

Leaving No One Behind In An Ageing World

World Social Report 2023

DEPARTMENT OF ECONOMIC AND SOCIAL AFFAIRS

WORLD SOCIAL REPORT 2023: LEAVING NO ONE BEHIND IN AN AGEING WORLD



CHAPTER 5

A CRISIS OF CARE

KEY MESSAGES

- Demand for long-term care is rising due to population ageing and changes in the living arrangements of older persons. The COVID-19 crisis exposed weaknesses in long-term care, yet care and support systems continue to receive insufficient policy attention.
- The absence of accessible and equitable long-term care services takes a heavy toll on older persons, their families and whole societies. Women bear the brunt of deficiencies as

they comprise the majority of both care recipients and paid and unpaid caregivers.

Rethinking how to provide long-term care will benefit today's older persons and those who care for them as well as future cohorts of older persons. Countries should pursue a more equitable, person-centred approach involving governments, businesses, civil society, communities and households, and addressing needs in paid, formal forms of care as well as unpaid, informal ones.

A CARE CRISIS IN NUMBERS



the number of women 65 and over that need long-term care in the EU.



and 1 in 5 men

13.6 MILLION the estimated deficit of long-term care workers.

80% of all long-term care in Europe is provided by informal caregivers.



9 in 10 the number of formal long-term care workers that are women in OECD countries.



1.5%

the average percentage of GDP in OECD countries spent on long-term care in 2019; down from 1.7 per cent in 2017 despite growing demand.

Rapidly ageing populations have increasingly complex health care as well as care and support needs. Traditionally, for better or worse, co-habiting extended families have met the care needs of older persons. Living arrangements for families and older individuals, across developed and developing countries, have changed in recent decades, however. These shifts, combined with ageing in general, have heightened demand for different forms of care. For societies and individuals, the implications of increased demand depend significantly on what type of care is being provided and by whom. Women are the main stakeholders in long-term care, comprising the majority of both care recipients and paid and unpaid caregivers.

The mechanisms of care and support for older populations are increasingly important policy concerns. Yet across developing and developed countries, long-term care has suffered a lack of concerted policy attention. Government spending on quality long-term care has rarely been sufficient to cover mounting demand. Paid care work is notable for its low wages and difficult working conditions, leading to poor outcomes for recipients and an insufficient supply of well-trained caregivers.

A lack of regulation of service provision has also undermined quality.

This chapter describes how rising needs for long-term care, combined with changes in living arrangements, impact families and societies, particularly women. It shows how disparities in both who provides care and the primary sources of care available to older adults affect well-being. Without accessible and equitable formal care services, older adults confront unmet health and care needs that prevent them from realizing dignity and inclusion in their community. Families, particularly women, and health-care systems struggle to keep up. During the COVID-19 crisis, existing weaknesses in both paid and unpaid and formal and informal long-term care systems surged to the surface, with devastating impacts. To solve the crisis of care, the chapter proposes different strategies for meeting the long-term care needs of older adults more fairly and sustainably.

Α.

AS POPULATIONS AGE, CARE HAS NOT KEPT UP

1. CARE NEEDS ARE GROWING

People in almost all countries are living longer. Globally, babies born in 2022 are expected to reach 72.3 years on average, 25 years longer than those born in 1950.⁴⁵ Living more years does not necessarily mean enjoying a better quality of life, however, especially at older ages. In fact, living longer is associated with increased non-communicable disease and disability. Older persons often experience hearing loss, cataracts and refractive errors, back and neck pain and osteoarthritis, chronic obstructive pulmonary disease and diabetes, and they are at greater

45 United Nations, *World Population Prospects 2019*. Available at <u>https://population.un.org/wpp/</u> (accessed on 3 March 2022).

Because they live longer and spend a relatively longer period of their lives in poor health, older women are more likely to need long-term care services compared with older men

> risk of depression and dementia. As people age, they are also more likely to experience several conditions at the same time.

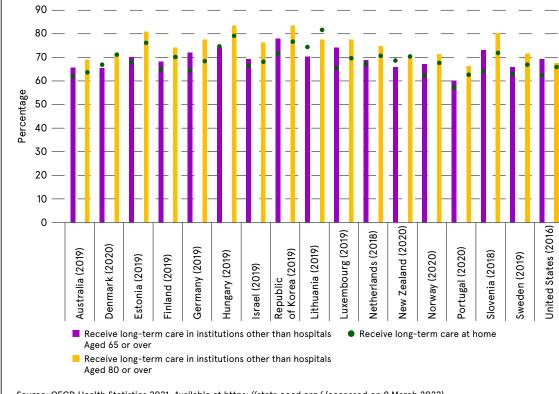
> Biological changes and increasing needs for support as people age have different implications for individuals and societies. At the individual level, people do not follow

the same path to older ages. While many older persons enjoy relatively good health into their later years, others may experience chronic diseases and other health risks.

For societies, an upward shift in the population age distribution means that shares of older persons are expected to grow in coming decades. In Europe and Northern America, population ageing is already well advanced. In Eastern and South-Eastern Asia, populations are ageing rapidly. Although individual older people may not require additional care or support, societies as a whole still face rapidly increasing demand for care services for older persons. In Japan, for instance, the number of older persons in need of care is

Figure 5.1

Share of women among long-term care recipients in institutions other than hospitals and at home, aged 65 or above and aged 80 or above, selected OECD countries



Source: OECD Health Statistics 2021. Available at <u>https://stats.oecd.org/</u> (accessed on 9 March 2022). *Note*: Countries are selected based on data availability.

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projected to rise from 8.3 per cent of the total population in 2020 to 14.4 per cent in 2065 (Marukawa, 2022).

Because they live longer and spend a relatively longer period of their lives in poor health, older women are more likely to need long-term care services compared with older men. Women are also usually frailer and have worse health at the end of life than men (Hägg and Jylhävä, 2021). As a result, they tend to account for a higher proportion of care recipients at home and in institutions (figure 5.1). For instance, in the European Union, at ages 65 or over, 33 per cent of women needed long-term care compared with 19 per cent of men (European Commission, 2021c). Moreover, greater female longevity means that a larger proportion of older women are widows and lack potential support from a spouse.

2. CARE NEEDS ARE CHANGING

High-quality care and support systems mean that older people can live more independently, with dignity and choice, personal safety and the ability to participate in their communities and society. In return, societies realize the rights and full potential of their ageing populations. As older people with different health conditions may have different needs, care and support systems should cover a wide spectrum of activities, including primary, acute and end-of-life care, and assistance with meals, housekeeping, bathing and other activities of daily living.

As populations age, needs evolve. Older persons may have specific care or healthcare requirements, including those that stem from having two or more long-term conditions. Some individuals may start to have limitations that prevent them from carrying out daily routines, such as getting out of bed, taking baths or showers, using the toilet, dressing and preparing meals. Functional limitations may not immediately require care services for extended periods but may call for assistance with some activities of daily living. In the United States, for instance, about one third of people aged 65 or older report functional limitations of some kind, a share that rises to two thirds among people aged 85 or older (United States, Congressional Budget Office, 2013).

Functional limitations can also increase demand for more extended services over time. For example, decreased mobility and falls among older persons can result in needs for hip and knee replacements and extended recovery, increasing demand for palliative, rehabilitation and ongoing care services (Pacific Prime, 2013).

Ageing amplifies the risks of cognitive impairments; 50 million people worldwide now live with dementia (Casafont and others, 2020). Still with no cure, dementia is linked to ageing and most commonly manifests as Alzheimer's disease. As dementia progresses, it results in increasing cognitive, psychosocial and eventually physical disabilities requiring enhanced support.

For people who grow older with chronic or disabling conditions, the focus may shift from finding a cure to providing quality of life and relief for disease-related symptoms as well as ensuring dignity and comfort during an individual's final days. End-of-life care, which includes palliative and hospice care, is expected to see a surge in demand yet countries remain largely unprepared for it (box 5.1).

BOX 5.1

ACUTE END-OF-LIFE VULNERABILITIES REQUIRE SPECIALIZED CARE

Countries are particularly unprepared for an expected jump in demand for end-of-life care as populations age and the burden of non-communicable diseases rises. Only an estimated 1 in 10 people needing palliative care worldwide is receiving it, even as demand is expected to double by 2060 (WHO, 2022). This type of care requires specialized skills, services and infrastructure, at a time in human life when vulnerabilities are acute. Even in countries with universal health coverage, however, the quality of end-of-life care varies dramatically. Shortfalls add to the burdens of those who are already experiencing severe pain and discomfort (Sallnow and others, 2022).

Because end-of-life care needs are complex, common care-related issues, such as insufficient training, high staff turnover, inadequate support for carers, a lack of access to medical or specialist support and high staff workloads, become especially concerning. Research on undergraduate nursing students, for instance, suggested they feel largely unprepared by their formal training to provide end-of-life care to dying patients and their families (Gillan, van der Riet and Jeong, 2014). With people dying further into old age, when dementia, multimorbidity and frailty are more common, and spousal, social and other forms of support are less available, end-of-life care provision requires urgent policy attention.

Countries could pursue several directions to improve and expand access to end-of-life care. Critical factors encompass adequate funding for formal end-of-life care infrastructure, training and education for care providers, and the availability and appropriate use of essential medicines, including controlled medicines for pain and symptom management. Families, community volunteers and other individuals acting as end-of-life caregivers need much more financial and logistical support, especially under the supervision of trained professionals. This would help to expand the opportunity to die at home, as many people wish. The rapid spread of COVID-19 in long-term and end-of-life care facilities highlighted the risks of concentrating those who are most vulnerable in one place while also robbing many older persons of the chance to die among loved ones.

B.

PROVIDING BETTER CARE: DETERMINANTS, STATUS AND CHALLENGES

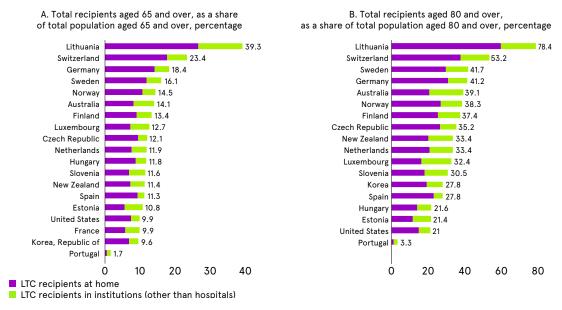
1. AGEING IN THE RIGHT PLACE

Rising care needs for older persons calls for providing quality care services. Growing old at home or "ageing in place" is a central desire for most older women and men, all over the world. A recent survey in the United States showed that nearly 80 per cent of adults aged 50 and over want to remain in their homes over the longer term, a proportion that has been consistent for more than a decade (Davis, 2021). "Ageing in place" refers to the ability to live in one's own home and community safely, independently and comfortably, regardless of age, income or capacity. "Ageing in the right place" extends the concept to the ability to live in the place most suited to a person's needs and preferences, which may or may not be one's own home. It highlights that the "right place" must satisfy the social, economic, health and infrastructure needs of older women and men, and offer adequate services, safety and affordability (Golant, 2015). Figure 5.2 shows that the share of people receiving long-term care at home is much greater than in institutions, for those aged 65 or above and aged 80 or above.

Multiple factors influence older persons' choices about where to receive care services. First, care options for older people and their families vary significantly by country and personal circumstances. Service availability and accessibility, cultural beliefs (such as the notion that the family is best placed to take care of its older members) and the financial situation of older persons and their families all affect care choices. Where older persons receive long-term care may also depend on their disease profile. Institutionalized care is typically reserved for frailer individuals who have difficulty managing on their own or need specialized medical services. Care services also have inextricable links with the living arrangements of older persons, as discussed below.

Figure 5.2

Long-term care recipients at home and in institutions other than hospitals, selected countries, latest available year



Source: OECD Health Statistics 2021. Available at <u>https://stats.oecd.org/</u> (accessed on 9 March 2022). Note: The numbers next to each bar indicate the share of older persons receiving long-term care in each age group. The share is the sum of those receiving long-term care at home and in institutions other than hospitals. Countries were selected based on data availability.

2. LIVING ARRANGEMENTS DEFINE CARE PROVISION

Living arrangements strongly determine the care services that older people receive. In many societies, co-residence with adult children is a common support mechanism. Adult children may be expected to remain with and support their ageing parents as part of "lifetime reciprocity" or "filial piety". Co-residence is also a way for parents to support adult children who have never left the parental home or have returned to cope with economic hardship or adverse life events. An older person may also move into the household of an adult child to help care for grandchildren or following the death of a spouse. Such living arrangements vary. According to the most recent global estimates, older persons live in households that range in size

from 2 to 12 persons, on average (United Nations, 2019c).

In more developed countries, such as in Western Europe and the United States, intergenerational co-residence has declined dramatically. Most older persons live either in single-person households or in households consisting of a couple only or a couple and their unmarried children. In 2019, the average size of such households was 1.9 persons in France, Switzerland and the United Kingdom and 2.1 in the United States. In countries with more older persons living in small households, especially many developed countries, people tend to marry later, have fewer children and have them later in life. While older people may choose to live close to their children or relatives to receive care and support when needed, as in some European countries, social programmes typically offer financial assistance or health-care benefits to retired adults. This can make it more affordable and convenient for older people to stay in their own homes and to live by themselves or only with a spouse (United Nations, 2019c, 2020e).

Intergenerational co-residence has declined dramatically in developed countries

In most developing countries, older persons are most likely to live with a child or extended family and to receive care and support within the family. Higher fertility in the recent past provides more opportunity for older persons to co-reside with their children and grandchildren, potentially including one or more children in the same household. Countries with the highest prevalence of this type of co-residence are in Africa, Asia and Latin America. In Africa, for instance, all countries (except Burundi, Egypt and São Tomé and Príncipe) have at least half of older persons living in households with extended family members (United Nations, 2019c, 2020e).

Urbanization can affect the living arrangements of older persons and the care services they receive. Cities usually offer a wide range of choices for housing and living configurations tailored to individual health, social and infrastructure needs and the economic means of older persons. Available options range from ageing in one's own place to retirement homes, senior homes, residential care homes, continuing care homes, and assisted living communities and nursing homes that provide 24/7 care and support.⁴⁶ Additional options are residential communities for older persons that typically cater to the wealthy with amenities such as club houses and golf courses, fitness centres and tennis courts. Fewer options exist in rapidly growing cities, especially in developing countries, where poor and disadvantaged older persons often live with extended family in overcrowded homes with minimal financial resources.

While some rural areas can be places of great natural beauty and offer a wide range of recreational activities for active ageing, finding health-care services can be a challenge for older persons, more so in remote areas. Outpatient and hospital-provided specialty care may not be available. Attracting and retaining formal and informal caregivers may be an ongoing struggle. Well-lit and safe walkways away from traffic; accessible, reliable and affordable public transportation; adequate housing; public and commercial services and opportunities for social participation are often lacking.

3. DEMAND FOR CARE OUTSTRIPS THE SUPPLY OF CAREGIVERS

Long-term care is a major component of care services for older persons. It refers to a broad range of personal, social and medical services over an extended period to "ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights,

⁴⁶ Residential care homes provide assistance with meals and the activities of daily living. Continuing care homes offer nursing services as needed, allow residents to transit into facilities on the same premises that provide more assistance if and as needed, and can accommodate couples with different care needs.

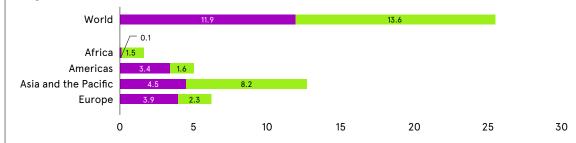
Figure 5.3

fundamental freedoms and human dignity" (WHO, 2017). This includes care provided at home, in the community or in institutions.

Long-term caregivers can be employed in the formal or informal economy, and their services may be paid or unpaid. A formal caregiver delivers professional and usually paid services to an individual or group of individuals. Informal caregivers provide care to those who need it, generally based on an existing relationship, such as with a family member, friend or neighbour (AIHW, 2021). They are typically unpaid but not all. In some cases, people without necessary travel documents, training or credentials move to other countries to provide care services, meaning they can only work in the informal sector and are usually poorly remunerated. That said, the distinctions between formal and informal, paid and unpaid care are blurring. Some European countries, for instance, provide cash payments directly to informal caregivers to incentivize and support them (Zigante, 2018).

Amid rising demand for long-term care, growth in the number of caregivers is not keeping pace. As of 2015, the world was experiencing a shortage of about 13.6 million formal care workers, according to a study of 46 countries with 80 per cent of the world's population.⁴⁷ The shortage was largest in Asia and the Pacific (8.2 million workers) and smallest in Africa and the Americas (1.5 million and 1.6 million workers, respectively).⁴⁸ In Europe, the shortage amounted to 2.3 million workers (figure 5.3). Such deficits mean that half the older population globally does not have access to quality formal long-term care.⁴⁹

Estimated numbers and deficits in formal long-term care workers, the world and by region, 2015



Estimated number of formally employed long-term care workers, millions
Estimated deficits in formal long-term care workers, millions

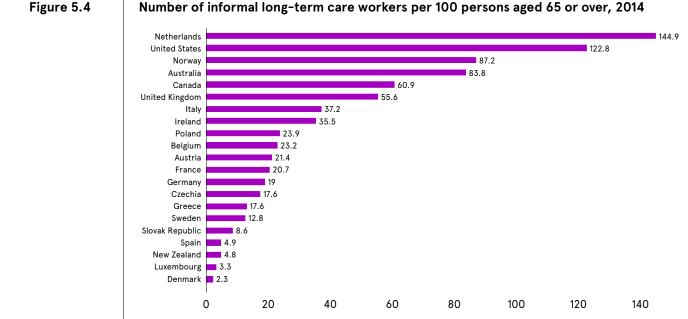
Source: Adapted from Scheil-Adlung (2015).

- 47 An ILO study estimated the shortfall in the numbers of long-term care workers based on a relative threshold of 4.2 formal long-term care workers per 100 persons aged 65 or above in 2015. The threshold derives from the population-weighted median value of formal long-term care workers per 100 persons aged 65 or above in a group of 18 selected countries in the Americas, Asia and the Pacific and Europe. Given scarce data on long-term care workers, the study followed several assumptions. For countries where data were not available in Africa, the number of formal care workers was estimated at 0.4 workers per 100 persons aged 65 or above. The related values for the Americas, Asia and the Pacific, and Europe were 1.69, 2.34 and 2.9. They were estimated based on a population-weighted average number of formal long-term care workers in countries with available data in respective regions (Scheil-Adlung, 2015).
- 48 The Americas include both North America and Latin American and the Caribbean. The ILO's study does not provide disaggregated estimates within the Americas.
- 49 Scheil-Adlung (2015) set a threshold for the basic provision of care services at 4.2 workers per 100 persons aged 65 or above, which is the median population-weighted number of formal long-term care workers in 18 selected countries in the Americas, Asia and the Pacific and Europe. If a country does not meet 4.2 care workers per 100 persons aged 65 or above, its people do not have access to quality formal long-term care provision.

The paucity of formal long-term care provision is expected to continue in coming decades. In the United States, an estimated 3.5 million additional workers or more will be needed to provide long-term care to older people by 2030 (Spetz and others, 2015). The number of formal jobs for these workers is projected to increase by only 1 million over the same period, however. In Japan, the Government (2015) estimates that the demand-supply gap in 2025 will be about 380,000 care workers, especially in metropolitan areas. By 2030, Germany will need additional care workers equivalent to around 263,000 to 500,000 full-time workers (Gerlinger, 2018).

Foreign-born migrants have filled care gaps in many countries. While comprehensive data on the migrant status of care workers are very limited, piecemeal evidence suggests the proportion of foreign-born care workers in high-income countries is great, having grown sharply in recent years amid rising demands for care and the unwillingness of native-born populations to take up what they see as low-status and poorly paid work (Sowa-Kofta and others, 2019). In Italy, an estimated 73 per cent of the paid care workforce in 2017 was foreign born (Bonizzoni, 2019). Some migrant care workers are undocumented or arrive in a country with a visitor or tourist visa. This strands them in the informal economy with limited protection and below official minimum wages.

Without enough formal caregivers, many countries, even rich ones, will continue to rely on informal care provision in private homes. In Europe, for instance, informal carers provide up to 80 per cent of all long-term care. They comprise from 10 per cent to as much as 25 per cent of the total population (Zigante, 2018). While the number of informal care workers varies significantly across countries (figure 5.4), most are unpaid family members, often also aged 65 or more.



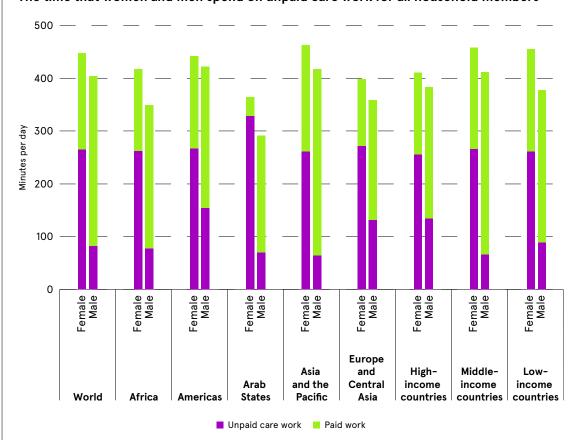
Source: Adapted from Scheil-Adlung (2015).

A. LONG-TERM CARE STILL DEPENDS ON WOMEN AND GIRLS

Most caregivers, paid and unpaid, in formal and informal sectors, are women. This phenomenon persists across regions and countries at different income levels. As figure 5.5 shows, women globally spend over 250 minutes per day on unpaid care work, on average, triple the time spent by men. In some cases, social and cultural expectations that women can and should care for older relatives and family members with disabilities may make women reluctant to seek support from formal or informal care services. Greater longevity also means that older women increasingly provide care to their parents and relatives in the oldest age categories.



The time that women and men spend on unpaid care work for all household members



Source: ILO, Models of care employment around the world. Available at <u>https://www.ilo.org/global/about-the-ilo/multimedia/maps-and-charts/enhanced/WCMS_721442/lang--en/index.htm</u> (accessed on 11 March 2022).

Among unpaid caregivers aged 50 years or more in OECD countries, 62 per cent are women. (OECD, 2020b).⁵⁰ Globally, women contribute 71 per cent of the estimated time devoted to unpaid care for people with dementia, a share that increases to 80 per cent in low-income countries (Alzheimer's Disease International, 2018).⁵¹ Significant cross-country variation exists, however, even among high-income countries with similar markers of gender equality. For instance, the share of unpaid, informal carers aged 50 or more who were women ranged from 53 per cent in Austria to 76 per cent in Spain (OECD, 2021c). The amount of unpaid caregiving is also unevenly spread within and across households and families. Women in wealthier families are more likely than poorer women to pay a formal non-family caregiver to support the care needs of older relatives (Shah and others, 2012; Ozen, 2020). Inequalities also occur within families, with research from Mexico and Peru suggesting that unpaid care work is sometimes imposed on less powerful family members, such as daughters-in-law and younger granddaughters (Lloyd-Sherlock and others, 2017).

Women are also more likely to perform paid care work, in both the formal and informal economy. Nine in 10 long-term care workers in OECD countries are women. Even in countries considered some of the world's most gender equal, Denmark and Norway, women comprise 95 per cent and 92 per cent of paid care workers, respectively (OECD, 2021c). This is closely related to the low social status and poor pay of care work as well as cultural and social norms that women should carry out care-related activities, whether paid or unpaid (Addati and others, 2018). Paid care work is also unevenly distributed across the female workforce, often drawing women from ethnic minority backgrounds. In the United States, black and Hispanic women make up almost half of paid care workers despite being only 14 per cent of the total workforce (Gould, Sawo and Banerjee, 2021).

B. CARE WORK IS UNDERVALUED, UNDERPAID, UNDERTRAINED

One reason for the general undervaluing of care work is that so much of it takes place at home without pay, even when it entails complex medical and nursing tasks. The actual value of unpaid care work is massive, with 16.4 billion hours spent on it every day, equivalent to 2 billion people working eight hours per day with no remuneration (Scheil-Adlung, 2015). The Ministry of Economy in Argentina (2021) estimated that unpaid care and domestic work accounted for 15.9 per cent of GDP in 2020, making it arguably one of the largest sectors of the economy. In 2015, 15.9 million family members and friends provided 18.1 billion hours of unpaid care to people with Alzheimer's and other dementias, with an estimated economic value of \$221.3 billion (Lord, 2016).

Paid care workers receive wages but often at marginal levels, coupled with little job

⁵⁰ These estimates likely undercount the amount of total caregiving and perhaps the extent of the gender divide in care, due to data limitations. The only nationally representative surveys that ask these questions are retirement surveys of people 50 and older (HRS/SHARE) so younger women are not included.

⁵¹ This is consistent with global findings on unpaid care work more broadly – encompassing childcare and routine household work – where women dedicate, on average, over three times more hours than men to unpaid care work: 4 hours and 25 minutes per day for women against 1 hour and 23 minutes for men (Addati and others, 2018).

security, poor working conditions and few or no benefits. Across the 27 members of the European Union, non-residential longterm care workers make 80 per cent of the average national hourly wage (Gould, Sawo and Banerjee, 2021). Caregivers tend to be underpaid even compared to other occupations where workers have similar skills, education and experience; this is referred to as the care penalty (England, Budig and Folbre, 2002). Wage penalties in care work reflect the fact that most care workers are women (Addati and others, 2018).

People, especially women, from countries with few economic opportunities may migrate to higher-income countries and work in the care sector. Migrant caregivers are more likely to hold short-term temporary visas, however, limiting their rights in the host country and amplifying their vulnerability to exploitative practices (IOM, 2010). Shorter in-country work histories combined with lesser value given to education credentials obtained abroad also place migrant care workers at a disadvantage relative to native-born caregivers (Behtoui and others, 2020). Foreign-born care workers in China, Taiwan, Province of China, for instance, only receive 86 per cent of the minimum wage of their native-born peers.

Ethnic minorities and foreign-born migrant caregivers may experience discrimination at work from co-workers and recipients of care, often caused by cultural or language differences and reflected in the preferences of care-receivers for support from people who are "more like them" (IOM, 2010). At the same time, as caregivers migrate to higher-income countries, they leave behind a growing gap in care provision in their countries of origin.

Lack of adequate training commensurate with the needs of care recipients is a significant barrier to high-quality care services and higher wages. Long-term care services require a broad spectrum of professional skills, such as helping older persons with dressing, bathing and eating; assisting with mobility; providing physical and occupational therapeutics; and supporting them with nutrition and food preparation. Quality services also call for knowledge in geriatrics, aimed at the unique health needs of older people. Most caregivers, paid and unpaid, have insufficient training, however. In OECD countries, about 70 per cent of formal care workers are personal care workers with no mandatory standard or minimum qualifications; the remaining 30 per cent are nurses with a minimum number of years of training (OECD, 2020b). Family caregivers typically have little care literacy or understanding of the ageing process and how it evolves. They may not understand frailty or what caregiving entails, and not know where to turn for services and information or how to monitor and improve the quality of care (Lloyd-Sherlock, 2017).

Undervalued and unappreciated care work has spurred various physical and mental health issues among caregivers, negatively impacting the quality of care. In care facilities, paid workers with low levels of training often experience a high burden of stress as they care for older people with the most complex needs and challenging behaviours. Paid home care work often involves complicated, poorly defined roles and responsibilities within the family. Female care workers, in particular, may experience isolation, harassment and violence. All these factors feed the undesirability of long-term care jobs, high turnover and low morale (United Nations, 2018b). Paid carer stress skyrocketed during the COVID-19 pandemic, especially early on when supplies of personal protective equipment, vaccinations and other protective measures were limited or non-existent (Smith and others, 2020).

Although providing care to a family member may have some positive aspects, including satisfaction in helping a loved one, unpaid family caregivers can experience mental stress and poor physical health, similar to paid workers. This may come, for example, from lifting and carrying older persons and a lack of rest and recuperation breaks (Qualls, 2021). Older caregivers may find tasks particularly challenging, such as those caring for a spouse. Family caregivers may experience multiple care-related burdens. For instance, when caring for older relatives, they may also tend to dependent children, manage household chores and finances, and engage in income-generating activities.

Paid leave entitlements as well as flexible working arrangements for family or other informal caregivers to provide care can protect the economic security and mental health of caregivers. Yet even among wealthier OECD countries, a third do not offer paid leave benefits to care for an ill family member (non-child). Among the two thirds that offer such benefits, there are varying amounts of pay and leave periods and qualifying "family members" are in most cases limited to partners/spouses, parents and sometimes siblings only (OECD, 2020b). Temporary respite care could provide relief for caregivers but is not available in all countries, especially in developing ones.

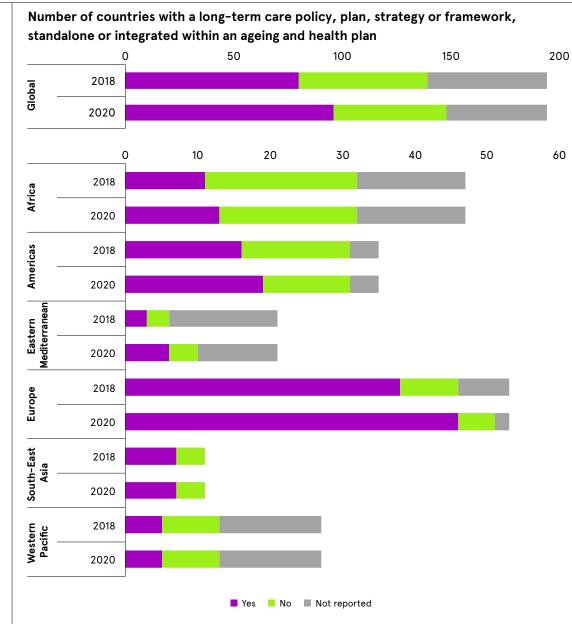
An individual's unpaid care responsibilities may limit their time for paid work. Many car-

ers choose to remain in part-time jobs with lower salaries that are easier to combine with care responsibilities (Barslund and others, 2021). Family caregiving is also associated with additional expenditure, including purchasing medical supplies, assistive technologies and physical adaptations to homes, putting further financial pressure on family caregivers. Such strains can spark family tensions and caregiver-recipient confrontations, including elder abuse (Burnes and others, 2015; Fang, Yan and Lai, 2019).

Insufficient numbers of caregivers and low-quality services reflect a general lack of strategic policy planning much less meaningful consultations with older persons, the group most affected by such policies. Many countries across regions lack a specific policy, plan or strategic framework for long-term care (figure 5.6). The situation is particularly critical in South-Eastern Asia where population ageing is occurring rapidly. Missing or inadequate regulations on long-term care and their enforcement can impair quality, put prospects for decent work at risk for care workers, and increase the vulnerability of older persons to abuse. A lack of legislation on labour standards, for instance, has left care workers without guarantees of minimum daily and weekly hours and little employment protection or assistance in case of unemployment. This situation drives rising inequality in working conditions and therefore high turnover and low morale (Addati and others, 2018).

Even in countries that do have care provision policies, poor implementation has often left caregivers with benefit packages that do not meet minimum requirements. Older persons, especially the most vulnerable, are stranded amid fragmented, confusing and inadequate care options (Scheil-Adlung, 2015).





Source: WHO, Maternal, Newborn, Child and Adolescent Health and Ageing data portal. Available at <u>https://platform.who.int/</u><u>data/maternal-newborn-child-adolescent-ageing/ageing-data/ageing---long-term-care-for-older-people</u> (accessed on 1 March 2022).

Note: The "Americas" includes both Northern America and Latin America and the Caribbean.

C. NOT ENOUGH PUBLIC SPENDING, HIGH OUT-OF-POCKET COSTS

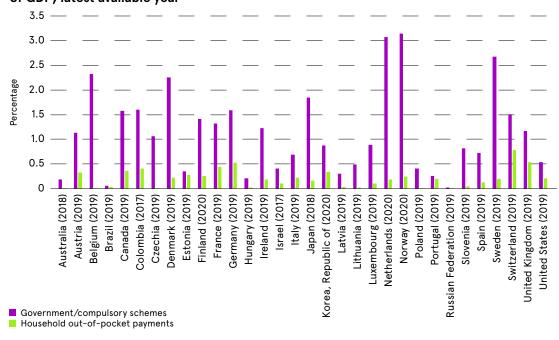
As societies age, pressure grows to ensure the availability and affordability of long-term care services for all people in need. Spending must keep pace. Globally, however, average public expenditure on long-term care is low, remaining below 1 per cent of GDP from 2006 to 2010 (Scheil-Adlung, 2015). Little has changed over the past decade. Among OECD countries, average public expenditure for formal long-term care was just above 1 per cent of GDP in 2016 and 2020.52

Public spending on long-term care varies across countries, reflecting differences in population structure and the develop-

ment of formal long-term care systems. In 2019-2020, the Netherlands and Scandinavian countries (Denmark, Norway and Sweden) spent the most by far on longterm care, at around 2.5 to 3 per cent of GDP. Elevated spending mirrors the more developed formal long-term care systems in these countries. A second group of high-income countries, including Finland, France, Germany, Japan, Switzerland and the United Kingdom, allocate between 1 and 2 per cent of GDP to long-term care. In some South-Eastern European and Latin American countries, which have relatively younger populations, formal provision of care is less comprehensive. People with long-term care needs rely to a greater extent on unpaid family members (figure 5.7).

Figure 5.7

Government spending and household out-of-pocket payments on long-term care, share of GDP, latest available year



Source: OECD Health Statistics. Available at https://stats.oecd.org/ (accessed on 9 March 2022).

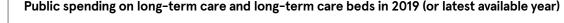
52 The calculation is based on OECD Health Statistics. Available at <u>https://doi.org/10.1787/health-data-en</u> (accessed on 1 March 2022).

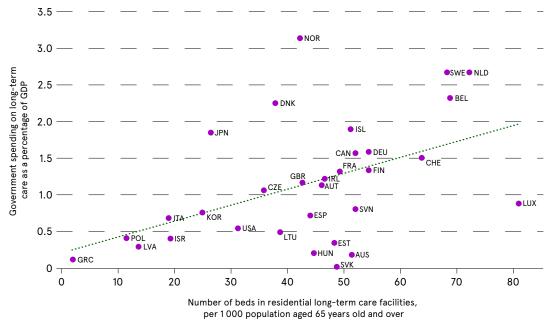
Figure 5.8

Insufficient public expenditure leads to inadequate care infrastructure, indicated, for instance, by a low number of beds in residential long-term care facilities (figure 5.8). Long-term care infrastructure is limited in most countries in Africa, Asia and Latin America, and in some European countries (Lloyd-Sherlock and others, 2019). In Brazil, fewer than 1 per cent of older people have the option to live in a nursing home. Long-term care institutions are concentrated in urban areas and are relatively small, accommodating only 23 people on average. Long-term care capacities are even more limited in many African countries (Scheil-Adlung, 2015).

Overall, most countries provide investment falling far short of the real costs of longterm care services. Since participation in long-term care insurance could provide financial protection to older adults, some countries have instituted mandatory participation in it while people are still employed, such as Germany and the Republic of Korea (Scheil-Adlung, 2015). Yet insurance coverage has remained low. In the United States, private long-term care insurance covered only 11 per cent of adults aged 65 or above in community settings (not nursing homes) in 2014, often because of unaffordable premiums or the mistaken belief that standard health insurance would cover long-term care expenses (Johnson, 2016).

Older persons in many countries face high out-of-pocket payments for longterm care, including home and institutional care. Over half of the older persons in some countries, including Austria, Italy and Spain, had to spend their own





Source: OECD Health Statistics 2021. Available at <u>https://stats.oecd.org/</u> (accessed on 24 March 2022). *Note*: The dotted line is a fitted one.

funds on long-term care with payments that can top 10 per cent of household income or more (Scheil-Adlung, 2015). Household out-of-pocket payments on long-term care are equivalent to over half of public spending in some countries, including Brazil, Estonia, Portugal and Switzerland (figure 5.7).

High out-of-pocket long-term care expenditures are likely to push older persons into poverty

High out-of-pocket long-term care expenditures are likely to push older persons into poverty. In the United States, nursing home stays have strong negative effects on total household wealth. One study found that after the first entry into a nursing home, a resident's total household wealth fell steadily over a six-year period, in contrast to those who stayed in their (owned) homes, the value of which may appreciate and increase household wealth (Banerjee, 2012).⁵³

C.

COVID-19 CUT A DEVASTATING SWATHE THROUGH LONG-TERM CARE

1. CLUSTERED IN FACILITIES, OLDER PEOPLE WERE MORE VULNERABLE

Serious illness and deaths from COVID-19 infection have been highly concentrated among the oldest people. Those with some conditions that are more prevalent in older ages, such as diabetes, were more likely to die from the virus. In high-income countries, 89 per cent of both official deaths and excess deaths from the pandemic occurred among those over age 65 (Demombynes and others, 2021). In Italy, 35 per cent of older persons aged 80 or over who contracted COVID-19 died from the disease, compared to 1 per cent of people aged 40 to 49 (Signorelli and Odone, 2020).

In other countries, the picture has been slightly different. Roughly 40 per cent of official deaths and excess deaths were under age 65 in upper-middle-income countries with data, and 54 per cent in lower-middle-income countries. A similar pattern of much younger death profiles in middle-income countries holds when adjusting for differences in age distribution across countries (Demombynes and others, 2021). Age-disaggregated data on COVID-19-related deaths in low-income

⁵³ In some cases, older persons in the United States transfer their assets to their children to qualify for Medicaid, which covers the costs of a long nursing home stay. Research finds that such Medicaid-induced asset transfers may be fairly small but not insignificant (Bassett, 2004).

countries are more limited but in 17 of these countries with data, an estimated 52 per cent of COVID-19 deaths were among people aged 65 or over.⁵⁴

The types of care that older persons receive influence the risk of getting and dying from a COVID-19 infection. A large proportion of deaths have occurred in long-term care facilities. This reflects how the oldest people with comorbid conditions are more highly care dependent as well as the heightened risk of infection in communal settings (Graham and others, 2020).

Two recent studies using COVID-19 data disaggregated by age and care home residential status confirmed that the two main determinants of elevated risk of death in care homes were the underlying frailty of older persons and higher infection prevalence in care homes, in addition to old age (Hardy and others, 2021; Lai, 2022). The underlying frailty of older people in care homes accounted for 46 per cent of the difference in mortality rates between care home residents and non-residents in Belgium, while in England and Wales, it accounted for 66 per cent of the difference in the first wave and 88 per cent in the second wave (Lai, 2022). Higher infection prevalence accounted for 40 per cent of the difference in mortality between care home residents and non-residents in Belgium, while in England and Wales, it accounted for 26 per cent during the first wave and was negative during the second wave. Higher immunization rates among care home residents and better infection control procedures in care homes helped to curb infection in England and Wales (ibid.).

In countries where a greater proportion of older people live in institutions, such as Australia, Denmark and Switzerland, they are 60 times more likely to die from COVID-19 than people at younger ages. By contrast, in countries with a smaller proportion of older persons living in institutions, such as China, Mexico and Nigeria, older persons are eight times as likely to die from COVID-19 compared to those at younger ages (United Nations, 2020f).

Higher COVID-19 mortality rates in care facilities are associated with poorer quality ratings and overcrowding (Weech-Maldonado and others, 2021). Multiple room occupancy tends to be more common in developing countries, and facility staffs generally have more limited training, possibly impeding infection control (Roqué and others, 2016; Mapira, Kelly and Geffen, 2019). The practice of transferring COVID-19-positive older people from hospitals to care facilities without due precautions as well as failing to prioritize the provision of protective equipment to care facilities during the early phase of the pandemic contributed to higher death rates (Gibson and Greene, 2021).

Across all countries, fewer data track COV-ID-19 infections among older people outside facilities. Previous research suggests that those in multigenerational households often have extensive and frequent contacts with other household members, which heightens the risk of disease transmission. This was especially so for lower-income families, who were more likely to have a household member classified as an essential worker, reinforcing overlapping and compounding health and economic

54 Max Planck Institute for Demographic Research, COVerAGE-Database. Available at <u>www.demogr.mpg.de/en/publications_databases_6118/online_databases_6676/</u> (accessed on 30 June 2022).

inequalities. Even when multigenerational families do not co-reside, older persons who live close to extended family members may have frequent contacts with them (Tomassini, Wolf and Rosina, 2003). Older persons living alone or with their spouse only would be expected to have the lowest infection rates due to their ability to limit social contacts (United Nations, 2020f).

Taken together, these findings suggest that if countries continue to incorporate large long-term care institutions into their care provision strategies, they must remain aware of how these concentrate vulnerabilities and require extra care and precautionary measures to stop the spread of new pathogens.

2. LONG-TERM CAREGIVERS PAID A HIGH PRICE, MANY TIMES OVER

The pandemic had profound impacts on caregivers. It increased caregiver stress and reduced the quality of care by limiting families' access to external support such as home visits, day centres and respite facilities (Kostyál and others, 2021; Onwumere and others, 2021). It also likely exacerbated pre-existing inequalities in informal care. The poorest families and caregivers of older persons with the most complex needs likely suffered most from compounding economic and other pressures and disruptions in health and care services (Lorenz-Dant and Comas-Herrera, 2021; United Nations, 2020f). Disadvantaged families without access to digital technology faced obstacles to alternative virtual services where these were introduced.

Most paid care workers have faced both the economic impact of the crisis and the

medical and psychological toll of higher exposure to the virus. Throughout the pandemic, care workers remained in close contact with those most susceptible to infection, thus raising their own risks. Due to low wages, some carers took on multiple part-time jobs at different facilities while a lack of sick pay discouraged many from caring for themselves when ill. Travel between care facilities on crowded public transport may have heightened exposure and the chance of carers becoming vectors for viral entry into facilities (Chen, Chevalier and Long, 2020).

Such factors have contributed to high rates of burnout, illness and death among care workers, especially migrants (White and others, 2021). A survey of migrant health and care workers across 32 countries found that 40 per cent experienced increased job insecurity, 48 per cent had inadequate access to personal protective equipment and 27 per cent were only offered unpaid leave when infected with COVID-19 (Pillinger, Gencianos and Yeates, 2021). In the United States, for example, Filipinos make up 4 per cent of nurses but accounted for 32 per cent of COVID-19 deaths among nurses in 2020 (ibid.).

D.

MORE EQUITABLE CARE CENTRES ON WHAT PEOPLE NEED – AND DECIDE

Population ageing, combined with changes in older persons' living arrangements, is

increasing demand for different forms of care and has left many countries grappling with the implications. Reducing care dependency in later life requires a life course approach to promoting healthy ageing and preventing poverty. Adequate care and support systems for people in need of care – especially women and those from marginalized groups – could help reduce existing inequalities *among* older persons.

Reducing care dependency in later life requires a life course approach to promoting healthy ageing and preventing poverty

Across countries, the COVID-19 pandemic exposed existing weaknesses in approaches to long-term care and showed how these can aggravate inequalities. Poor quality and underfunded care facilities, insufficient provisions for care at home, and low wages and precarious conditions for paid care workers all increased the threat to older persons. The scale of the crisis has sounded a call for fundamental reform of care and support systems, including long-term care. Failure to do so will harm today's older persons and those who care for them, as well as future cohorts of older people.

A more equitable approach to providing care and support systems, especially for long-term care, would be person-centred, and tailored to the needs, values and preferences of care recipients and their caregivers. This goes beyond the medical aspects of care, encompassing an individual's culture, life history, social support network and identity, and giving recipients of care control over decisions that affect them. It would be holistic, involving governments, businesses, communities and households, and addressing needs for both paid, formal care and informal, unpaid care.

1. REGULATING IMPROVEMENTS IN CARE QUALITY AND CONDITIONS

Governments need to develop and implement long-term care strategies that include a sound regulatory framework, training and support for caregivers, coordination and integration across sectors, and mechanisms such as accreditation and monitoring to ensure quality. Older persons should be systematically involved in policymaking to ensure that policies meet their health and care needs. Population-based studies of older persons living at home, in communities and in institutions could inform policymaking by identifying the levels and distribution of care services, how they change over time, and the extent to which they meet the needs and expectations of older people.

For paid care workers, a range of measures can enhance the quality of their jobs and, therefore, the quality of long-term care services. Many countries need to pass legislation consistent with international labour standards to recognize and protect care workers and end inequalities in working conditions. Care jobs should provide at least the legal minimum wage. Higher wage levels should align with an expanded job scope, upgraded skills or career progression. Measures to improve working conditions may include guaranteeing minimum hours for care workers, many of whom have no guaranteed hours and are paid per client visit. It could also mean ensuring that care workers making home visits are paid for the time and fuel used in travelling between homes. Providing weekly rest days and paid annual vacation, reducing the maximum duration of shifts and adopting flexible work arrangements can all improve job retention and morale.

National legislation should also guarantee care workers' rights to access social protection coverage. Care worker participation in collective action and consultations between employers and worker organizations should be encouraged. In addition, national training standards can articulate core skills and competencies for care work, which could then be developed through regulated training facilities that provide training and certification to promote proper recognition and career advancement.

Supportive migration policies through regular channels can improve the supply of skilled care workers from other countries when the domestic supply is insufficient. Such arrangements must not be extractive, however. Making migration partnerships mutually beneficial requires efforts to build skills and talent within countries of origin. Countries should also consider policies, including labour laws, to protect migrant caregivers' rights, such as to adequate housing and living conditions; health care; rest and recuperation periods, encompassing weekly time off and paid annual leave; recognition of existing qualifications and credentials; continued possession of travel and identity documents; and access to justice and effective redress mechanisms. Host and sending countries need to discuss responsibilities in providing and ensuring access to adequate social protection and health-care services for migrant caregivers.

2. INVESTING IN LONG-TERM CARE

Expanding and improving long-term care provision, care-related infrastructure,55 social protection coverage for caregivers and care-related training all entail additional investments. The COVID-19 crisis underscored the critical importance of investing in emergency preparedness for long-term care. Many high-income countries are projected to boost public spending on long-term care over time. For countries of the European Union, public long-term spending is estimated to rise from 1.6 to 2.2 per cent of GDP between 2016 and 2040. In Australia, national government expenditure on care services for older persons accounted for 0.9 per cent of GDP in 2014-2015 and is projected to rise to at least 1.7 per cent of GDP by 2054-2055. These increases are attributable to population ageing, a decline in informal family caregivers and the greater availability and costs of formal long-term care as well as growing household wealth (WHO and OECD, 2021). Raising public spending is challenging, however, especially in the wake of the pandemic, which has devastated fiscal space and worsened debt situations in most countries, developing ones, in particular (see chapters 3 and 4 on financing policy responses).

55 This includes infrastructure related to obtaining water, improving sanitation and providing energy.

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To complement public programmes, individuals could purchase private long-term care insurance. In some countries, such as France and the United States, individuals enrol in such insurance on a voluntary basis (WHO and OECD, 2021). Yet private long-term care insurance markets remain relatively small (Fang, 2016); they do not represent a major source of funds to finance long-term services. To bolster a larger private market, Governments can incentivize participation by regulating long-term care insurance pricing and maintaining market stability. In tandem, they can take measures to improve perceptions of risk by the working-age population and their ability to estimate longterm care dependency. Tax exemptions for long-term care facilities, equipment, medicine and other health-care auxiliaries could encourage private investment.

3. HELPING PEOPLE AGE IN PLACE

Countries should provide additional support to help people age in place, so that they can retain family and other social connections. An important element is to better support unpaid care providers. Governments can do much more to recognize the value of unpaid care and reduce its financial, physical and mental burdens. This includes establishing and expanding formal long-term care systems that provide a continuum of respite care, either at home, in day centres or in residential institutions. Accessible housing and transportation services can also help ease the burden on caregivers. National ministries, local governments, non-governmental service providers and other stakeholders could collaborate and

explore innovative community-based service models, such as integrating social care services through co-location and collaboration with community service organizations, developing case management capacity, and promoting healthy and active ageing. Sharing lessons and good practices from community-based service models could foster their transfer and uptake across countries.

Governments can do much more to recognize the value of unpaid care and reduce its financial, physical and mental burdens

Extending paid leave entitlements as well as flexible working arrangements for family caregivers enables older people to remain at home and reduces the need for more expensive residential care. At the same time, financial support for family caregivers can help with the ongoing costs of providing care - for example, by replacing lost wages and tax deductions - while helping to avoid more costly interventions, such as hospitalization. Governments can also provide training for unpaid caregivers to improve the quality of services as well as encourage investment in new technology to support them, for instance, by easing physically challenging tasks, facilitating online learning and dissemination of information about worker rights and mobilization, and improving communication, including with family members. Use of digital long-term care services, such as remote telecare, rose during the pandemic. It may not be practical to deploy all new technologies in

the care sector, however. Countries should ensure that such innovations help to break down, rather than reinforce, the digital divide affecting older persons.

Government policies need to complement measures adopted by businesses. Private long-term care insurance could protect older persons from high out-of-pocket costs if they need assistance at home or in nursing or assisted-living facilities. Incentivized by government policies, employers could offer access to long-term care insurance through workplace retirement plans on an opt-out basis.

4. CREATING AN ENVIRONMENT THAT FOSTERS BETTER CARE

A combination of these measures can enhance the well-being of caregivers and improve care outcomes. They can challenge gender norms around caregiving by recognizing the inherent value of unpaid care work. Paid care work would become a more attractive employment proposition for both men and women. New business opportunities could open and boost the broader economy.

Such measures can also foster social cohesion through the sharing of risk across a community. Target 5.4 under the SDGs urges recognizing unpaid care and domestic work, providing public services, infrastructure and social protection policies, and promoting shared responsibility for care at the household level (United Nations, 2015b). More data on gender norms in care are needed to inform governments and other stakeholders. Formalizing care work can create jobs and trigger new opportunities for women to participate in the economy. A sustainable and equitable system for long-term care needs to free women to pursue what they value, such as education or participation in the workforce, while encouraging men to assume their fair share of care duties, including those at home.

Formalizing care work can create jobs and trigger new opportunities for women to participate in the economy

Finally, better oversight and regulation of care facilities can help address inequalities in care provision. As shown during the COVID-19 crisis, many long-term care facilities are poor quality and leave residents highly exposed to disease and death. Governments and private providers should work together to ensure that care facilities meet agreed minimum standards and that workers have quality training sensitive to the needs of older persons. Governments should enhance pandemic preparedness, including around offering support for the mental well-being of caregivers.