contribute more under ElderShield on the grounds of their longer life expectancy (Singapore, 2020). From 2020, those enrolled into the CareShield Life scheme can also use their medical savings account (MediSave) to pay for contributions. For future cohorts of Singapore residents who join CareShield Life, the Government will also provide premium subsidies and support to ensure affordability. In particular, the Government will provide means-tested subsidies for lower- to middle-income Singapore residents and around two thirds of resident households will be eligible for CareShield Life subsidies of up to 30 per cent (Singapore, 2018).

Singaporean citizens and permanent residents with severe disability are eligible for cash benefits. Severe disability is defined as "the inability of an individual to perform three or more Activities of Daily Living (ADLs) independently, with or without mobility aids (e.g. walking aids, wheelchair)" (Singapore, 2021). ADLs comprise six activities, namely: "washing, dressing, feeding, toileting, walking or moving around, and "transferring" (which is defined as "the ability to move from bed to an upright chair or wheelchair"). In short, an eligible person is someone who will require the physical assistance of another person for the ADL.

The level of benefits received depends on the amount and length of contributions. ElderShield provided monthly cash benefits of varying levels for up to 5 or 6 years depending on the package (Singapore, 2020). However, pre-existing severe disabilities were excluded (Singapore, 2020). As of 2020, those who have chosen to upgrade to CareShield Life can benefit from an improved benefit package that features higher payouts, increasing payouts over time and no cap on payout duration (Singapore, 2020). Significantly, CareShield Life covers lifetime cash payouts if a beneficiary has to live with severe disability.

<sup>&</sup>lt;sup>17</sup> The Republic of Singapore, CareShield Life and Long-Term Care Bill, Bill No. 24/2019, available at: https://sso.agc.gov.sg/Bills-Supp/24-2019/Published/20190806?DocDate=20190806

# 3 The role of universal social protection in securing coverage of all carers

Attention must be paid to coordination across social protection, social care and health care systems in order to define and provide an integrated package of quality benefits that is responsive to the needs of older persons as well as their caregivers. This implies the adoption of social protection policies that are supportive, informed by a gender-transformative approach and effectively cover all caregivers. In this way, social protection systems can contribute to care policies that respect the human and labour rights of paid and unpaid caregivers in all care settings and support workers with family responsibilities, in line with ILO Conventions Nos 111 and 156. This section explores the current barriers to extending social security coverage to caregivers in light of their diversity of status in employment. It further links the current coverage gaps to the broader decent work deficits in the care economy and their consequences in terms of the quality and continuity of LTC services provided to older persons.

# Gender-transformative social protection policies for unpaid family caregivers and volunteers

## Unpaid family caregivers

As has been previously mentioned, some 70 countries set a legal obligation for family members to provide LTC to their older relatives when it is needed, thereby limiting collective responsibility for LTC and risk sharing within society (Addati et al., 2022). It is worth noting that some countries also adopt a mixed approach as their family structures and the geographical distribution of their population vary. For example, the traditional Chinese cultural virtue of filial piety makes younger family members primary caregivers for their older relatives (ESCAP, 2015). However, owing to the fertility decline (linked to the newly discontinued one-child policy) and migration from rural to urban areas for employment opportunities by younger cohorts, this traditional model of care has become more difficult to achieve. Thus, some cities, including Qingdao, have been prompted to explore the possibility of developing LTC insurance (Hong, 2021).

While there is no one-size-fits-all solution and countries need to tailor solutions to their own demographic, epidemiologic, socio-economic and cultural contexts, the bulk of LTC is nonetheless provided today by relatives. Unpaid LTC work represents a significant volume of time that cannot otherwise be dedicated to paid employment. In the European Union, while the employment rate of women increased in 2019, 7.8 per cent of women aged 50–65 did not seek employment owing to family responsibilities, compared with 0.8 per cent of men (European Commission, 2021a). LTC provided by unpaid family members, usually women, compounds a situation where women already perform most of the unpaid work undertaken in the home. This is a statistically significant issue as the time spent by women on unpaid care work represents 4½ hours daily, albeit with significant variations across and within countries (ILO, 2018). In turn, this situation impacts the ability of caregivers to remain within or reintegrate into the labour market and thus continue to be covered adequately by social security systems, as illustrated by box 11.

#### Box 11: Women as primary caregivers: the example of Poland

The family is traditionally the main provider of LTC in Poland. People exhibit a significant commitment to care for family members, in particular women. The high index rates of coresidence (older parents residing with their children) and the similarly high percentage of women aged 50 and above not engaged in the labour market are illustrative in this respect. This situation is strongly linked with traditions of family care and the gender division of labour. Coupled with an insufficient supply of public care and a lack of affordable private care, households are left with few alternative solutions or support outside of the family unit.

#### Source: Hirose and Czepulis-Rutkowska, 2016.

Social protection policies need to support families to provide some of the care across a broader continuum of care complemented by professional services (WHO, 2021c). This entails social protection systems becoming gender-transformative as per the principles enunciated in the Social Protection Floors Recommendation, 2012 (No. 202), the ILO Centenary Declaration for the Future of Work and the International Labour Conference (ILC) Resolution on Social Protection adopted in June 2021. It is essential to proactively address gender-related contingencies before inequalities become cemented across the life cycle. This can be achieved, for example, by recognizing spouses as caregivers and putting in place adequate mechanisms such as care credits or benefits for care leave with job protection, or any other measure that ensures that caregivers have the flexibility to provide care directly while remaining in the labour force. Additionally, they can be credited for their pension and continue to be covered by social security. Support should be given to family caregivers and tailored solutions found for both those who are engaged in the labour force and those who are not.

Many countries have updated their regulations to allow persons in employment to take care leave (Becker and Reinhard, 2018). In this context, social protection systems need to ensure adequate social security entitlements so that unpaid carers are not penalized when they have to interrupt their professional activity to care for a relative. For example, in the United Kingdom, a carer's allowance guarantees financial support of £67.60 per week for family carers who perform care work for more than 35 hours in a week. Similarly, carers who perform unpaid care work for at least 20 hours a week are provided with credits to fill the gap in the record of their National Insurance contributions (United Kingdom, n.d.). Canada, Finland, France, Germany, Japan and Sweden have adopted similar policies (Fultz, 2011). Some countries, such as Germany, include unpaid carers within their social security LTC schemes (see box 12). In Mauritius, the Government provides a monthly allowance as well as training for family members giving care to older people experiencing significant declines in capacity (WHO, 2017b).

#### Box 12: Social security for family carers in Germany

In Germany, unpaid carers providing LTC are covered by social security. They are defined along with other carers in German law (Social Code - Book XI - Social Care - Section 19) as being "people who provide non-professional home care to other people in need of LTC, due to a physical, mental or emotional illness or disability". The LTC insurance scheme has provisions to pay contributions toward statutory pension insurance for caregivers (Wetzstein et al., 2015) and caregivers who provide care for over 14 hours per week are covered under social security (Eurocarers, n.d.). Additionally, unpaid caregivers attending to relatives and who work in companies with over 15 employees are entitled to take care leave of up to ten days and receive a benefit equivalent to 90 per cent of their salary in a situation requiring urgent care. Unpaid leave of up to three months with employment protection and continued social insurance coverage is also available (Eurocarers, n.d.). During the COVID-19 pandemic, recognizing how important it was to facilitate family care, the Government raised care leave to 20 days and encouraged access to vocational training for caregivers who wished to go back to work when their care ceased to be required (Eurocarers, n.d.).

Source: Eurocarers, n.d.; ILO, 2022b.

### Supporting volunteers

In a number of countries, LTC provision also extends to include some of the care provided by volunteers. This often comes in response to evidence of the effectiveness of community-based volunteers in providing peer support, fostering social integration and cohesion and improving well-being at the community, household and individual levels (Public Health England, 2015). The boundaries of volunteer work may be defined very differently in terms of their specific role and the form of activities and care they provide within the continuum of LTC across countries and regions. This further reflects the wide diversity of volunteer work globally (see box 13).

Some countries have focused their efforts on providing skills enhancement and psychosocial support for unpaid caregivers (WHO, 2021c). For example, Thailand's Home Care Service Volunteers for the Elderly programme fosters volunteering in the community and offers volunteers 18 hours of training. In 2013, there was a total of 51,000 volunteers, individually entitled to receive US\$14 per month to cover their travel expenses (Lloyd-Sherlock et al., 2017). In Costa Rica, the Progressive Attention Network for Integral Elder Care, which was established by the National Council for Older People, has set up a body of community-based volunteers distributed across 50 community care networks to support 10,000 older persons identified as being particularly vulnerable to poverty (Lloyd-Sherlock et al., 2017). In Tonga, the Government via the Ministry of Internal Affairs has mobilized volunteers to make home-based visits where they attend specifically to disabled older persons and monitor their diets as diabetes and obesity are endemic among them and increase the risks of functional loss and subsequent demand for care (Carandang, 2022). Such efforts as these need to be complemented by measures to ensure the continuity of social protection coverage of caregivers.

#### Box 13: Volunteer work

According to Article 37 of Resolution I: Resolution concerning statistics of work, employment and labour underutilization adopted by the Nineteenth International Conference of Labour Statisticians (October 2013), "Persons in volunteer work are defined as all those of working age who perform unpaid, non-compulsory activities to produce goods or provide services for others. In this context, "unpaid" is interpreted as the absence of remuneration in cash or in kind for work done or hours worked. However, volunteer workers may receive some small form of support or stipend in cash, when below one third of local market wages (e.g. for out-of-pocket expenses or to cover living expenses incurred for the activity), or in kind (e.g. meals, transportation, symbolic gifts)" (ILO, 2013b).

While this definition has been internationally agreed upon, its application in practice may greatly vary and some concerns have been raised in the health sector on the over-use of volunteers or their use in contexts that warrant professional remunerated work. Moreover, the 2017 Tripartite Meeting on Improving Employment and Working Conditions in Health Services concluded that "Auxiliary and volunteer workers can also be used to fill the health worker gaps, but regulations are needed to ensure decent work" (ILO, 2017b).

### Articulations with paid care work

Social protection policies therefore need to adopt gender-transformative approaches that allow families to play a role in the continuum of LTC without jeopardizing their social security entitlements and their opportunities for labour market participation. Social protection policies moreover need to support the development of LTC guarantees substantiated by professional LTC services. With women's increased participation in the labour force, there is higher demand for professional LTC services; for, as women become less available to provide LTC to family members (see box 14), there is accordingly a need to expand the formal provision of LTC. This, in turn, requires the creation of decent work opportunities and conditions for paid care workers and facilitating the transition from the informal to the formal economy for many of them. This is explored further in the next section of this paper.

#### Box 14: Family care in Asia and the Pacific

Family care is the default mechanism to ensure LTC for older persons in much of Asia. Some countries – such as China, India, Nepal, Sri Lanka and Viet Nam – have legislation that mandates the family's responsibility to care for older persons. However, in many Asian and the Pacific countries rather than spread the risk across all of society through social protection mechanisms, there is a reliance on unpaid family caregivers, often women. This results in an undue burden on households whose older members have lost their ability to take care of themselves (ILO, 2018). To help alleviate that burden, some countries have adopted policies that go some way towards acknowledging the economic significance of the caregiving role, such as through the provision of tax incentives in India, Malaysia and the Philippines. Even when a family is not exposed to financial hardship in the course of caring for their loved ones, it may lack appropriate skills or endure psychosocial distress. To help remedy this situation and support family caregiving, governments in some countries have implemented policies that provide support services, such as counselling in Islamic Republic of Iran, India and Sri Lanka and education and training for paid and unpaid caregivers in China, the Democratic People's Republic of Korea, Fiji, India, Islamic Republic of Iran, Myanmar, Sri Lanka and Viet Nam. Fiji explicitly addresses support for older women caregivers (UNFPA, 2017).

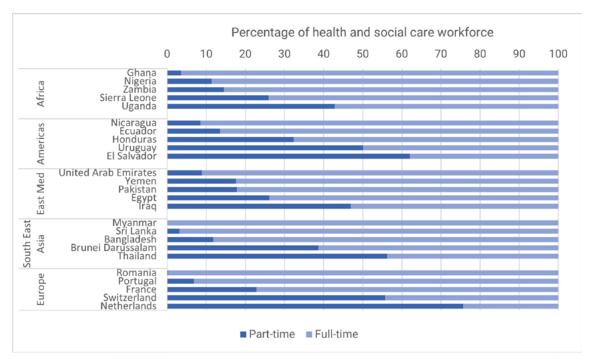
Source: ILO, 2021d.

# Decent working conditions and extension of social security coverage to paid health and care workers

There is an urgent need to secure decent work along with social security coverage for health and care workers. This urgency arises from the relatively poor working conditions and social protection coverage gaps they experience, which in turn have an impact on the attractiveness of the sector, global migration dynamics and the overall shortage in health and care worker supply. In turn, these elements directly affect the quality of the care that is provided by paid care workers to older persons in need of LTC.

Globally, the care economy is characterized by significant decent work deficits, which can vary considerably depending on the nature of country context, workplace type and cadre of workers (ILO, 2022b). The most vulnerable category is personal care workers. They are particularly important in LTC provision, both in institutional settings and in home-based and community care. In high-income countries, they represent more than half of total LTC employment and the majority of them are home-based (ILO, 2018), yet salaries are comparatively low and working time patterns with night and broken shifts are more prevalent in homebased care than in other sectors, as illustrated by figure 8. Care workers are more likely to experience time spent in being "on call", which all too often is unremunerated (Deutsche Welle, 2021).

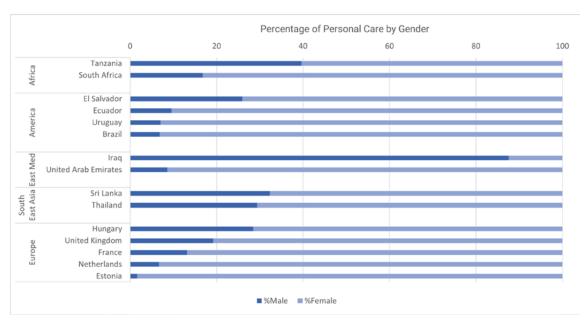
The isolated nature of work provided in the home can make care workers' environments unsafe, and conflicts of interests between LTC recipients, family members and personal care workers can arise that adversely impact health and safety (ILO, 2018). Similarly, the intrinsic nature of the work, if appropriate training and respite is not provided, can also impact care workers' health, such as in the physical exertion needed to support persons with very limited motor capacities or as a result of mental exhaustion resulting from having to care for persons affected by dementia or depression. Owing to inadequate work contracts and isolation, care workers are at higher risk of experiencing the kind of violence and harassment at work defined in Article 1 of ILO Convention No. 190. This is compounded by the fact that lack of full-time and long-term employment contracts often mean that care workers need to work in multiple facilities or homes in order to make a living. This situation made them particularly vulnerable during the COVID-19 pandemic, where they were at a higher risk of both contracting and transmitting the virus (ILO, 2020a).



#### Figure 8: Personal care workers' working pattern in selected countries, latest year available.

**Source:** ILO-OECD-WHO Working for Health Programme, forthcoming.

As mentioned in the introduction, the paid care workforce is predominantly made up of women. In the same vein, figure 9 shows clearly that in almost all the countries displayed in it, women are particularly represented among personal care workers, who typically also constitute the majority of formal LTC caregivers. Therefore, the sector is inherently susceptible to the gender discrimination common in labour policies and practices. Indeed, the gender pay gap in the health sector has been found to be over 25 per cent higher than in other sectors (ILO and WHO, 2022; WHO, 2019b).



#### ▶ Figure 9: Personal care workers<sup>18</sup> by gender, selected countries, latest year available

**Source:** ILO-OECD-WHO Working for Health Programme, forthcoming.

The care workforce is as diverse as the providers across the continuum of care described in the previous section of this paper. It is also heterogeneous in terms of skill levels, occupations, and employment status. Some LTC workers are licensed health professionals operating in the health sectors while others are licensed professionals operating in the social care sector. Many licensed and unlicensed care workers also operate in the home as domestic workers, meaning that they may be subject to different sectoral labour regulations.

Poor working conditions are often compounded by a lack of social security coverage, which in turn is both a source and a consequence of informality.<sup>19</sup> In many countries, care work is to a large extent undertaken alongside domestic work, which is often excluded from social security coverage. The ILO estimates that 61.4 million (81.2 per cent) of all domestic workers are in informal employment – that means eight out of every ten domestic workers, almost twice the share of informal employment of other employees (ILO, 2022c, 2021f). This impacts their social security coverage. Globally, only half of all domestic workers are legally covered by at least one branch of social security and only 6 per cent of all domestic workers are legally covered for all benefits. New estimates show the critical discrepancy between legal coverage and the implementation of these laws in practice, which essentially translates into significant gaps in effective coverage. Worldwide, more than 80 per cent of domestic workers are not effectively covered by employment-based social security (ILO, 2021f).

Social security coverage needs to be considered within the package of measures that will contribute to facilitating the transition of care workers from the informal economy to the formal economy (see box 15) (ILO, 2021g). During the COVID-19 pandemic, it came to light that many frontline workers in the health sector, particularly those engaged in temporary, part-time and self-employment and at the lowest end of the skills and wage spectrum, were not themselves benefiting from health and safety measures and were either inadequately covered by social protection or not covered at all (ILO, 2020d).

Personal care occupations are in the group 532 under ISCO 08 (and 513 as per former classification ISCO 88) 'Personal Care Workers in Health Services'. These comprise 5,321 (5,132) health care assistants, 5,322 (5,133) home-based personal care workers and 5,329 personal care workers in health services, not elsewhere classified.

<sup>&</sup>lt;sup>19</sup> One of the criteria to identify whether a job is formal or informal is registration for social security. The absence of coverage creates informality.

#### Box 15: The formalization of care work as a prerequisite for contracting with the social security system – the example of France

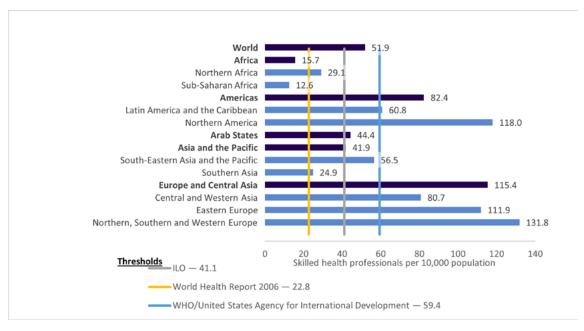
"The French Central Agency of Social Security Bodies (Agence centrale des organismes de sécurité sociale - ACOSS), which steers the Social Security and Family Allowance Collection Unions (Union de recouvrement des cotisations de sécurité sociale et d'allocations familiales - URSSAF), has implemented a policy dedicated to the formalization and professionalization of personal care services. The aim is to professionalize and formalize home-help caregiving services, especially for those whose work is associated with aiding older persons to live independently, including domestic workers. Using the 'Dematerialized universal service employment voucher' (CESU+), the process for people to formalize the home help they receive and reduce their tax bill has been simplified.

In practice, this entails a simplified online enrolment system, whereby the State bears half of the cost of social security contributions for the caregiver. Similarly, a tax deduction system for part of the caregiver salary has been put in place to support the most vulnerable in need of care. The aim is to ensure the professionalization of home caregiving services and to give those who work in this area formal employment status, with associated rights to social security and professional training."

#### Source: Social Security and Family Allowance Contribution Collection Network, 2022.

Working conditions and wages are also determined by the marketization and outsourcing of LTC services with the objective of lowering provision costs. Cutbacks in public spending translate into lower prices being paid to LTC providers, with further repercussions on working conditions and wages (ILO 2018). This situation is worsened by the fact that in many countries social protection policies and systems to guarantee access to childcare, health care and LTC without hardship are still under development (Scheil-Adlung, 2015). With no sustainable mechanism to finance such guarantees, low investments in both formal and informal care provision are widespread.

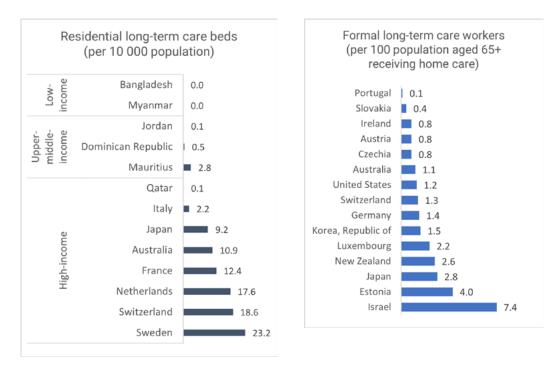
Poor working conditions and lack of adequate social protection render the health and social care sectors less attractive to workers. The related shortage in health and care workers makes for further impacts on quality of care. Before the outbreak of the COVID-19 pandemic, it was estimated that 17.4 million health workers, comprising approximately 2.6 million doctors, 9 million nurses and midwives, and 5.8 million workers from other cadres were needed to attain the SDG health index threshold as of 2013 (ILO, 2018). The existing shortage could be further exacerbated by the effects of the ongoing pandemic with increased numbers of health workers having left the profession or else declaring their intention to do so once the pandemic is over on the grounds of dissatisfaction with working conditions and insufficient staffing (International Council of Nurses, 2021; WHO, 2022). Low- and middle-income countries experience severer shortage than in high-income countries, with a shortfall of 6.9 million in South-Eastern Asia and 4.2 million in Africa (ILO, 2018). Figure 10 illustrates the marked inequalities across regions and subregions with regard to health workforce density. Such inequalities are further reflected in the density of formal LTC workers and residential LTC beds, though the available data is both scarce and not readily amenable to comparison (see figure 11).



#### ▶ Figure 10: Skilled health staff density against three thresholds across regions<sup>20</sup>

Source: ILO, 2021b.

#### Figure 11: Inequalities in residential LTC bed density and LTC worker density



#### Source: WHO, n.d.

This pronounced shortage in countries with fewer resources is partly exacerbated by the globalized labour market for health and social care workers. In many countries, migrant workers in the care economy, whether

<sup>20</sup> More details on the use of these reference points can be found at: https://www.who.int/workforcealliance/knowledge/resources/GHWA-a\_universal\_truth\_report.pdf they are providing care in institutions or in the home, face unique difficulties in having their skills recognized and in gaining access to social security and decent working conditions. Good practices that contribute towards remedying these difficulties include the conclusion of multilateral and bilateral labour and social security agreements, as well as the engagement of actors throughout the supply chain to respect ILO General Principles and Operational Guidelines for Fair Recruitment and the United Nations Guidance on Bilateral labour migration agreements (ILO, 2021h; United Nations Network on Migration, 2022). Therefore, greater commitment is needed to level the playing field when it comes to ameliorating working conditions and social security coverage of health and care workers. An insufficient number of ratifications of international Conventions in this respect highlights the urgent need for action (see box 16) (ILO, 2022b).

#### Box 16: International labour standards and the protection of health and care workers

International Labour Standards on nursing and domestic work recall the need to secure comprehensive and adequate social protection coverage for all concerned workers as a core part of securing decent jobs. For instance, Article 6 of C149 Nursing Personnel Convention states: "Nursing personnel shall enjoy conditions at least equivalent to those of other workers in the country concerned in the following fields: (a) hours of work, including regulation and compensation of overtime, inconvenient hours and shift work; (b) weekly rest; (c) paid annual holidays; (d) educational leave; (e) maternity leave; (f) sick leave; (g) social security."

While those instruments represent a global consensus among governments, employers and workers, decent work is not yet a reality for many in the health and care sectors. A total of 35 countries have ratified Convention No. 189, 13 of these within the last six years, while the Nursing Personnel Convention, 1977 (No. 149) has been ratified by 41 Member States (ILO, 2022b).

In light of the shortage of health and care workers in many countries of origin, it is important to give due consideration to the care needs at both ends of the migration spectrum. For instance, the population in low- and middle-income countries is ageing more rapidly than in high-income countries where most of the reserve of domestic migrant workers and health migrant workers is channeled. In countries of origin, social protection policies guaranteeing access without hardship to such services may not be in place to provide the needed care and support that should urgently be provided to ensure that migration does not translate into an even more acute shortage of health and social care workers in those countries.

Promoting decent work in the care economy implies coordination across health, social care, social protection and employment policies. For instance, certification and accreditation processes can contribute to both enhanced quality assurance and skill profile, recognition and remuneration. In Japan, there is a national "Certified Care Worker" accreditation system. To be certified, two years of study at Government-accredited institutions, graduation from a high school specializing in welfare, or three years' work experience in care with six months training are required together with passing a nationwide exam (Social Welfare Promotion and National Examination Center, n.d.).

Technological development is likely to have a significant impact on care services and ways of working. The use of technology to achieve more efficient health services will most likely redefine jobs in the health sector and provide opportunities in the form of new types of work and related occupational profiles (see box 17). While technological developments might on the one hand enable care workers to focus more on patient care, it may at the same time also result in tasks of greater complexity, risking cognitive and emotional overload for health and care workers. Owing to the inherent nature of the profession, the people-centred and relational aspect of providing care work is likely to endure. However, with new technologies, health apps and big data, it is expected that patients and relatives will take more responsibility and control over their health, which will have an impact on the relationship between care recipient and care worker and affect how care is provided. It is therefore important to develop mechanisms that ensure lifelong learning, flexible education and training systems that can anticipate the skills demanded for care workers by the labour market and that also ensure adequate preparation of care professionals for rapidly changing realities (ILO, 2019).

#### **Box 17. Digital training solutions**

Digital solutions are also used to train the different actors involved in LTC. In Mexico, for example, the State Employees' Social Security and Social Services Institute (Instituto de Seguridad y Servicios Sociales de los Trabajadores del Estado - ISSSTE) offers a multimedia training course. This is available via its institutional portal and can be accessed by anyone who needs to acquire knowledge on techniques, procedures and information related to the care of vulnerable and older people with dementia (State Employees' Social Security and Social Services Institute, 2017). The Catholic Workers' Circle of the Uruguay Mutual Fund (Círculo Católico de Obreros del Uruguay Mutualista - CCOUM) has increased the use of ICT for it to become an essential tool in ensuring equal access to training of nursing staff and thus contribute towards improving the quality of services and patient safety in LTC (Catholic Workers' Circle of the Uruguay Mutual Fund, 2016; ISSA, 2021a).

# 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/social security systems to develop tailored responses rapidly. Strategies for addressing these challenges include more effective coordination between institutions and service providers, an enlarged and strengthened role for prevention and health promotion, rehabilitation and ageing-in-place strategies, as well as the use of innovative technologies.

Depending on context, countries may vary greatly in the way LTC is organized, delivered and financed. LTC involves diverse types of benefits related to health care, social care and income support. In addition, the complementarity of LTC benefits with other social protection benefits, in particular health care and old-age pensions, plays a key role. Furthermore, the governance of the LTC system includes multiple sectors, making coordination of the essence. Since LTC encompasses a diversity of service providers and delivery mechanisms, ensuring its adequacy also remains challenging. Social and health care models need to be designed, or else redesigned, in order to allow a greater focus on prevention, to address staff shortages and to improve access to person-centred quality care. Paying attention to caregivers is central to the implementation of LTC and is currently a critical gap overlapping various gender inequalities.

International social security standards provide guiding principles which, when followed, can maximize the contribution of universal social protection to prevention and the response to growing LTC needs. While there is no one-size-fits all solution, these guiding principles provide a useful set of criteria for tailoring country-owned solutions that adhere to a rights-based approach. Universality of coverage, solidarity in financing, broad risk pooling, gender equality and non-discrimination, as well as strong coordination among health, social and employment policies can all contribute to realizing people's rights to LTC without hard-ship in a way that promotes their well-being while combating ageism. This contributes not only to achieving the SDGs but also to the Decade of Healthy Ageing. In this respect, the life-cycle approach contained in the Universal Social Protection concept is most adapted to addressing some of the social determinants of disease and disability in old age, while also ensuring that both older persons in need of LTC and their caregivers are protected by adequate, inclusive and gender-transformative social protection systems.

There is an urgent need to invest more strongly in both preventing disease and disability in old age and providing quality LTC without hardship in order to promote people's autonomy and independence. This requires addressing social determinants of health through the adoption of a life-cycle approach. Orchestration of the various constituent parts of social security systems is needed as are close coordination and the joining of forces with health and other social ministries. Such alliances, geared towards strong social policies and having the potential to address social determinants of health that lie within systemic inequality in living and working conditions, are of particular importance when it comes to influencing trends in the determinants of loss of function in a way that is aligned with broader societal well-being and cobenefits of climate action.

At the same time, investing in LTC in a way that adequately protects both older persons and caregivers is also an urgent need in many countries with a rapidly ageing population. The complexity of LTC needs and societal responses highlights the urgency for social protection policies to fully acknowledge the scale of their health impact and engage with health and employment policies accordingly. As the world is facing major upheaval owing to climate change, which is likely to impact on the health of older persons and their capacity to cope with existing disease burdens, social protection policies need to adopt a life-cycle approach to the prevention of life contingencies that are rarely predictable at the individual level and to secure the protection of older persons when LTC needs arise. Failure to do so will result in further impoverishment of older persons and their households. An undue burden of care will fall on the family, and especially women, whose capacity to maintain autonomy and well-being across the life cycle, including in old age, will be undermined. A cycle of impoverishment and gender inequality will hence be perpetuated.

Such investments need to be envisaged within the scope of broader objectives of universal health coverage and universal social protection, leaving no one behind. In particular, significant gaps in protection remain when it comes to the health and care workers who provide LTC. This situation diminishes the attractiveness

of the sector, which is already subject to labour shortages. Compounded by additional decent work deficits, this situation ultimately has implications for LTC service delivery and the quality of such services. In this context, the extension of social security needs to be considered within the package of measures that will contribute to facilitating the transition of many health and care workers from the informal economy to the formal economy.

A number of knowledge gaps 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 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 long-term care 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 health care, 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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