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Delegations will find attached the full report (Volume I) on the subject under reference, established by the Social Protection Committee (SPC) together with the Commission. Volume II (country profiles) is contained in doc. 9144/21 ADD 2.

The key conclusions which are drawn from this report are contained in doc. 9144/21 and are submitted to the Council (EPSCO) with a view to the meeting on 14 June 2019.

2021 Long-Term Care Report

Trends, challenges and opportunities in an ageing society

Volume I

Joint Report prepared by the Social Protection Committee (SPC) and the European Commission (DG EMPL)

2021

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1 INTRODUCTION

1.1 Objectives and scope of the report

The aim of this report is to increase specialised knowledge on long-term care in the EU-27. It explores the main common challenges in the area of long-term care as well as the extent of preparedness of Member States, with a focus on: access and affordability in long-term care services; quality of care; long-term care workers and informal carers; financing; and sustainability. Furthermore, the report identifies promising measures to counteract these challenges, taking into account the specificities of national contexts, including a mapping of relevant services, policies, and best practices in Member States. It identifies knowledge gaps and areas where further evidence is needed. It also puts forward suggestions targeted at a broad range of national and EU stakeholders, for further policy measures that could better support Member States in their efforts to provide access to affordable long-term care services of good quality, in particular homecare and community-based services. The report may, therefore, help to deepen policy dialogue on long-term care with Member States and other key stakeholders.

The report builds on earlier knowledge gathered on long-term care at the EU level. In line with preceding work, the report aims to provide a situational analysis of long-term healthcare and social care for the older population. The report complements an earlier report "Adequate social protection for long-term care needs in an ageing society", published in 2014 (European Commission and SPC, 2014). As set out in Section 1.5, that report – also jointly prepared by the European Commission and the Social Protection Committee (SPC) – remains highly relevant. The current report applies the definition of long-term care agreed by the SPC in 2014, namely**:**

> *'Long-term care is defined as a range of services and assistance for people who, as a result of mental and/or physical frailty and/or disability over an extended period of time, depend on help with daily living activities and/or are in need of some permanent nursing care. The daily living activities for which help is needed may be the self-care activities that a person must perform every day (Activities of Daily Living, or ADLs, such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and controlling bladder and bowel functions) or may be related to independent living (Instrumental Activities of Daily Living, or IADLs, such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone).'*[1/2]

Although it is acknowledged that people of all ages may require long-term care services, the focus of this report is on older people. The rising demand for long-term care is clearly

[1] Long-term care should also be distinguished from the notion of social support, although the two concepts are interconnected. According to one definition: '*social support can be described as the formal (government services, private companies, and NGOs) and informal (family and friends) connections or relationships, based on empathy and trust, particularly useful in times of stress, where a vulnerable person interacts to find help by means of information, accompaniment or physical material*' (Carabott, 2018.)

[2] For definitions of the different types of long-term care settings, please refer to explanations in Annex I.

driven by population ageing, as the need for long-term care increases with age. The report, therefore, focuses on long-term care for older people, using those aged 65 or over as a general proxy for older people. Where data availability allows, the report also highlights the situation of people aged 75 or over, who are most likely to need long-term care. The report acknowledges that there may be specific challenges regarding the provision of long-term care for other age groups (see Box 10). In order to cover long-term care needs as broadly as possible, the report focuses on all older people who have long-term care needs over an extended period, independently of whether their care needs have arisen due to physical or mental frailty, disability or other factors. It also acknowledges the most common long-term care challenges for age groups younger than 65.

The report covers different types of long-term care provision, both formal and informal. Formal long-term care is typically provided by a qualified workforce and may be delivered in different settings (residential care, formal homecare or semi-residential care). Informal long-term care is typically provided by someone from the care receiver's social environment (e.g. a family member, friend or neighbour) and the provider is not hired as care professional. For a detailed definition of the different concepts, see Annex 1.

1.2 Demographic trends and population projections

The European population is ageing. Increasing life expectancy in conjunction with low birth rates is projected to lead to an increasing quantitative weight of older population groups in the EU. The number of people aged 65 or over is projected to increase by 41 % over the next 30 years, (from 92.1 million in 2020 to 130.2 million in 2050), while the number of people aged 80 or over is projected to increase even more, by 88 % (from 26.6 million in 2020 to 49.9 million in 2050).[3] As a consequence, the old-age-dependency ratio[4] is projected to increase significantly, from 32 in 2020 to 52 in 2050 – an increase of more than 62 %.

Population ageing has significant implications for long-term care systems. Many older people are living healthy lives[5] and are able to live actively and contribute to their communities and society as a whole, for instance via voluntary work, formal employment or by helping their families. However, as will be shown in Chapter 0, the need for long-term care increases with age and is especially prevalent among the very old. With an increasing number of older people, the need for long-term care is therefore set to rise. Among those aged 65 or over, 47.8 % have disabilities.[6] These people are protected by the UN Convention on the Rights of Persons with Disabilities (UNCRPD) to which the EU and all Member States are party. In accordance with Article 19 of the UNCRPD, people with disabilities have an equal right to live in the community, with choices equal to others; and states must take effective and

[3] The population aged 65+ is projected to be 128,569,692 in 2070, and the population aged 80+ is projected to be 55,813,523. Source: Eurostat population projections.

[4] Eurostat (tps00200): the number of people aged 65+ (the age when they are generally economically inactive) for every 100 of people of working age (15-64).

[5] In 2019, people aged 65 had an average life expectancy of 20 years across the EU-27, of which 9.9 were healthy life years. Source: Eurostat demographic statistics; see also data table in Annex II to this report.

[6] Eurostat (hlth_silc_06): self-perceived long-standing limitations in usual activities due to health problem by sex, age and labour status.

appropriate measures to facilitate the full enjoyment by people with disabilities of this right, and their full inclusion and participation in the community. Services provided for long-term care have to be delivered in line with the UNCRPD, fully respecting the rights and fundamental freedoms of people with disabilities. A key challenge will thus be to meet the growing demand for accessible and good-quality long-term care services, in particular given labour shortages in the long-term care sector, as experienced already by a number of Member States (see Chapter 0). At the same time, the declining share of the working-age population will make it more difficult to finance ageing-related spending, including for long-term care, thus putting the sustainability of current welfare systems at risk and increasing the risk of poverty for those in need of care and for their families (see Chapter 5).

Migration and mobility play and important role in long-term care provision. In addition to immigration from third countries, the EU also sees significant population movements between Member States, thanks to the free movement of people. In 2019, 13.3 million EU citizens were living in a Member State other than their country of origin (European Commission, 2020b). These movements can mitigate the negative impacts of ageing in receiving regions, while aggravating already adverse demographic trends in regions facing population decline. Rural and remote areas often lack adequate social services, including long-term care. Mobility may furthermore imply that children live far away from their parents and thus are not able to care for them.

Long-term care has a strong gender dimension. Women live longer than men,[7] but often do so in bad health.[8] In addition, women have lower earnings (including pensions) across the EU9 and are exposed to a higher risk of poverty or social exclusion in all Member States.[10] At the same time, older women[11] are more likely to live alone and thus may not be able to rely on support from other household members. Consequently, more older women than older men may be in need of long-term care, while being less able to afford it. Women also carry out the bulk of caring activities (including those related to old age), as long-term care is often provided informally by family members, mostly women. Furthermore, the formal care workforce is predominantly made up of women (90 % of workers in the long-term care sector are women; see Chapter 0).

Increasing labour market participation by women adds to the need to expand formal long-term care provision. The employment rate of women increased from 67.8 % in 2010 to 73.1 % in 2019.[12] Women are thus increasingly participating in the labour market – a positive development in the context of ageing societies and a decreasing working-age population. Nevertheless, in 2019, 7.8 % of women aged 50-65 did not seek employment due to family/caring responsibilities, compared with 0.8 % of men.[13] Increased mobility and labour

[7] Life expectancy at birth in 2018 – men 78.2 years; women 83.7 years.
[8] Healthy life years at birth in 2017 – men 63.5 years; women 64 years.
[9] Gender pension gap of 29.5 % in the (then) EU-28 in 2019.
[10] People aged 65+ at risk of poverty or social exclusion in 2019 – 18.2 % among women; 13.4 % among men.
[11] In 2019, 40 % of older women were living alone, double the share for men. See Eurostat *press release*, 23 June 2020. https://ec.europa.eu/eurostat/web/products-eurostat-news/-/DDN-20200623-1
[12] Eurostat 2019: employment rate by sex (SDG_08_30).
[13] Eurostat 2019: inactive population not seeking employment by sex, age and main reason (lfsa_igar).

market participation by women, who are the majority of informal carers, means that they become less available to provide long-term care to others in their social environment. In addition, increasing retirement ages may also play a role (for both genders). Adequate and affordable formal long-term care services and policies helping to reconcile paid employment with caring/familial responsibilities are therefore essential to meet the rising demand for care and to sustain the growth in women's labour market participation, whilst keeping in mind work-life balance and the health of all involved.

1.3 Current and political context

Long-term care has come into sharper policy focus at the EU level through the strong commitment to the European Pillar of Social Rights.[14] The European Pillar of Social Rights ('the Pillar'), jointly proclaimed by the European Parliament, the Council of the EU, and the European Commission on 17 November 2017, sets out key principles and rights for a renewed process of upward convergence towards better working and living conditions among Member States. Principle 18 of the Pillar states: '*Everyone has the right to affordable long-term care services of good quality, in particular homecare and community-based services*'. It thus establishes the right to care at the EU level for the first time, giving visibility to long-term care as a social policy field. Implementing the Pillar is a joint endeavour to be taken forward by the EU, Member States, social partners, and other stakeholders, in line with their respective competences. In March 2021 the European Commission put forward an action plan to implement the Pillar (European Commission, 2021b). The action plan announced that the Commission will propose an initiative on long-term care in 2022, designed to set a framework for policy reforms that will guide the development of sustainable long-term care and ensure better access to high-quality services for those in need.

The COVID-19 pandemic has put long-term care even higher on the political agenda in many Member States. Long-term care systems have been strongly affected by the pandemic, due to their users' high vulnerability to the virus. In particular, high mortality rates in care homes have raised serious concerns about the capacity of long-term care systems to cope with the crisis. The crisis has also brought to the fore the already existing structural challenges that many long-term care systems are facing. The current report will provide a preliminary overview of the impacts of COVID-19 on the national systems and of Member States' corresponding responses. It is not to be excluded that this crisis will have long-lasting effects and will require a review of long-term care services provision, including their organisation and financing. However, as the pandemic was still continuing at the time this report was prepared, such conclusions cannot yet be drawn.

The European Commission is focusing its work on mitigating the social and economic consequences of demographic change and population ageing. In her political guidelines, President Ursula von der Leyen makes clear that a social Europe is of high priority for the current Commission: '*A prosperous and social Europe depends on us all. We need equality*

[14] European Commission, *The European Pillar of Social Rights in 20 principles*, https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en

for all and equality in all of its senses. … With the demographic challenges ahead of us, we cannot afford to leave any potential behind.' (von der Leyen, 2019) The European Commission published a report on the impact of demographic change in June 2020, which sets out the main drivers of demographic change and the impact they are having across Europe.[15] The report states that a key challenge of demographic change '*is meeting a growing demand for sufficient, accessible, good quality and affordable health and long-term care services as enshrined in the European Pillar of Social Rights*.' Although it sets out that more demand for healthcare and long-term care may lead to increased public and private expenditure, it also points to the opportunity of an emerging 'silver economy' in the healthcare and long-term care sectors. The European Commission has furthermore published a green paper on ageing.[16] The green paper is designed to launch a broad policy debate on ageing, including a discussion of the options for anticipating and responding to the challenges and opportunities ageing brings, and questions related to long-term care. The current report is anchored in this work on population ageing and in the overarching efforts to support the implementation of the Pillar.

1.4 Key common challenges in long-term care

Against the background of population ageing, Member States face common challenges in the area of long-term care despite the pronounced differences between national systems. There are enormous differences across Member States in the supply and organisation of long-term care, and in the corresponding social protection systems and public expenditure levels. Despite these differences, Member States generally face four common challenges in relation to long-term care that structure the analysis in this report:

1. the challenge of providing affordable and adequate access to long-term care services for all in need;
2. the challenge of providing long-term care services of good quality;
3. the challenge of ensuring an adequate long-term care workforce with good working conditions, and of supporting informal carers; and
4. the challenge of financing long-term care in times of rising demand for care.

An underlying difficulty is the limited availability of data on long-term care, which makes it difficult to have an in-depth understanding of all these challenges.

In the context of ageing societies, a key challenge is to provide adequate, accessible, and affordable formal long-term care services to those who need it. The availability of formal long-term care services differs greatly among Member States. With a large increase in demand ahead, already today many people in need of long-term care services cannot access or afford them. Barriers to ensuring equal access to adequate long-term care include: high

[15] European Commission, *The impact of demographic change in Europe*, https://ec.europa.eu/info/strategy/priorities-2019-2024/new-push-european-democracy/impact-demographic-change-europe_en

[16] European Commission, *Green Paper on Ageing: Fostering solidarity and responsibility between generations*, https://ec.europa.eu/info/sites/info/files/1_en_act_part1_v8_0.pdf

financial costs; a lack of social protection or private insurance coverage; geographical disparities or even shortages in supply; a lack of information; complex administrative procedures; and lack of support to informal carers. Simulations show that, even for moderate care needs, the full unsubsidised cost of long-term care could exceed a person's income across a large part of the income distribution in many Member States. Insufficient and unaffordable access to formal long-term care implies a greater reliance on informal care, and may therefore lead to unmet needs for long-term care (Cravo Oliveira Hashiguchi and Llena-Nozal, 2020).

Although there is a consensus about the need to provide high-quality long-term care, opinions differ as to what quality in long-term care means, while strategies to ensure it remain sketchy and uneven. Although the projected increase in demand may contribute to tensions between the quantity and quality of long-term care, the latter is important to ensure personal dignity, help protect vulnerable people from potential neglect or abuse, enable personal choice, and maintain well-being. National systems differ in their definitions of quality and strategies to ensure it, with generally more focus on residential care than homecare or informal care. It is therefore important to take the debate further at national and EU level, starting with a look at how to operationalise the concept for policy-making, having a debate on what type of indicators could be used to monitor progress, and identifying the policy measures and practices that can help achieve the best results.

Access, availability, and quality in relation to long-term care services depend on an adequate workforce and good working conditions. The long-term care sector is highly labour-intensive. However, already today many Member States face difficulties attracting and retaining sufficient numbers of skilled care workers. The sector is marked by the prevalence of part-time work and temporary contracts. Pay is often low and working conditions are challenging. These conditions were put under a spotlight by the COVID-19 pandemic, which also emphasised the crucial role of professional and informal carers. Informal carers, predominantly women, carry out a large part of long-term care in most Member States. Without sufficient support, this may have major implications not only for their health and well-being, but also for their labour market participation, income, and social protection, in both the short and long run.

Public expenditure on long-term care is projected to rise more quickly than on other social policy areas, including healthcare and pensions. Although public spending on long-term care is currently low in many Member States, significant increases are projected in view of population ageing and the corresponding rise in demand. The projected expenditure increases are unsurprisingly even larger for many Member States when allowing upward convergence in long-term care policies. Financing such expenditure will pose new challenges since, with increasing life expectancy and a shrinking working-age population, the EU will go from 3.3 to only 2 working-age people for every person aged 65 or over during the course of the next 30 years.[17] These developments underline the need for Member States to ensure fiscally sustainable foundations for long-term care systems, to enable them to meet older people's needs today and in the future.

[17] Eurostat population projections.

1.5 Long-term care as a social policy field at EU level

Although long-term care policy is primarily the competence of Member States, the EU is supporting them via different activities. While the following chapters provide an overview of national measures and reforms in different areas of long-term care, this section provides a short overview of EU-level activities on long-term care.

The European Commission facilitates knowledge-gathering on long-term care. The first joint report on long-term care (European Commission and SPC, 2014) identified key common challenges, which remain largely valid today, and argued that social protection against the risk of long-term care dependency was needed for equity and efficiency reasons. The primary responsibility for obtaining social care often lay with the dependent person and their relatives. The report identified three major inter-related challenges with regards to long-term care: a huge increase in need, a threat to the supply of long-term carers, and the pressure that higher demand would put on ensuring care quality. Closing the gap between the need for, and supply of, long-term care required pro-active approaches. The report also pointed out that adequate social protection against long-term care dependency was important to ensure equality between women and men in old age as well as during working life. The European Council endorsed the key messages from the report on 19 June 2014.[18]

The European Commission has addressed most of the suggestions for action at European level outlined in the first report on long-term care. Annex 1 of the first joint report outlined a number of suggestions for further work, including: better use of the data available to monitor the social and employment impact of dependency, and the degree of social protection against this risk; continuing joint work by the European Commission and the OECD on measuring effective social protection in long-term care; facilitating mutual learning activities under the open method of coordination; making EU funding available for long-term care; and implementing prevention strategies. Most of these suggestions have been implemented.

The adequacy and sustainability of long-term care systems are monitored in the European semester. Country reports outline challenges at national level, including in relation to long-term care systems. Country specific recommendations concerning long-term care have mostly focused on fiscal sustainability, women's labour market participation and informal care provision, and adequate access to long-term care.

The social open method of coordination is an important channel of dialogue with Member States in the area of long-term care. In the context of the social open method of coordination, Member States agreed common objectives for healthcare and long-term care accessibility, quality, and sustainability. These objectives guide collaboration on long-term care issues in the SPC, which is a vehicle for dialogue with and among the Member States.

[18] European Commission press release, 23 June 2014 (*Council endorses a report on adequate social protection for long-term care needs in an ageing society*). https://ec.europa.eu/eip/ageing/news/council-endorses-report-adequate-social-protection-long-term-care-needs-ageing-society_en

The European Commission supports the development of common long-term care indicators and organises mutual learning activities. Work on developing common indicators on long-term care is ongoing. The Indicators Sub-Group of the SPC (SPC ISG) is developing a portfolio of agreed indicators to monitor long-term care in Member States, along the dimensions of access, sustainability, and quality. These indicators will help to monitor and guide long-term care policy reforms via the European semester. This report takes into account the indicators already agreed in its analysis. The European Commission furthermore supports Member States by organising mutual learning activities, such as peer reviews on the work-life balance of informal carers, the promotion of equal sharing of informal care between women and men, and on long-term care financing models. The Commission has also organised a series of expert workshops to exchange views and information with academic experts and the main stakeholders on the key challenges facing long-term care.

EU funding is available to support long-term care systems in Member States. Through the multi-annual financial framework – and in particular the European Social Fund Plus (ESF+) – funding is available for Member States to support long-term care provision and address challenges in the field of long-term care. In addition, the new recovery and resilience facility will provide large-scale financial support to both public investment and reforms that contribute to strengthening social and economic resilience. It will thus also be an important resource to support reforms and investment in the area of long-term care, in line with national priorities.

Recent legislative measures at EU level have (inter alia) addressed the needs of informal carers and the co-ordination of long-term care benefits. The Directive on work-life balance,[19] adopted in June 2019, is designed to promote the participation of women in the labour market, and the take-up of family-related leave and flexible working arrangements for caring purposes. The directive also provides opportunities for workers to be granted leave to care for relatives who need support. In 2016, the European Commission proposed a revision of Regulation 883/2004 on social security co-ordination.[20] If an agreement is reached on the proposal with the European Parliament and the European Council, the revised regulation will clarify what long-term care benefits are and where mobile citizens can claim them, bringing more legal certainty. With the European Council Recommendation on access to social protection,[21] Member States committed to extend the coverage of social protection systems to non-standard forms of employment, including the long-term care workforce. The European skills agenda[22] will also contribute to up-skilling and reskilling in the long-term care sector.

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[19] *Directive (EU) 2019/1158 of the European Parliament and of the Council of 20 June 2019 on work-life balance for parents and carers and repealing Council Directive 2010/18/EU*. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32019L1158

[20] European Commission press release, 13 December 2016 (*Fairness at the heart of Commission's proposal to update EU rules on social security coordination*). https://ec.europa.eu/social/main.jsp?langId=en&catId=849&newsId=2699&furtherNews=yes

[21] *Council Recommendation of 8 November 2019 on access to social protection for workers and the self-employed*, 2019/C 387/01. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32019H1115%2801%29

[22] European Commission press release, 1 July 2020 (*Commission presents European Skills Agenda for sustainable competitiveness, social fairness and resilience*). https://ec.europa.eu/commission/presscorner/detail/en/ip_20_1196

Long-term care policies have to be seen together with other policies that have a direct impact on long-term care, in particular policies on pensions, healthcare, and healthy and active ageing. Adequate pensions, as the main income for older people, are an important element in ensuring the affordability of long-term care. The European Commission's 2021 Pension Adequacy Report[23], jointly prepared by the European Commission and the SPC, presents the state of play on pensions adequacy in the EU, including in relation to the availability and cost of long-term care services. One of the key messages from the report is that affordable and high-quality long-term care services are important to maintain adequate living standards throughout retirement, in particular for women; and it observes that pension credits for caring for a dependent adult are becoming more widespread, though gaps remain. Long-term care is also strongly interlinked with the provision of healthcare, as people with long-term care needs often have healthcare needs due to multiple chronic conditions or co-morbidities. The provision of integrated care, where different professionals work closely together to address people's healthcare and long-term care needs, is thus essential. Furthermore, adequate healthcare provision can help to prevent, limit or postpone long-term care dependency. The promotion of healthy and active ageing can help preserve older people's well-being, and prevent or postpone the need for long-term care in old age, as well as develop, as far as possible, an environment of community support in case of need. The Active Ageing Index,[24] a composite policy advocacy and monitoring tool prepared by the European Commission and the United Nations Economic Commission for Europe, measures the extent to which the environment older people live in enables them to realise their full potential in terms of employment, participation in social and cultural life, and independent living. It may thus serve as a guide to the fields where policy action might be needed, including long-term care.[25]

Structure of the report

The report consists of two volumes. Volume I provides a horizontal analysis of common challenges facing national long-term care systems in the EU, namely in the areas of access and affordability (Chapter 2), quality (Chapter 3), workforce and informal carers (Chapter 4), and financing and sustainability (Chapter 5). It also comprises chapters on recent reforms in Member States and their likely impact (Chapter 6), and on the implications of COVID-19 for long-term care systems (Chapter 7). Volume II complements this with in-depth analysis of the long-term care situation in each Member State in the form of 27 country fiches.

[23] European Commission and SPC, 2021

[24] European Commission press release, 14 March 2013 (*Active ageing index (AAI) to measure untapped potential of seniors in the EU, now available on a dedicated wiki*).
https://ec.europa.eu/social/main.jsp?langId=en&catId=89&newsId=1837&furtherNews=yes

[25] It is necessary to use both the Active Ageing Index and the underlying indicators to be able to reach correct interpretations.

2 ACCESS AND AFFORDABILITY IN RELATION TO LONG-TERM CARE

The increasing longevity of the European population, together with changing family structures, increases the number of people in need of formal long-term care services. It will be a major challenge to meet this rising demand and help all those in need to live as autonomously and independently as possible by providing affordable services, while simultaneously avoiding risks to the stability of public finances. The approaches to ensure access and affordability in relation to long-term care differ across Member States.

Access to long-term care relates to the conditions facilitating its use, such as cost/affordability, availability, awareness (about the existence of a particular service), and physical accessibility.[26/27] Access is determined by the legal entitlement to services and how it is translated into practice, including through targeted information to people in need of care. Affordability is understood as the ability of people in need to meet the out-of-pocket costs [28] of long-term care services after benefiting from social protection. Most social protection schemes rely on cost-sharing arrangements with people in need of long-term care and their families, for example via co-payments, means-testing, and asset-testing. In addition, unpaid informal care, usually provided by family members, can be considered as an in-kind contribution to the cost of long-term care. Overall, it is important that all people in need of long-term care are able to afford the care services they need with the help of social protection. This right to affordable long-term care services is enshrined in the European Pillar of Social Rights[29].

This chapter will explore issues of need, access, availability, and affordability in relation to long-term care, while providing insights into the market for long-term care services. The chapter will illustrate how many people are potentially in need of long-term care today, as well as providing relevant projections of need (Section 2.1). It will then address the availability and use of long-term care services, and discuss the changing market structure of long-term care provision (Section 2.2). Social protection coverage for long-term care and its depth will be explored (Section 2.3). Finally, the non-take-up of long-term care services, and aspects of ensuring equal access, will be discussed (Section 2.4).

2.1 Measuring the need for long-term care among older people

The rising number of old and very old people is likely to lead to an increase in the number of people who need long-term care (European Commission, 2020b). As discussed in Chapter 1, the size of the older population will increase significantly across the EU-27. The

[26] Accessibility is about the prevention and removal of barriers that hinder access by people with disabilities to products, services, and infrastructure on an equal basis with others.

[27] As defined for social services by the SPC ISG in May 2019.

[28] A user's 'out-of-pocket payment' means a direct payment for long-term care goods and services from primary income or savings, where the payment is made by the user at the time of the purchase of goods or the use of the services and not reimbursed by a third party. The out-of-pocket payment is for the cost remaining after social protection.

[29] European Commission, *The European Pillar of Social Rights in 20 principles*, https://ec.europa.eu/commission/priorities/deeper-and-fairer-economic-and-monetary-union/european-pillar-social-rights/european-pillar-social-rights-20-principles_en

impact of population ageing on care needs depends on the extent to which greater longevity is accompanied by a corresponding improvement or worsening in the health status of the population. The prevalence of physical or mental disability, which increases with age, often leads to dependency on help with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs), thus corresponding to a need for long-term care as defined by the SPC (see Chapter 1).

There is no single internationally accepted and standardised definition of what constitutes long-term care needs. As a result, it is currently not possible to unambiguously identify the number of people in need of long-term care. Member States typically perform an individual needs assessment that takes into account the presence and extent of difficulties with ADLs/IADLs, cognitive limitations, and other criteria (e.g. social environment, availability of family support, medical history) to determine a person's need for care or services and the corresponding social protection coverage.[30] Because the European Health Interview Survey (EHIS) focuses on limitations with ADLs and IADLs, which are the most important and common criteria Member States and the SPC apply to define long-term care needs, data from the EHIS are used by the SPC to operationalise the number of people in need of long-term care. In line with the usual eligibility conditions of public schemes that define a minimum threshold for long-term care needs, it is common to focus on difficulties categorised as 'severe'.[31]

On average, 30.9 % of people aged 65 or over living in private households were in need of long-term care, according to the EU-22 2019 data.[32/33] Taking the presence of self-reported severe difficulties with ADLs and/or IADLs as a proxy for the need for long-term care, in line with the definition used by the SPC, self-reported long-term care needs among older people living in private households ranged from 11.6 % in Luxembourg to 56.5 % in Romania (see Figure 1). Furthermore, older people with lower levels of income were more likely to be in need of long-term care than people with higher incomes. In the first (i.e. lowest) income quintile, 37.2 % were in need of long-term care, compared with 22.4 % in the fifth income quintile across the EU-22.[34] The higher need for long-term care of people with lower incomes is related to the generally worse health status of this group. People with low socio-economic status are exposed to more health-related risk factors such as poor living and working conditions; and some lifestyle behaviours (such as nutrition habits, physical inactivity, obesity, smoking) may be important risk factors for many diseases that later lead to

[30] Aggregated national data on the outcomes of such needs assessments cannot, however, be taken as a basis for estimating the number of people with long-term care needs. Such data would not be comparable among the Member States, due to the different assessment criteria, and would also not capture people in need of long-term care who do not apply for benefits (e.g. because they are aware their income or assets are too high for them to receive any benefits).

[31] In this context, it is important to acknowledge that, due to the different types and extent of long-term care needs (in both the healthcare and social care sector), a standardised provision of long-term care does not actually exist either. The provision should therefore be an individual response to diverse needs.

[32] The EU-22 average for 2019 does not include data for Belgium, France, Germany, Malta, and Spain.

[33] A key limitation of this survey-based measure is, however, the fact that it only captures people living in private households, thus neglecting the very relevant group of long-term care users living in residential care settings. More information can be found here https://ec.europa.eu/eurostat/cache/metadata/en/hlth_det_esms.htm

[34] In the first (i.e. lowest) income quintile, 34.0 % of people aged 65+ were in need of long-term care, compared with 17.6 % in the fifth income quintile, across the EU-27 in 2014.

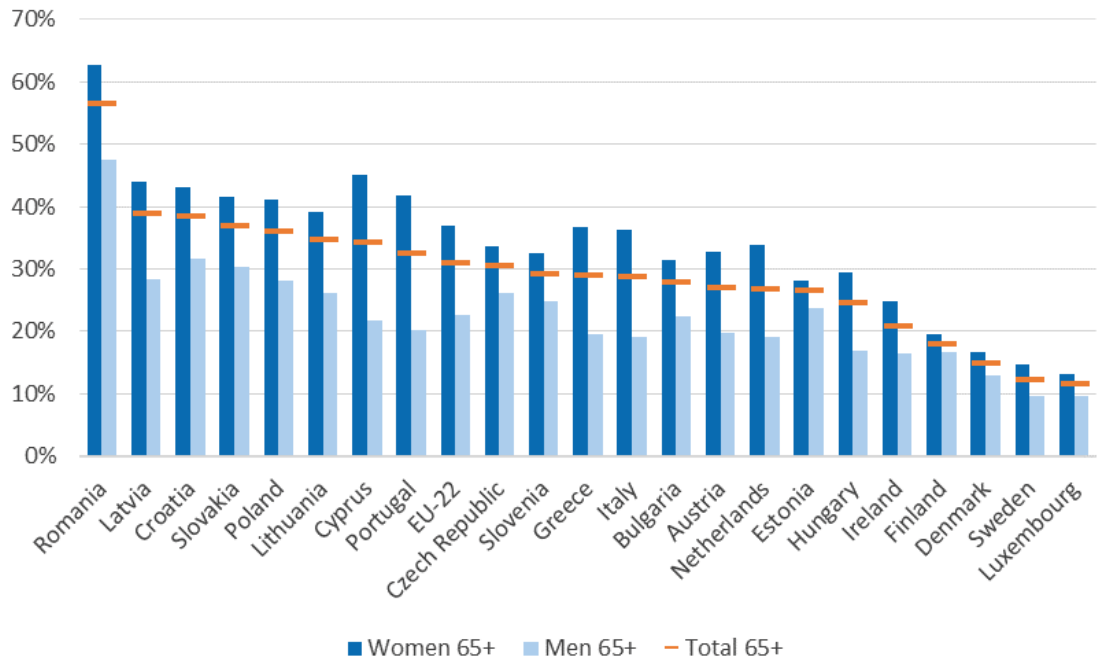
a need for long-term care. Importantly, people with low socio-economic status also report more difficulties in accessing healthcare (OECD, 2019a). Comparing data for 2019 and 2014 for the 22 Member States where recent data are so far available shows that self-reported needs for long-term care among people aged 65 or over remained broadly unchanged (30.9 % in 2019 compared with 30.6 % in 2014).[35]

Women are significantly more likely to be in need of long-term care than men in the same age group. Figure 1 shows that 36.9 % of women aged 65 or over were in need of long-term care compared with 22.7 % of men in the same age group, according to the EU-22 2019 data. This share ranged from 62.7 % of older women and 47.4 % of older men in Romania, to 13.2 % of older women and 9.6 % of older men in Luxembourg.[36] Data for the EU-27 in 2014 showed that 33.3 % of all women aged 65 or over needed long-term care compared with only 19.4 % of men. This gender gap is also influenced by the fact that, within this age group, women are on average older than men, having a higher life expectancy. Relatedly, women spend more years in ill-health than men. In the EU in 2018, the number of ill-health life years at birth was estimated at 19.5 for women and 14.5 for men.[37/38] Data from the survey of health, ageing and retirement in Europe (SHARE)[39] show that although a higher educational level represents an important protective factor, Member States with the greatest gender differences in activity limitations are found to be those with the greatest social gender inequalities, with women experiencing a significant disadvantage (Barbosa de Lima et al., 2018).

[35] Germany is included in the 2014 figure, but not the 2019 figure: only 15.2 % of the population in Germany aged 65+ had severe needs in 2014, thus lowering the average for that year significantly. The EU-27 average in 2014 was 27.3 %.
[36] Although the different survey data shown give an indication of the relative numbers of people requiring long-term care in different Member States, they should be treated with caution; people's assessment of their limitations is subjective, and may also be affected by cultural factors.
[37] Life expectancy at birth in the EU-27 was estimated at 81.0 years in 2018 (83.7 for women and 78.2 for men). The number of healthy life years at birth was estimated at 64.2 for women and 63.7 for men, representing approximately 76.7 % and 81.4 % of the total life expectancy for women and men.
[38] Eurostat, Healthy life years statistics, https://ec.europa.eu/eurostat/statistics-explained/index.php/Healthy_life_years_statistics
[39] http://www.share-project.org/home0.html

Figure 1: Share of people aged 65+ living in private households with a severe level of difficulty with personal care or household activities

On average, 30.9 % of people aged 65+ were in need of long-term care in the EU-22 (2019 data), with marked gender differences



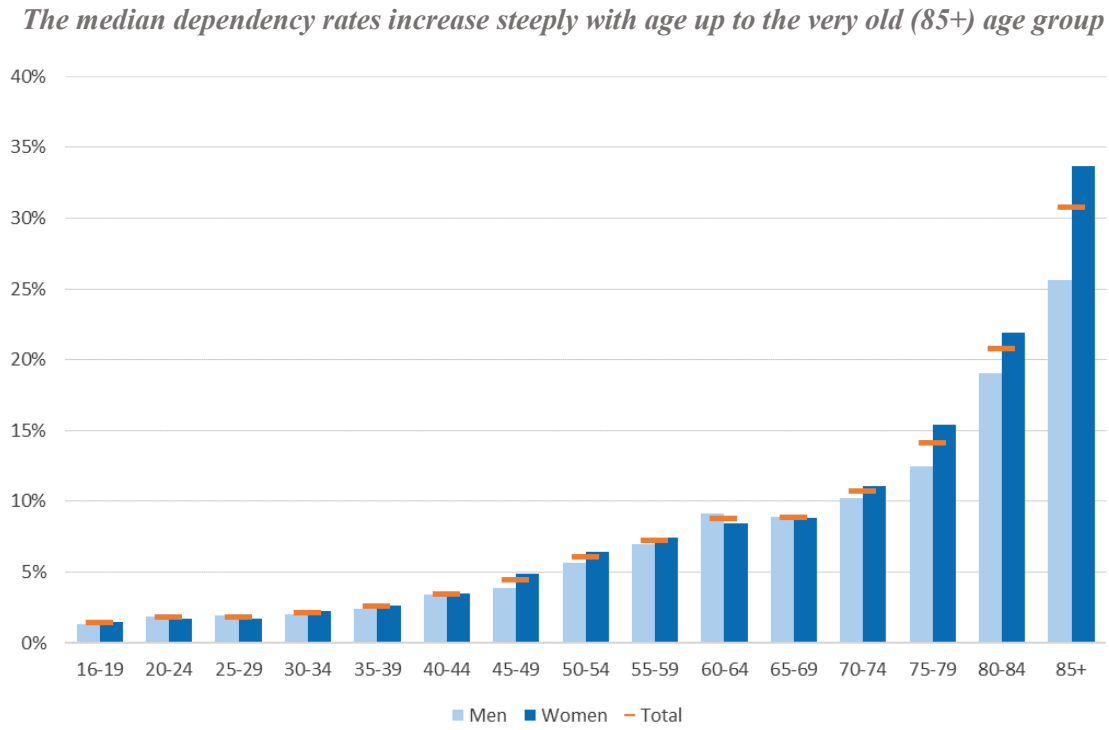
Note: At the time of publication, EHIS wave 3 data were available for all except five Member States. In wave 2 (2014), data for BE, DE, ES, FR, and MT showed that, respectively, 36 %, 24.9 %, 15.2 %, 25.9 %, and 34 % of the total population aged 65+ had at least one severe difficulty with ADLs and/or IADLs.

Source: EHIS wave 3, 2019, hlth_ehis_tadle.

The prevalence rates of disabilities potentially giving rise to long-term care needs significantly increase with age, and are especially high among the very old (aged 80 or over). Examining self-reported severe limitations in ADLs due to health problems is another approach to measuring the potential dependencies of the population that result in a need for long-term care. The indicator is also known as the Global Activity Limitation Indicator (GALI) and was developed to monitor disability. Due to the annual availability of results, it is often used as a proxy for long-term care needs.[40] Figure 2 shows that in the EU-27 the median dependency rates of people with disability living at home increase rapidly in old age (from 8.9 % for the 65-69 age group to 14.1 % for the 75-79 age group and 30.7 % for those aged 85 or over). A severe activity limitation was reported by 15.9 % of women aged 65 or over, 22.3 % of women aged 75 or over, 12.9 % of men aged 65 or over, and 17.4 % of men aged 75 or over. The survey moreover shows that people aged 65 or over in rural areas faced severe limitations (16.9 %) more frequently than people in cities (14.0 %). Given that women have a higher life expectancy than men on average, and spend relatively more years in ill-health, they are also more likely to need long-term care due to a disability in very old age.

[40] However, long-term care needs can be best measured by directly asking people about their severe difficulties with ADLs and IADLs, which is surveyed by the EHIS and SHARE.

Figure 2: Share of the population in private households by age group with a severe level of activity limitation



Source: EU-SILC, 2019, PH030 (GALI), for people with self-perceived long-standing severe limitation in activities because of health problems; EU-27.

It is important to include the number of people in residential care when estimating the number of people in need of long-term care. Widely used surveys[41] only cover people living in private households. However, it may be expected that people in the frailest situations live in residential care, and everybody in receipt of residential care is evidently in need of long-term care. The 2021 Ageing Report[42] therefore adds administrative data on people in publicly provided or funded residential care to survey data from the EU-SILC covering private households, for a more complete estimate of the number of people in need of long-term care.[43] This results in an estimated 30.8 million dependent people in 2019, which represents 7 % of the total population. Among those aged 65 or over, 17.0 million people, or 19 %, are potentially dependent on long-term care.

As population ageing, and specifically greater longevity, increases the number of older people, the number of people with long-term care needs is also expected to rise steeply. According to the projections from the Ageing Working Group (AWG) reference scenario in the 2021 Ageing Report (European Commission and EPC, 2021), the number of potential

[41] Notably including the EHIS and the European Union Statistics on Income and Living Conditions (EU-SILC) survey.
[42] European Commission and EPC, 2021.
[43] It calculates the median number of people with severe activity limitations living in private households over the last four years from the EU-SILC, and adds the number of people in public residential care per Member State from administrative data to determine the number of potential dependants in each Member State. This number of potential dependants is in particular used to establish the reference group for calculating indicators on social protection coverage (see data tables in Volume II of this report).

dependants in the EU-27 is expected to rise from about 30.8 million in 2019 to 33.7 million in 2030 and 38.1 million in 2050, corresponding to an overall increase of 23.5 %. The projections in this scenario assume that half of the expected gains in life expectancy are spent without disability (i.e. not demanding care), positively influenced by improvements in people's health status, longevity, living conditions, and healthcare. Even with such uncertainties, the steep increase projected underlines the importance of timely action to ensure access to long-term care services for future generations.

2.2 Providing long-term care services in an ageing society

The availability and use of formal care services differ significantly between and within Member States. Member States differ vastly in terms of the proportion of people in need who use informal care or formal care services, and in the way formal care is provided. Differences in the use of care reflect personal preferences and differences in family structures, as well as the availability and affordability of formal long-term care services. The extent of coverage of long-term care costs by the state may also explain the choices being made. However, there is no directly comparable information on the availability of informal and formal long-term care services in the EU-27. This section therefore combines information from different household surveys with administrative data.

Long-term care is not defined as a specific social security branch or distinct policy field in most Member States, but is covered by different social and health policies and provisions. At the European level, the Court of Justice has considered that long-term care benefits (for the purposes of the 2004 Regulation on the co-ordination of social security systems[44]) are benefits intended to improve the health and quality of life of people reliant on care and, as such, are intended to supplement sickness-insurance benefits. Within many Member States, long-term care is typically funded from various sources and organised at different levels. In terms of regulation, funding, and service provision, the provision of long-term care services may be closely interlinked with (or be part of) policies such as those in healthcare, social care, housing and housing support services, and for people with disabilities. This horizontal division may hamper the co-ordination of care and even service provision. In some cases, competencies may be also vertically split between the national, regional, and local institutional levels, adding to these challenges.[45]

There is a clear trend towards prioritising homecare and community-based care over residential care[46]. Many Member States have developed policies to reinforce homecare and community-based care, with the aim of helping care recipients to live as long as possible in their home environment. One of the consequences of the priority given to homecare and community-based services has been that the availability of residential care has been

[44] *Regulation (EC) No 883/2004 of the European Parliament and of the Council of 29 April 2004 on the coordination of social security systems*. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32004R0883
[45] Spasova et al., 2018.
[46] Ibid.

decreasing in several (Nordic) Member States over recent years.[47] This may be a sign of long-term care being rebalanced towards more user-centred care options. However, the shift towards de-institutionalisation can become a challenge when it is not matched with sufficient investment in affordable homecare and community care services, and with action to ensure good working conditions in de-institutionalised settings. For example, effective access to care is often hindered in rural and remote areas (e.g. BG, FR, NO, SK). De-institutionalisation should therefore be part of a wider strategy of ensuring accessible and affordable long-term care services, adapted to the regional situation (Spasova et al., 2018).

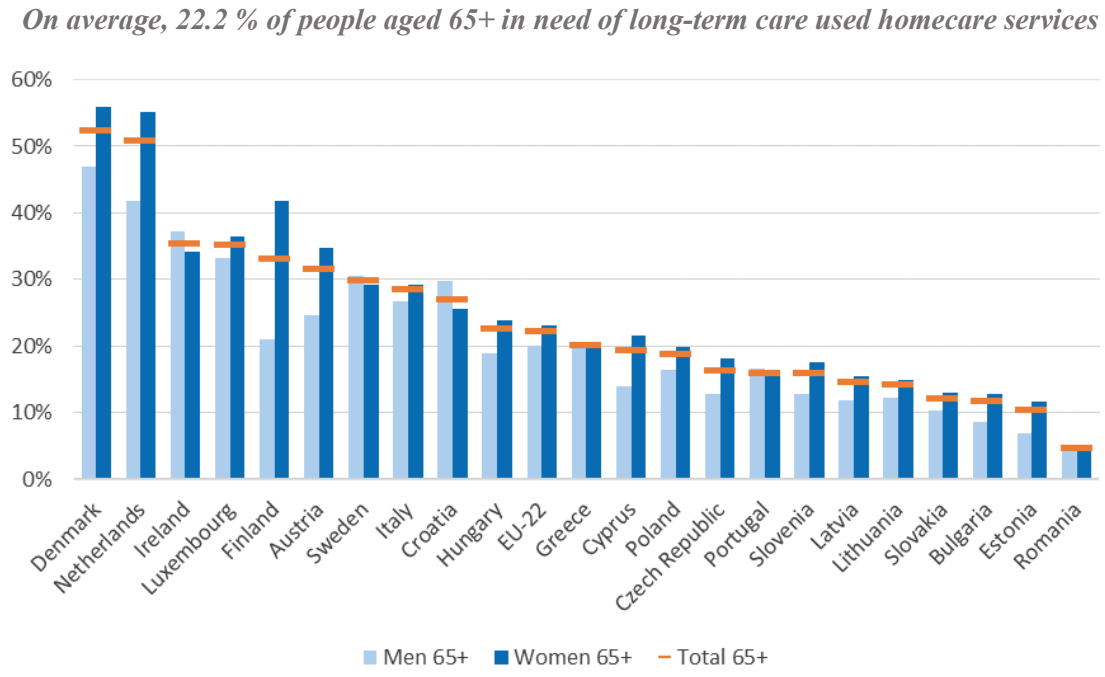
The use of homecare differs significantly across the EU. According to the EU-22 2019 data,[48] although homecare services were used by on average one fifth (22.2 %) of people aged 65 or over living in private households who needed long-term care (at least one severe difficulty in ADLs or IADLs), Figure 3 shows that the share ranged from 4.7 % in Romania to 52.3 % in Denmark. Among the respective populations with long-term care needs, slightly more women than men used homecare services (23.2 % vs 20.1 %). The use of homecare services is also influenced by household composition. Although 29.5 % of older people with long-term care needs living alone used homecare, only 17.6 % of people living with others did so. Furthermore, there was a regional dimension in the coverage by homecare services. In cities, 23.1 % of older people in need used homecare services, compared with 22.7 % in towns and suburbs, and only 20.9 % in rural areas. Coverage by homecare services fell slightly during 2014-2019, from 23.8 % to 22.2 %. Across the EU-27 in 2014, 29.8 % of people aged 65 or over reported the use of homecare services.[49]

[47] The availability of residential care, however, has to be seen in connection with the possibility of receiving extensive care as homecare.

[48] Data for Belgium, France, Germany, Malta, and Spain were not yet available.

[49] The EU-27 average in 2014 was significantly higher (at 29.8 %) than in 2019, because four of the five Member States for which wave 3 (2019) data were not yet available had coverage rates well above the average.

Figure 3: Share of people aged 65+ who self-report the use of homecare services with a severe level of difficulty with personal care or household activities



Note: At the time of publication, EHIS wave 3 data were available for all except five Member States. In wave 2 (2014), data for BE, DE, ES, FR, and MT showed that homecare services were used by 49.5 %, 53.4 %, 31.6 %, 50.2 %, and 28.3 % respectively of the population aged 65+ with at least one severe difficulty in ADLs or IADLs.

Source: EHIS wave 3.2019, hlth_ehis_am7ta.

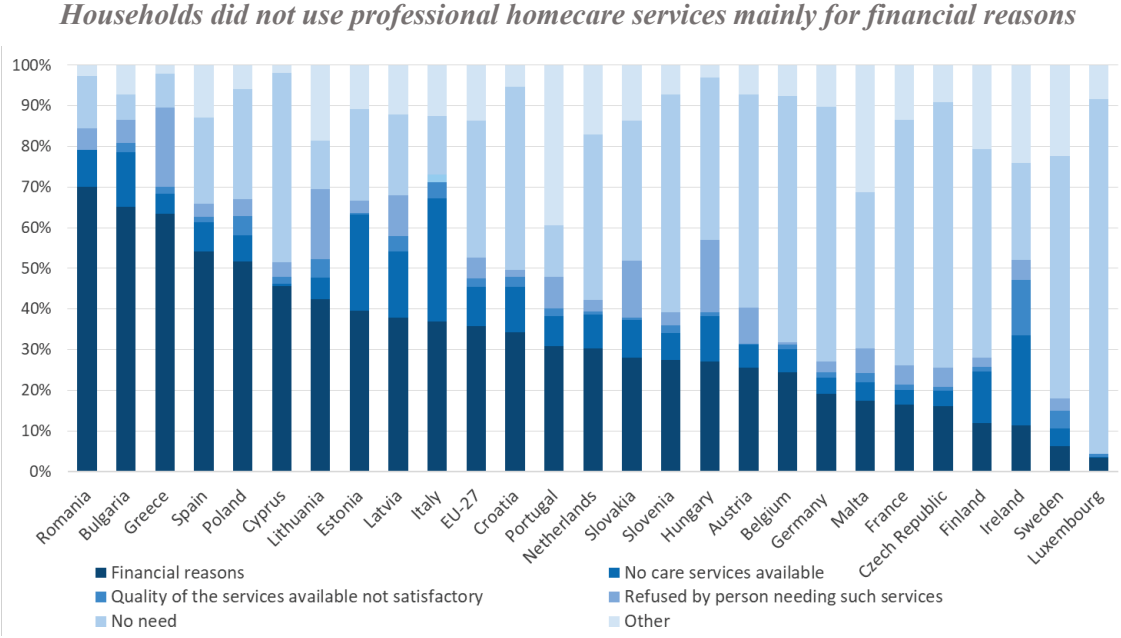
Households in need of long-term care often do not use (more) formal homecare services because they are unaffordable or unavailable. Lack of access to formal care could mean that people in need of care have unmet care needs unless they can arrange for care informally. In the 2019 EU-22 data, 47.2 % of people aged 65 or over with severe difficulties in personal care or household activities reported that they had an unmet need for help in those activities. This lack of help was more pronounced for older women (48.5 %) than for older men (44.4 %), and for the lowest income quintile (53.1 %) compared with the highest (38.6 %).[50] Figure 4 shows the main reasons why households who did not use homecare services reported not using them. These self-reported data may be influenced by cultural differences in expectations in relation to factors such as costs and quality of care**.** In Luxembourg, for example, professional homecare services seem accessible, affordable, and of good quality, so that for 80 % of households, 'no need' was the main reason for not using formal care, and only 3.3 % did not use long-term care services because they could not afford them. By contrast, in several Member States (BG,[51] EL, ES, PL, RO) most households who did not use homecare services said that they could not afford them. At the same time, in a number of

[50] The EU-22 2019 average (EHIS wave 3, indicator hlth_ehis_tadlh and hlth_ehis_tadlhi) does not include data for BE, DE, ES, FR, and MT. The self-reported lack of help does not distinguish between formal or informal care.

[51] This is despite Bulgaria providing significant funds for long-term care and offering social services free of charge for people without an income. More information can be found in the country fiche in Volume II.

Member States (BG, EE, FI, HR, HU, IE, IT, LV) important shortages in supply were mentioned by more than 10 % of households in the EU-SILC survey.

Figure 4: Main reasons for not using (more) professional homecare services



Source: EU-SILC ad hoc module, 2016, ilc_ats15.[52]

Data on residential care infrastructure suggest very heterogeneous availability across the EU-27. The number of long-term care beds[53] per 100,000 residents of all ages ranged from 31 in Bulgaria to 1388 in Sweden in 2017, underlining the fact that some Member States have a highly developed residential long-term care sector for older people. In some other Member States, residential care facilities are historically underdeveloped, while in yet others the supply of residential care has been reduced as a result of de-institutionalisation policies. Several southern and eastern Member States, where residential care settings were previously less prevalent, have been increasing residential places, as the demand for care considerably and increasingly exceeds the supply. Semi-residential care is care provided in a residential setting for care-dependent people who do not permanently reside in the residential care facility. It includes centres where frail older people can be cared for only during the day, or during the night. Daycare is provided in nearly all Member States, night care much less so (Spasova et al., 2018).

Informal care is still a major source of long-term care-giving across the EU.[54] Around 53 million people provide informal care in the EU-27 (see Chapter 4). No data are available on how many people receive informal long-term care in the EU, as one person may be cared for by several informal carers, or one informal carer may care for more than one dependent

[52] Data for Denmark are not available. Long-term care services are mostly free of charge in Denmark. More information can be found in the country fiche in Volume II.

[53] The numbers per Member State are available in the country fiches in Volume II.

[54] In some Member States, family responsibilities between children and parents are enshrined in law (e.g. LV) and even in the constitution (e.g. HU, LT); see Chapter 4.

person. The relationship between formal and informal care is complex: they not only complement each other but also counterbalance each other in the provision of long-term care.

Box 1: Long-term care services at the interplay of market forces

An ongoing study[55/56] (contracted by the European Commission) of the market for the supply of formal long-term care is designed to increase understanding of long-term care supply structures in Member States. *For a quantitative analysis of long-term care service provision, a representative sample of 16 Member States[57] is currently being examined, with a focus on provider structures. The first preliminary findings are presented below, and will be validated in further stages of the study.*

There is evidence of significant changes in the supply structure of the long-term care market across the Member States analysed. *Over the last three decades, more market-based provision through private actors (both for-profit and non-profit) could be observed. Whereas care provision was initially offered or organised mainly by public authorities, and sometimes also by non-profit institutions and organisations, in some Member States (e.g. SE) private for-profit institutions have developed as a result of policies to increase freedom of choice in long-term care provision (Spasova et al., 2018). At the same time, for-profit providers have also emerged or increased their presence in other Member States, even in the absence of similar policies. Altogether, different forms of long-term care provision co-exist in the Member States: these include public providers, private providers (both for-profit and not-for-profit), and informal care providers – with the share of each of these forms differing widely across Member States.*

Private providers are involved in long-term care services in all the Member States analysed, and preliminary quantitative data from five of them show a trend towards privatisation in the market,[58] *with an increasing number of private for-profit and private non-profit providers[59] – for example, in Italy (residential and semi-residential care), Germany (residential, home, and semi-residential care), Romania (residential care), Belgium (residential care), and Ireland (residential care and homecare). Data from the Netherlands (residential, home, and semi-residential care) and Germany (homecare) also show an increased share of profit-oriented providers in the market. As private providers are involved in the provision of long-term care services in all the Member States analysed, it appears that there is no exclusive 'traditional' public sector provision in any of them. Furthermore, the numbers of public, private for-profit, and private non-profit providers vary in the Member States analysed. In a number of cases (BG, CZ, FR, SE), the markets are characterised by a high number of public providers, whereas in others (BE, DE, ES) private for-profit providers are the main operators in the long-term care market. In Austria and Greece, most providers of long-term care are private non-profit providers.*

The shares of residential care, semi-residential care, and homecare in the long-term care

[55] KPMG, 'Study on the long-term care supply and market in EU Member States', 2021 (forthcoming).

[56] The work progress of the study is summarised in the following paragraphs. As the data-gathering and data-validation steps were not completed at the time this report was prepared, the final results of the study may differ from the preliminary findings outlined in this box.

[57] The sample of 16 Member States includes: AT, BE, BG, CZ, DE, EE, EL, ES, FI, FR, IE, IT, NL, PL, RO, SE.

[58] Privatisation here refers to shifts in ownership structure from public to private for-profit and non-profit entities.

[59] The available data and identified trends covered different timeframes during the past two decades.

market differ significantly between the Member States analysed. *These shares are measured in relation to the number of recipients of formal care in each setting. Home care is the main setting in a number of Member States (AT, CZ, DE, EE, EL, FI, IT, SE[60]) while in others (FR, RO) most recipients of formal care are cared for in a residential setting.*

Notwithstanding these differences, some common features are shared by most Member States, as follows.

- *First, the promotion of home care as the preferred care setting is a common theme across the Member States analysed (particularly DE, FR, FI, NL, SE).*
- *Second, public procurement of long-term care services is not – or only to a small extent – used (exceptions: EE, FR, IE, FI, SE).*
- *Third, although in most Member States the ministries of health and/or social affairs are responsible for regulating the provision of long-term care services, some responsibilities may be delegated to state/local authorities or insurance funds (e.g. AT, BE, BG, CZ, DE, EE, FI, FR, RO, SE).*

The vast majority of long-term care-providers are organisations based in the respective country in all the Member States analysed; but cross-national activity in the long-term care market can also be perceived. *Data from 13 Member States show multinational providers operating in all three care settings, but typically focusing on residential care. France is the country of origin of various multinational private providers (primarily operating in BE, DE, ES, FR, IT, NL). Furthermore, there are several multinational providers that mainly serve Nordic Member States (e.g. DK, FI, SE) as well as non-EU countries such as Norway. Most of the identified multinational providers operate on a for-profit basis, and the importance of multinational providers for the whole market differs significantly among the Member States.*

The relationship between the funding of long-term care and the evolution of formal long-term care markets is not straightforward. *Overall, long-term care markets in some Member States with high long-term care expenditure relative to their GDP (e.g. FI, SE) have not shown significant growth in recent years. However, a shift is noticeable within the long-term care markets as some segments, in particular homecare markets, show a growing trend in these Member States, possibly reflecting efforts to promote homecare.[61] In contrast, some Member States with relatively low long-term care expenditure relative to their GDP (e.g. BG, EE, RO) show a market growth in formal long-term care. In general, most Member States show a continuous growth in the long-term care market. This indicates that demand exceeds supply in many Member States, which is in line with general demographic projections. Moreover, subsidies from legislators and governments might also have a positive effect on the attractiveness of the market for private investors, reinforcing the supply side.*

[60] For three Member States (BG, ES, IE) the available data were not sufficient to identify a dominant care setting based on the number of care recipients.

[61] Kok et al., 2015.

2.3 Providing social protection coverage for long-term care in an ageing society

Social protection coverage is an important factor for determining the affordability of long-term care services. Figure 4 indicates that, in many Member States, financial constraints are the most important reason why households do not use (more) homecare services if needs are present. Social protection can play a key role in addressing such financial risks. It refers to all interventions from public or private bodies intended to relieve households and individuals of the burden of a defined set of risks or needs.

2.3.1 Varying approaches to social protection in long-term care

The institutions, regulations, and social traditions of the Member States diverge widely in the field of long-term care. In some Member States long-term care is part of social security, and in others long-term care is considered to be social assistance.[62] This section discusses the resources and benefits provided for people with long-term care needs, irrespective of the legislative or institutional structures behind them. However, as a consequence of the varying approaches, social protection in long-term care varies in particular along three dimensions: the subgroup among people in need who have coverage; the types of services covered; and the depth of financial protection (reflecting cost-sharing arrangements).

Social protection coverage for people in need of long-term care may follow a universalist and/or selectivist approach. Universalist schemes are characterised by high social protection coverage for all residents, and universal publicly provided services. By contrast, selectivism refers to the targeting or customising of services and policies for particular groups.[63] Historically, social protection models have been categorised as Bismarckian systems that relate each wage-earner's rights to the contributions they have paid, or their employer has made on their behalf, following a selectivist approach; whereas (tax-based) Beveridge-style models involve a universal scheme for the whole country, but sometimes with a minimal provision of services (Chassard and Quintin, 1992). In practice, recent reforms imply that the approaches may be in flux. Most Member States apply some targeting when granting access to long-term care services and benefits, and long-term care systems may combine both universalist and selectivist approaches. As a result, irrespective of their need, some residents may not be entitled to long-term care. The selectivity (risk selection) criteria may include, for example: insurance eligibility; residence; nationality; age; health condition; income; personal or family assets; and the services covered. In systems that take into account a person's economic situation, users on lower incomes or assets are typically entitled to greater public support.

[62] The European Court of Justice has ruled that a co-ordinated social security benefit cannot be granted in a discretionary manner. A benefit should therefore be granted to the recipients, without any individual and discretionary assessment of personal needs. When the allowance is granted based on an exercise of discretion, the court has classified it as social assistance. See C-433/13, Commission v. Slovakia (difference between a social security benefit and social assistance).

[63] This form of targeting may occur based on means-testing ('negative selectivism'), although it may also be based on other factors, such as need ('positive selectivism').

Access to social protection coverage for long-term care is often determined via an individual needs assessment.[64] These assessments usually take into account the presence and extent of difficulties with ADLs/IADLs, along with cognitive and/or other limitations. The common denominator for standardised assessments in Member States is the measurement of dependency on help with ADLs and IADLs, sometimes weighting needs differently in the final assessment. Several Member States (e.g. BE, HU, MT) use rather quantitative overall assessments based on the degree of need of an individual, using a scale of point values and calculating a final score. Similarly, Germany uses a qualitative and individual-based assessment tool, translating the outcomes into a points scheme leading to a measure of the grade of an individual's self-reliance and abilities. For example, needs for self-care account for 40 % of the overall assessment, while cognitive and communication skills account for 15 %.[65] On the other hand, some Member States (CZ, EE, FR, LV) use more qualitative scales in assessing to what extent an individual is dependent or autonomous in daily activities.

About half of the Member States regulate a standardised needs assessment at the national level. In other cases, the methodology for needs assessment may differ at the regional and even local level, and between sectors and sources of financing. In Denmark, for example, the municipality makes an assessment based on an individual's needs for homecare. The municipalities have developed a 'common language' for doing this, but it is not regulated by law. Across the EU, the needs assessment may be performed by a variety of professions (e.g. nurses, doctors, specialised healthcare staff, social workers), who are sometimes grouped in multi-disciplinary teams.

In many Member States, the level of support is determined by mapping the result of the needs assessment against predefined thresholds. Long-term care services are usually only granted above a certain minimum threshold of long-term care needs. The numbers of levels of support differ widely between Member States, with some having three levels (ES, LT, MT), while others have seven (AT), or even 15 (LU), levels. A cross-country comparison is made difficult by the different national assessment scales, thresholds, and levels of support. Even within a single Member State, residents in different regions or municipalities may be subject to different entitlement criteria and thresholds, depending on the level responsible for policies (national, regional, local).

Member States provide formal long-term care either as in-kind services, cash benefits or combinations of both. In-kind services usually include homecare or a place in residential care, but may also cover other necessities such as adaptations of the home (e.g. lift) or technical devices (as part of homecare). Cash benefits are funds that recipients can use to purchase services themselves, and are often used to compensate informal carers. In some (mostly Nordic) Member States, help is mostly delivered in the form of services (e.g. DK, FI, SE); in others, long-term care coverage is predominantly based on cash benefits (e.g. AT, CY,

[64] Some services that fall within long-term care may be available and subsidised population-wide without needs assessment; e.g. housekeeping services in the case of Belgium.

[65] Medizinischer Dienst der Krankenversicherung, https://www.mdk.de/fileadmin/MDK-zentraler-Ordner/Downloads/01_Pflegebegutachtung/MDK_66_A4-VERSION_2021_ENG_01_BF.pdf

IE, IT, RO); and in yet others, beneficiaries have a choice between cash benefits, in-kind services, or a combination of the two (e.g. DE) (Spasova et al., 2018).

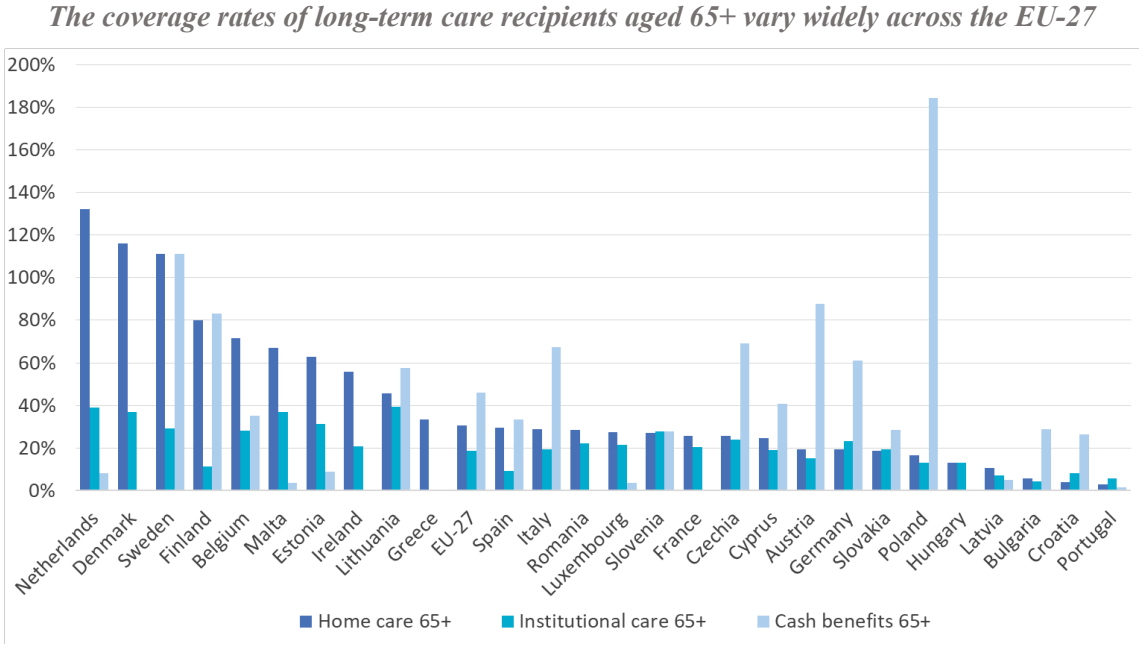
The coverage rates for people with limitations receiving public long-term care services and benefits vary significantly between the Member States.

Figure 5 shows that the estimated number of potential dependants aged 65 or over receiving publicly provided or funded homecare varies between 132 % (NL) and 3 % (PT). The EU-27 average stands at 31 %.[66] By comparison, the EU-27 average for publicly provided or funded residential care coverage is 19 %, and for cash benefits it is 46 %. The lowest rate of public residential care coverage is 0.2 % (EL), and the highest is more than 39 % (LT, NL) for potential dependants aged 65 or over. Although several Member States do not provide cash benefits to finance long-term care needs, in Poland nearly 184 % of potential dependants aged 65 or over receive them. The fragmentation of long-term care systems, implying different organisational structures and conditions of services in different Member States, limits the comparability of corresponding administrative data (for instance, some Member States may focus more on specific care settings than others) and will lead to some double-counting if the coverage of the three different care settings is aggregated without adjustment[67] (European Commission and EPC, forthcoming).

[66] The high coverage rates, exceeding 100 %, for homecare (DK, NL, SE) and cash benefits (PL) can be explained by the fact that, in these Member States, coverage for these types of care is provided in relation to non-severe limitations as well as severe limitations (whereas people with non-severe needs are not included in the reference group of potential dependants that is used to estimate the number of potential dependants). In the case of Poland, a cash allowance is paid to all people above age 75 independently of their disability status. This may also be the case for other Member States. For instance, in, Bulgaria, 85 % of the cash benefits are cash allowances paid on top of the disability pension to people with high degree of disability (90 % or more). See also note to Figure 5.

[67] For instance, it is possible in some Member States for the same recipient to receive both in-kind and cash benefits, and as the statistics on each type of care tend to be collected and managed separately by different public bodies or government departments, aggregation issues may exist. This may lead to estimated coverage rates above 100 %. Furthermore, parts of the in-kind or cash benefits are attributed to people who do not report severe limitations. Benefits could also go to younger people with disabilities, or chronically ill people.

Figure 5: Share of potential dependants aged 65+ who receive public care or cash benefits



Note: Coverage rates in the base year of 2019. Coverage estimated as ratio between recipients aged 65+ and potential dependants aged 65+. Recipient data provided by Member States. Coverage may be above 100 %, as the EU-SILC variable used to define dependency status focuses on (self-reported) 'severe' limitations only, whereas some social protection systems may also provide coverage for less severe needs, such as people who need help with IADLs: this biases the estimation of coverage upwards as it under-estimates the dependent population. In addition, adding the coverage across settings would in many cases yield coverage rates above 100 %, as some recipients may receive cash benefits and in-kind benefits at the same time. The population of potential dependants based on the 2015-2018 average of EU-SILC data on 'self-perceived long-standing limitation in activities because of health problems [for at least the last 6 months]' is used and adjusted for the number of people living in residential homes. For Germany, coverage refers to the social insurance funds' members only.

Source: 2021 Ageing Report (European Commission and EPC, 2021), for potential dependants aged 65+.

Given the significant increase in the number of people in need of long-term care that is projected,[68] unchanged social protection arrangements would mean that the number of people covered by public long-term care services and benefits would also increase. Such an increase in the number of recipients presupposes that the current provision of long-term care is proportionally extended to future generations, which is a political decision. Assuming that social protection coverage remains at current levels, the AWG reference scenario in the EU Ageing Report (European Commission and EPC, 2021) projects that the EU-27 would see an absolute increase in the number of recipients (of all ages) of public long-term care services and benefits as follows: (a) homecare recipients from 6.9 million in 2019 to 8.2 million in 2030 and 10.5 million in 2050; (b) residential care recipients from 4.5 million to 5.1 million and 6.7 million respectively; and (c) recipients of cash benefits from 10.2 million to 12.3 million and 15.4 million respectively. Note that this scenario is based on the assumption that half of the projected gains in life expectancy are spent without disability (i.e. not demanding care).

[68] See Section 2.1.

2.3.2 Comparing the social protection in long-term care across Member States

A framework based on stylised cases of long-term care needs allows social protection for long-term care to be compared across Member States, despite significant differences in terms of how care is organised. To measure the depth of social protection for long-term care in old age and compare it across Member States, the OECD[69] developed a set of eight typical cases of long-term care needs. These cases describe an older person in terms of the types and severity of their needs, the professional services they require, and their level of income and assets. The costs of care and public support available are then analysed for each of the typical cases. *Box 2* below provides a brief description of the methodology used.

Box 2: Methodology of OECD study on effectiveness of social protection for long-term care in old age[70]

Typical cases

The typical cases span different levels of severity of the need for care (low, moderate, and severe) and different ways in which these needs are met (professional homecare, informal care, and residential care). Information on household composition and social structures is also provided. Low, moderate, and severe needs are defined as corresponding to 6.5, 22.5, and 41.25 hours of care per week, respectively.

Income refers to disposable income sourced from the OECD income distribution database. Disposable income measures the income of households[71] (wages and salaries, self-employed income, capital and property income, social benefits, etc.), after taking into account the payment of taxes and social contributions and transfers received. Low income refers to the upper boundary of the 20th percentile of the income distribution among people aged 65 or over in the corresponding Member State, and high income to the upper boundary of the 80th percentile. Wealth, or net worth, is the value of all the assets owned by a household minus the value of all its liabilities at a particular point in time. Mean net wealth is the average of all household net wealth in those Member States for which data are available.

Total costs of long-term care

The estimates of the total costs of care have been collected directly from representatives and experts in the ministries and national and regional bodies responsible for long-term care policy of Member States and regions. Costs include the monetary amount corresponding to all care, including cash benefits and the value of any in-kind services provided. Member States were asked to exclude certain cost categories (e.g. medical care) and asked to provide details on the methodology used to estimate unit costs (e.g. top-down vs bottom-up approaches). Only publicly funded social protection benefits and services are included.

Geographical coverage

The study currently covers the 19 Member States and subnational areas that provided the necessary information (AT – Vienna, BE – Flanders, CZ, DE, EE – Tallinn, ES, FI, FR, HR, HU, IE, IT –

[69] Cravo Oliveira Hashiguchi and Llena-Nozal, 2020.
[70] Ibid.
[71] The unit of observation is the household, while the unit of analysis is the individual.

South Tyrol, LT, LU, LV, NL, SE, SI, SK). These geographical and administrative entities are henceforth referred to as jurisdictions. Due to the fragmentation of long-term care systems and a lack of data, social protection could only be modelled for one subnational area in the case of four Member States, whereas in the other cases the entire Member State was covered.

Population-level estimates

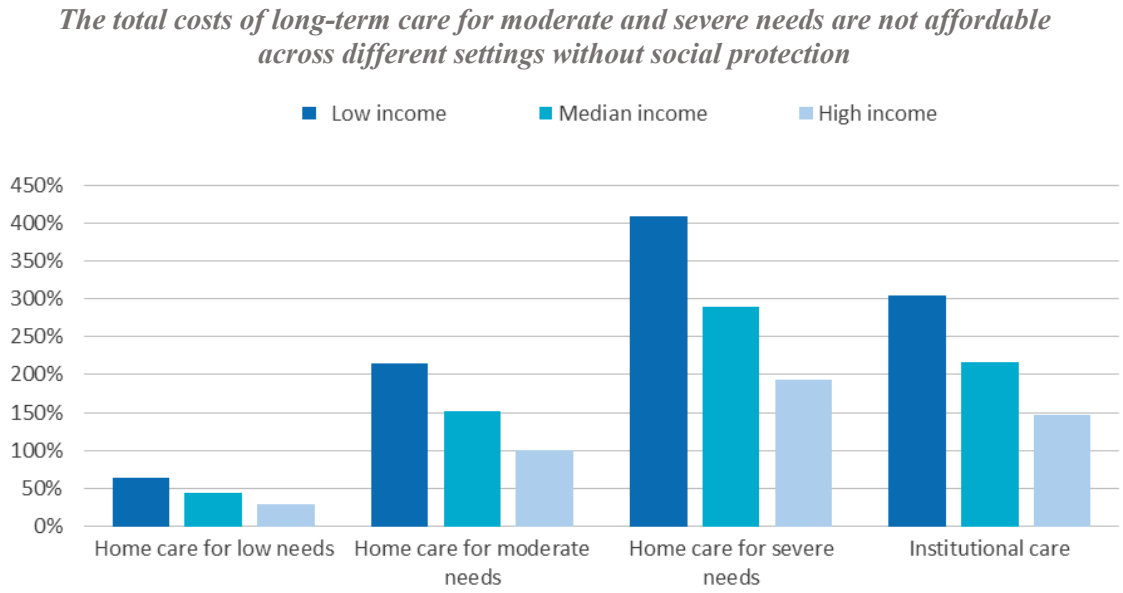
Besides estimating the effects of public social protection in stylised cases of long-term care needs, the study also uses responses to SHARE wave 7 to estimate the need for, and effectiveness of, public social protection at the population level. Respondents' self-assessed difficulties in relation to ADLs, IADLs, and physical functioning are used to determine their level of long-term care needs (matched to the typical cases previously mentioned, using at least two approaches). Estimates of total costs, public support, and out-of-pocket costs are then produced based on respondents' income and wealth. The impact of public social protection on poverty and affordability is then quantified. In interpreting the results, it should be borne in mind that for Member States where only subnational areas were modelled, the subnational systems are assumed to be representative of the national systems.[72]

Without social protection, the estimated total costs of long-term care often exceed the disposable income of people in need of long-term care. Across the jurisdictions included in the study (see *Box 2*), the estimated total costs of long-term care represent between one half and three times the median disposable income of individuals of retirement age or older (see Figure 6). Even for as little as 6.5 hours of care per week for people with low needs, the total costs of homecare would represent more than half of the disposable income of an older person with a low income. Without social protection, the cost of care for people with moderate and severe needs would be at least equal to disposable income for all income levels considered. These findings indicate that dependants would either have to use savings or rely on their family to cover the cost, in the absence of social protection. A detailed overview of the material situation of retired people can be found in the 2021 Pension Adequacy Report.[73]

[72] Although this assumption is not likely to hold, it can be relaxed as more subnational systems are modelled. Furthermore, while not all subnational systems can be modelled due to, for example, lack of data, it is often possible to determine the direction of potential biases, so that the estimates presented here can be seen as either conservative or optimistic.

[73] European Commission and SPC, 2021.

Figure 6: Total costs of long-term care as a share of the disposable income of people aged 65+ across different settings and different levels of need, without social protection



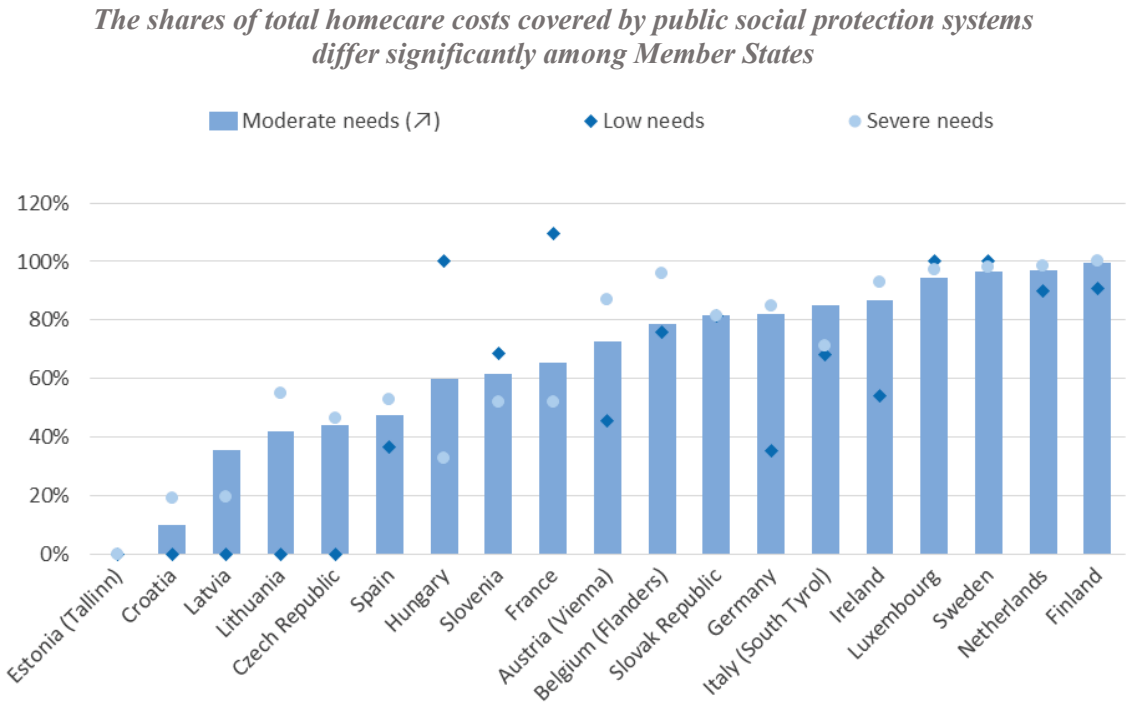
Note: Bars show unweighted averages for jurisdictions in 19 Member States. The costs of residential care include the provision of food and accommodation, so are over-estimated relative to homecare.

Source: OECD analyses based on the long-term care social protection questionnaire and the OECD income distribution database.

In the majority of the 19 jurisdictions modelled, public social protection systems would not cover 40 % of the total costs of long-term care services for people with moderate needs (see Figure 7). The degree of public support would be above 90 % of total long-term care costs in four jurisdictions and below 50 % in another six jurisdictions. In northern Europe (FI, NL, SE) and in Luxembourg, public social protection systems would cover almost the full costs of homecare regardless of the severity of needs. The shares of total care costs that are met by public social protection systems in the EU for recipients with severe care needs is higher for homecare than for residential care, in almost every jurisdiction analysed (Cravo Oliveira Hashiguchi and Llena-Nozal, 2020[74]).

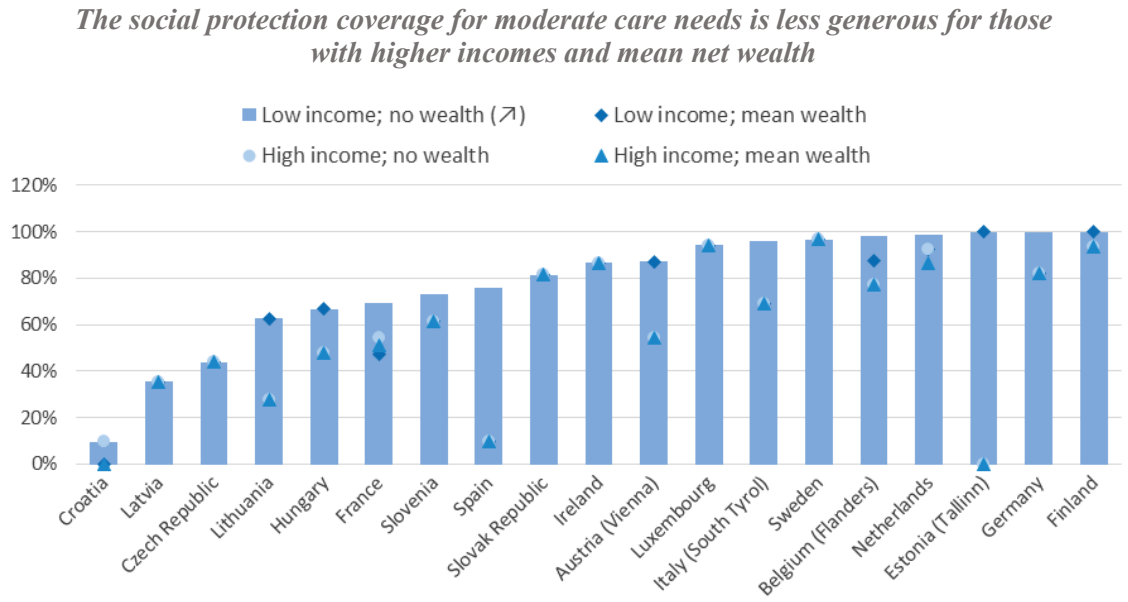
[74] See in particular p. 22.

Figure 7: Shares of total homecare costs that would be covered by public social protection systems, for care recipients earning a median income and with no net wealth, by severity level



Source: OECD analyses based on the OECD long-term care social protection questionnaire, the OECD income distribution database, and the OECD wealth distribution database.

Figure 8: Shares of total homecare costs for moderate needs covered by public social protection systems, for care recipients earning different combinations of income and net wealth



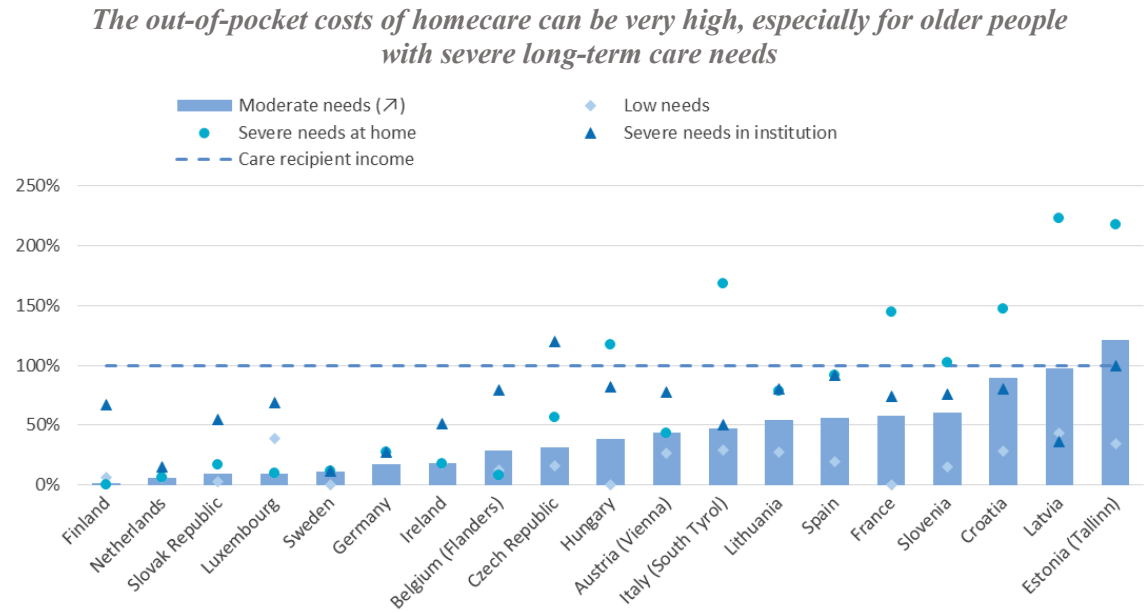
Source: OECD analyses based on the OECD long-term care social protection questionnaire, the OECD income distribution database, and the OECD wealth distribution database.

Public social protection systems across the EU provide greater support for older people with more severe long-term care needs and with lower incomes, and less generous support for those with assets. The depth of public social protection generally varies, in

particular, with the level of care need. In Tallinn (Estonia) and Croatia, for example, the share of homecare costs met by public social protection would be close to zero for people with low needs and median income. In 11 jurisdictions, the coverage of total care costs for older people on low incomes is between 6 and 65 p.p. higher than that received by older people with high incomes. Differences in the coverage of total homecare costs as between recipients with the lowest and highest income are most significant in Tallinn (Estonia), Lithuania, Vienna (Austria), and Spain. On the other hand, four jurisdictions (FI, LU, NL, SE) have nearly equal financial coverage for homecare, irrespective of income, meeting the total costs of care almost in full. In nine jurisdictions, older people with mean net wealth would have a lower share of costs covered by public support than in the case of those with zero wealth, with the difference averaging 18 p.p. (for an older person earning a median income).[75]

The out-of-pocket costs for care can be very high, especially for older people with severe long-term care needs receiving homecare (see Figure 9). Out-of-pocket costs are the share of the total long-term care costs that is left for older people to meet, after taking into account public support. In seven of the jurisdictions, older people with severe long-term care needs living at home would face out-of-pocket costs that are higher than the median income of their group, and in an additional three jurisdictions they would represent more than half the median income. High out-of-pocket homecare costs can put older people living at home at risk of poverty, as they still need to pay for the basic costs of living, such as electricity, food, and clothing. Looking at residential care, additional analysis (Cravo Oliveira Hashiguchi and Llena-Nozal, 2020) shows that out-of-pocket costs for residential care would be high compared with incomes only in the Czech Republic and Tallinn (Estonia).

Figure 9: Out-of-pocket costs of homecare as a share of old-age income after public support, for care recipients earning a median income and with no net wealth, by severity level

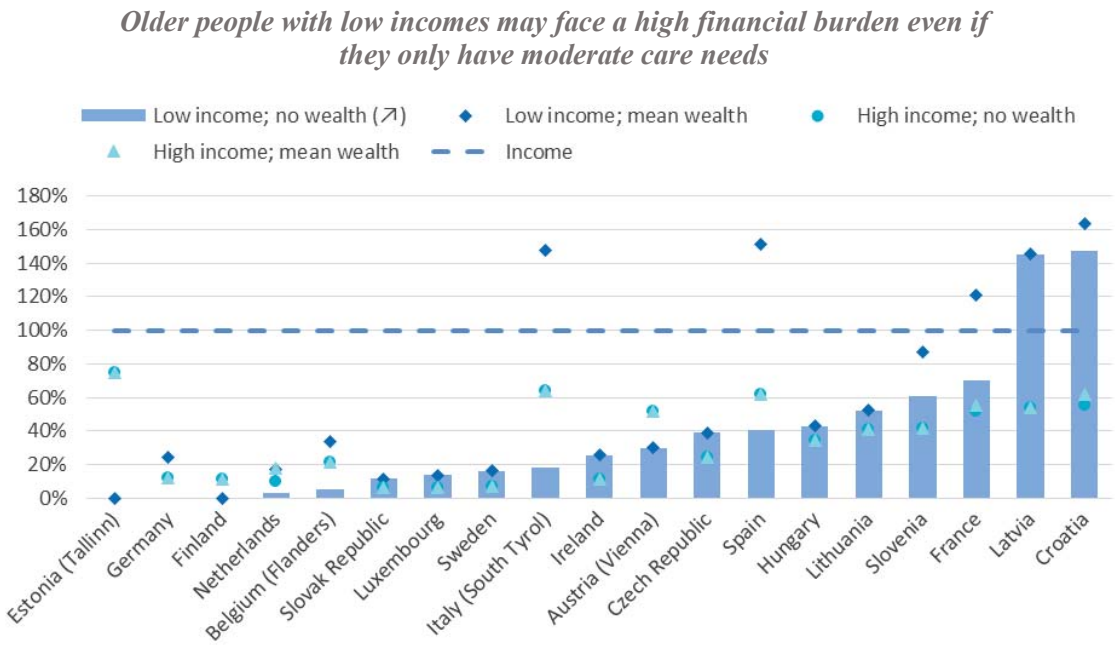


[75] Ranging from 2 p.p. to 54 p.p.

Source: OECD analyses based on the OECD long-term care social protection questionnaire, the OECD income distribution database, and the OECD wealth distribution database.

Older people with low incomes may face a heavy financial burden, even if they only have moderate care needs. In two jurisdictions, older people on low incomes and no net wealth would face out-of-pocket costs for moderate long-term care needs that exceed their income, and in three other jurisdictions out-of-pocket costs would represent more than half of their income. Many jurisdictions have safety nets to protect older people with low income, in particular, from falling into poverty, but they are not always effective in doing so. For instance, nine jurisdictions set income thresholds below which care recipients are eligible for higher public support. However, in seven Member States these thresholds are set far below relative income poverty lines – 'at-risk-of-poverty' (AROP) thresholds – and thus may not prevent many people with low incomes and long-term care needs from falling into poverty. In seven jurisdictions, older people with mean net wealth and median incomes would face out-of-pocket costs of residential care that are higher than their income, as they are expected to use their wealth to pay for care (Cravo Oliveira Hashiguchi and Llena-Nozal, 2020).

Figure 10: Out-of-pocket costs of homecare for moderate needs as a share of old-age income after public support, for different combinations of care recipient income and net wealth



Source: OECD analyses based on the OECD long-term care social protection questionnaire, the OECD income distribution database, and the OECD wealth distribution database.

An adjusted measure of poverty to gauge the performance of social protection systems looks at the risk of poverty associated with the out-of-pocket costs of long-term care. Although people in need may be able to pay for care, they often cannot afford it without going below a certain level of income. This remaining income is needed to cover all the other normal expenses of daily life. The measurement of poverty in this section is based on the threshold of 60 % of equivalised median disposable income, before any expenditure and after social transfers (i.e. the AROP threshold as used at EU level). However, disposable income is adjusted by out-of-pocket expenditure on long-term care. The reasoning behind this is that

people with long-term care needs living in their own homes will still face living expenses that are similar to people without long-term care needs (namely rent, electricity, food, and clothing, among others).

Without social protection for long-term care in old age, the majority of older people in the EU jurisdictions analysed would not be able to meet the out-of-pocket costs of care from their incomes alone without being at risk of poverty, as defined here. Looking at the financial situation of older people across the income distribution in a hypothetical situation where they face the need to pay for care services shows the following across the 19 jurisdictions assessed:

- in 10 jurisdictions, a majority of older people with *low needs* would be at risk of poverty as defined here after meeting the costs of *homecare* from their income alone without social protection;
- in all 19 jurisdictions, a majority of those with *moderate or severe needs* would be at risk of poverty as defined here after meeting the costs of *homecare* from their income alone without social protection;
- in 18 jurisdictions, over 90 % of older people would be at risk of poverty as defined here after meeting the costs of *homecare* for *severe needs*, without social protection; and
- in 17 jurisdictions, a majority with *severe needs* would not be able to afford[76] the total costs of *residential care* from their income alone without social protection.

In 11 jurisdictions, at least 60 % of older people would be at risk of poverty after paying for homecare for severe needs, even after receiving support. Although there is no agreement about what constitutes 'adequate social protection', it is worthwhile analysing whether existing social protection systems for long-term care could guarantee that no older person is at an increased risk of poverty due to developing long-term care needs. This can be seen by comparing two situations, as follows. The first metric is the share of older people who are at risk of poverty (in the traditional definition, i.e. regardless of costs associated with the potential use of long-term care). The second is the share of older people who would be at risk of poverty (after taking into account out-of-pocket payments on long-term care) *if* they needed long-term care *and* had access to public social protection. Figure 11 shows whether social protection for long-term care prevents a higher risk of poverty being associated with severe long-term care needs,[77] compared with overall poverty risks among older people.[78] Importantly, this figure focuses on social protection for severe needs, as the effectiveness of social protection differs significantly by severity of long-term care needs. Social protection is

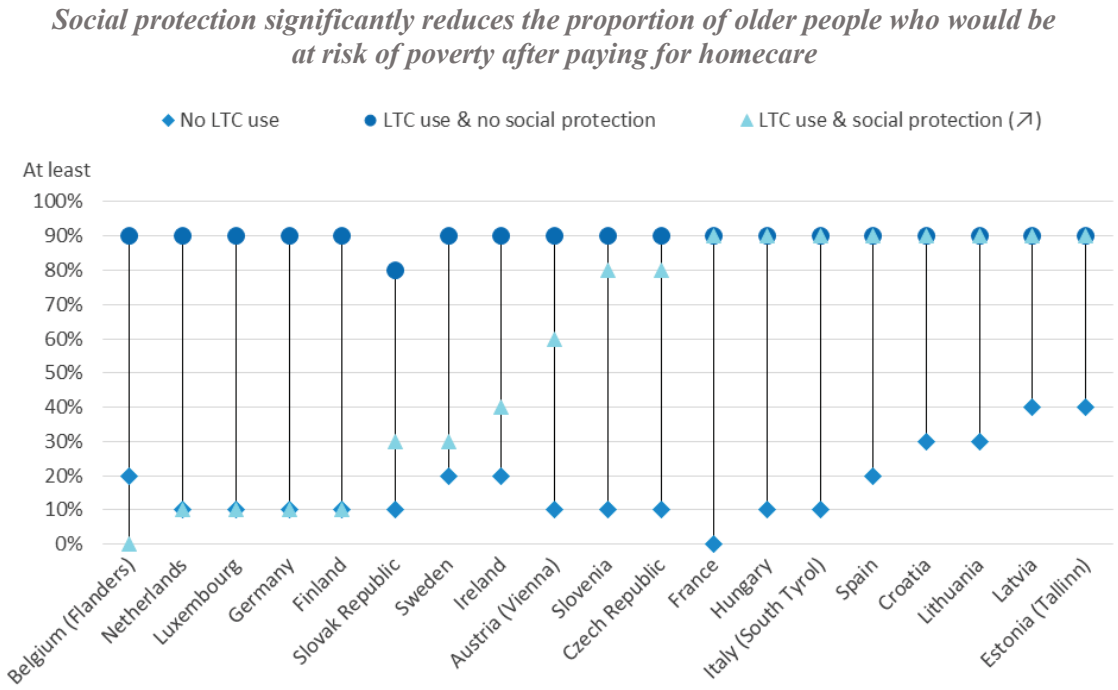
[76] It is assumed that people in residential care have no living costs in addition to their expenditure on residential care. This means that they are able to spend 100 % of their income on the out-of-pocket cost of residential care. Unaffordable in this context therefore means that the costs of residential care exceed someone's total income.

[77] The risk of poverty here takes into account out-of-pocket expenditure on long-term care. By comparison, the overall poverty risks among older populations do not envisage any expenditure on long-term care.

[78] This may reflect social protection systems' effectiveness in meeting objectives in relation to poverty prevention, but also societal choices in relation to collective versus individual responsibility in coping with social risks.

estimated to reduce the share of people facing the risk of poverty in 11 jurisdictions (very significantly in most cases) but not in all. In two jurisdictions (CZ, SI), the estimated share of people facing a relative risk of poverty would be reduced by 10 p.p. points only. In eight jurisdictions, social protection is insufficient to lift recipients above the threshold associated with the risk of poverty.

Figure 11: Proportion of the older population that would be at risk of poverty after meeting the out-of-pocket costs of homecare for severe needs



Note: Care recipients have no net total wealth. The diamonds represent the share of older people who are at risk of poverty, regardless of long-term care needs. The circles represent the share of older people who would be at risk of poverty if they were to meet the total costs of long-term care in full out-of-pocket. The circles represent the share of older people who would be at risk of poverty should they meet the out-of-pocket costs of long-term care after receiving public support. For example, in Ireland, where around 20 % of older people are at risk of poverty, at least 90 % of older people would not be able to afford the total costs of homecare for severe needs, and at least 40 % would not be able to afford the out-of-pocket costs of homecare for severe needs after receiving public support.

Source: OECD analyses based on the OECD long-term care social protection questionnaire, the OECD income distribution database, and the OECD wealth distribution database.

Box 3: Population-level estimates of long-term care needs and impact of social protection

An ongoing study carried out by the OECD[79] in co-operation with the European Commission presents new estimates of the number of older people in need of long-term care in Europe. *The study also estimates the out-of-pocket costs that they could face should they seek care for their estimated level of needs, and the impact currently available social protection systems could have on poverty risks associated with those out-of-pocket costs. The study thereby builds on the previous work on typical cases outlined in this chapter and matches the theoretical typical cases with responses from the SHARE and TILDA surveys (waves 7 and 3 respectively).[80/81] Although the survey questions on ADLs and IADLs are broadly comparable in the SHARE and EHIS, the SHARE provided the most up-to-date information and data on a large number of variables of interest including assets, detailed information on children, and detailed information on partners (including their own difficulties and limitations), and has been harmonised with surveys of ageing and retirement in other non-EU OECD countries.[82]*

Estimates of population-level long-term care needs

Averaging across the EU-27 for people aged 65 or over, 22-34 % are estimated to have low, moderate or severe long-term care needs. *The intervals reflect different approaches used to match typical cases to self-reported difficulties. More specifically, the OECD estimates that, across the EU-27, 9.5-16.5 % of Europeans aged 65 or over have low needs, 6.8-10 % have moderate needs, and 5.3-7.7 % have severe needs. These estimates suggest that 8.4-14.6 million Europeans aged 65 or over have low needs, 6-8.9 million have moderate needs, and 4.7-6.8 million have severe needs.*

Table 1: Share of population aged 65+ estimated to have long-term care needs, by level of severity and by gender, based on self-reported difficulties

EU-27	Low needs		Moderate needs		Severe needs		Any needs	
	Men	Women	Men	Women	Men	Women	Men	Women
%	7.5-13.3	11.0-18.9	5.3-7.6	7.8-11.8	73.9-83.5	60.6-75.6	16.2-25.8	25.5-40.4
Totals %	2,821,450-5,034,971	5,590,295-9,577,778	2,0123,15-2,862,424	3,979,452-6,008,052	2,789,3949-3,151,7272	3,074,8664-3,831,8193	6,114,543-9,737,866	12,940,155-20,509,683

Note: Percentages are based on adjusted calibrated sample weights from SHARE wave 7 (equal weights are used in the Netherlands) and TILDA wave 3. Shares are calculated by excluding observations with missing data (e.g. difficulties in ADLs). Intervals reflect different approaches used to match typical cases to self-reported difficulties from SHARE and TILDA.

Source: OECD analyses of responses to SHARE wave 7 and TILDA wave 3.

[79] Cravo Oliveira Hashiguchi et al., forthcoming.

[80] SHARE is a multidisciplinary and cross-national panel study, conducted bi-annually since 2004. The survey collects data on health, socio-economic status, and social and family networks from individuals aged 50+ and their partners in Europe. In wave 7, the survey achieved full coverage of the 26 EU continental Member States. Ireland is covered in the Irish longitudinal study on ageing (TILDA), which is harmonised with SHARE.

[81] Methods estimating the number of potential dependants based on subjective self-assessments are limited in general, since dependency as reported does not depend on any type of assessment, but depends only on a person's perception of their ability to perform activities associated with daily living. Comparability between Member States might be biased due to cultural differences in perceptions and different levels of potential long-term care services in very heterogeneous long-term care systems.

[82] Comparisons of the percentage of respondents who report having at least one difficulty in ADLs or IADLs in the EHIS and SHARE indicate that, on average across Member States, the percentages differ only slightly. However, the average does not reflect the wide range of differences across Member States, and reasons for discrepancies between the EHIS and SHARE are likely to differ between them. Reasons behind these discrepancies could include differences in survey methodologies (e.g. sampling, instruments) and how individual Member States implement these surveys.

Estimates of the population-level effects of public social protection

On average across 19 Member States[83], just over 21 % of people aged 65 or over were at risk of poverty[84] in 2017, corresponding to just over 10 million people. These findings are based on respondents' incomes reported in SHARE wave 7 and TILDA wave 3 (2017), across the 19 Member States modelled by the OECD as part of its work on the effectiveness of social protection for long-term care in old age. Across the 19 Member States, the share of the population that is at risk of poverty is higher among older people with long-term care needs than it is among those with no long-term care needs, indicating limited capacity to meet the out-of-pocket costs of long-term care. Across all 19 Member States, older people with any level of long-term care needs are 28-50 % more likely to be at risk of poverty, even before incurring any out-of-pocket expenses for long-term care.

Without public support, it is estimated that 75.1-76.2 % of older people with long-term care needs would see their remaining income reduced to less than the AROP threshold, should they choose to purchase homecare services at full cost. *On average (unweighted) across 19 Member States and all three levels of needs (low, moderate or severe), this could result in 8.6-13.3 million older people with any level of long-term care needs falling below the thresholds for poverty[85] (after paying for long-term care), should they choose to purchase homecare services at full cost without social protection. With access to public social protection, on average across 19 Member States and three levels of needs, an estimated 47.9-49 % of older people with any level of long-term care needs would still be below the thresholds for poverty after meeting the out-of-pocket costs of homecare, even after public support. There is wide variation in the reduction in poverty risks that social protection systems afford across Member States and levels of needs. For example, in France and Finland, social protection systems almost completely eliminate the poverty risks associated with the out-of-pocket costs of homecare for low needs.[86] On the other hand, in Latvia, Estonia (using long-term care benefits and schemes available in Tallinn) and Croatia, there are no reductions in the poverty risks associated with out-of-pocket costs of homecare for moderate needs.[87] The table below illustrates a very wide variation in the estimated effectiveness of social protection for long-term care across the EU. A range of 0.5-100 % indicates there is at least one country where almost everyone can afford care without going into poverty, and there is at least one where no one can afford care without being pushed into poverty. The range within each metric captures the different*

[83] In Member States where long-term care policies are devolved, and when it is not possible to model national long-term care benefits and schemes due to a lack of data or information, the OECD models subnational benefits and schemes. Models for subnational long-term care benefits and services are then used to estimate the effects of social protection based on data at national level (e.g. responses to surveys of ageing and retirement, or national distributions of income and wealth).

[84] The AROP rate is the share of people with an equivalised disposable income (after social transfers) below 60 % of the national median.

[85] An adjusted measure of poverty to gauge the performance of social protection systems is to look at the risk of poverty associated with the out-of-pocket costs of long-term care. Although people may be able to pay for care, they often cannot afford it without going below a certain level of income (e.g. 60 % of equivalised median disposable income, the AROP threshold). This remaining income is needed to cover all other normal expenses of daily life.

[86] Conclusions are drawn on the assumption that the rules applicable in the jurisdictions considered would apply to the entire Member States concerned.

[87] Older people who cannot afford the out-of-pocket costs of care from their incomes might still be able to use their wealth to make up for shortfalls. More detailed analyses can be found in OECD, 2021.

matching methodologies.

Table 2: Share of older people, by gender, with different severities of needs who are estimated to be below the poverty threshold after the out-of-pocket costs of homecare (after social protection), across 19 Member States and EU jurisdictions[88]

%	Low needs		Moderate needs		Severe needs		Any needs	
	Men	Women	Men	Women	Men	Women	Men	Women
Average	33.3-37.0	28.6- 31.9	65.5- 68.5	54.2-62.4	16.0-17.1	11.3-11.7	53.4- 57.6	67.3-67.7
Minimum	0.5-9.1	0.9-4.8	16.7- 19.6	6.3- 17.9	6.9-8.0	2.8-4.1	5.9-10.1	6.7-14.3
Maximum	88.0-91.9	89.3- 95.3	96.2- 100.0	94.4- 99.3	49.1-51.7	34.8-36.6	100.0-100.0	100.0-100.0

Note: Percentages are unweighted averages for the jurisdictions, which in turn are based on adjusted calibrated sample weights from SHARE wave 7 (equal weights are used in NL) and TILDA wave 3. Shares are calculated by excluding observations with missing data (e.g. income and net wealth) relevant to each jurisdiction's long-term care system. Where wealth variables are missing in SHARE and TILDA, it is assumed respondents have zero net wealth (this leads to the highest level of social protection in most Member States). Intervals reflect different approaches used to match typical cases to self-reported difficulties from SHARE and TILDA.

Source: OECD analyses based on the OECD long-term care social protection questionnaire and wave 7 of SHARE.

2.4 Removing barriers to the take-up of long-term care services and benefits

The availability of long-term care services and the corresponding social protection coverage are not always a sufficient condition for actual access. A problem of take-up exists, as some people do not apply for the long-term care services and benefits which they are entitled to. As a consequence, social protection is potentially ineffective, particularly to the extent that those not claiming support are the most vulnerable. The available evidence indicates that non-take-up of long-term care benefits is a quantitatively significant phenomenon.[89] Policies to increase the take-up of long-term care support thus help to implement Principle 18 of the Pillar, by ensuring access to affordable long-term care services for all people in need.

There may be both objective barriers and subjective motives for non-take-up. Older people may lack awareness of, or have misperceptions about, eligibility or application procedures. Stigma as well as a desire to protect their privacy may play a role. Finally, the application procedure may be overly complex and older people may lack the necessary resources, such as time and the ability, to cope with this.[90] This inability to apply may be linked to the observation that non-take-up of services is general more common among the more vulnerable groups of society (the 'Matthew effect'[91]). In digitalised systems, a lack of digital skills may further discourage older people from embarking on the application process. Additionally, non-take-up may be affected by the level of the allowance itself, as a result of a

[88] The minimum and maximum values are across Member States (i.e. each number corresponds to one Member State).

[89] In 2005, a French qualitative study on the public allowance programme (offering financial support to older people with disabilities for their long-term care needs) highlighted the fact that 9 % of eligible older people did not claim the allowance. See: Arrighi et al., 2015.

[90] Dubois and Ludwinek, 2015.

[91] For an example of a national study, see: Deleeck et al., 1983.

trade-off between costs (time, effort, stigma, etc.) and benefits. For instance, a study of the non-take-up of long-term care benefits in France confirmed that the higher the benefit level, the more likely older people in need of long-term care were to claim it. Old age, poor health, and level of disability were also associated with higher take-up rates in the study, whereas the better-off and those living with a partner or daughter(s) – not with a son(s) – were less likely to apply to the public allowance programme (Arrighi et al., 2015).

The variety of reasons for non-take-up suggests that approaches to addressing it may need to be similarly diverse, with multiple strategies applied simultaneously. Successful practices highlighted in a Eurofound study (Dubois and Ludwinek, 2015) as ways of improving administrative procedures and increasing take-up of social benefits include the following.

- Simple, transparent, stable, and readily available benefit criteria.
- Application procedures through social welfare offices are prone to stigma; in addition to online options (which may discourage people lacking digital skills), decoupling benefit applications from social welfare may provide a solution.
- Simply informing people about various benefits and entitlement criteria is not always enough. There may be a need to provide information about where and how to apply for specific benefits, for active support with the application process, or to enable people to find out about entitlements more generally.
- Benefits that are established at local level are at risk of non-take-up when they are part of a complex, fragmented benefit structure. Communication is key to reach out to all potential users. Differentiation in channels will be needed, as the public and their skills are extremely diverse. Along with local websites, national websites where people can check their entitlements to municipal benefits, and submit applications, can improve access, but will need to be integrated within an overarching strategy.

Box 4 reports on selected national policy approaches designed to improve the take-up of long-term care services and benefits.

Good practices for the design and application of any needs assessment make this procedure as easy and user-friendly as possible. As the needs assessment is the central entry point to support for many users, the findings above also have implications for the design of such tools. This can usefully include: the involvement of non-governmental organisations and stakeholders in the design of the assessment; eliminating multiple (methods of) assessment, which should reduce the burden on applicants; and independent, regular reviews of assessment processes. The assessment should be conducted in a way that allows for the identification and elimination of obstacles and barriers to its accessibility.[92]

[92] Waddington, 2018.

Box 4: Examples of Member States' policies designed to improve the take-up of long-term care services and benefits

The Swedish National Board of Health and Welfare has produced a guide to the public on 'your right to healthcare and social care'.[93] *With a view to granting older people long-term care services in a simpler way, and with greater scope for participation and self-determination, the government introduced a new provision in the Social Services Act (2001: 453) that allows municipalities to offer homecare to older people without the traditional form of needs assessment.*

The Austrian Ministry for Social Affairs, Health, Care and Consumer Protection hosts a website[94] *offering a nationwide, non-commercial collection of providers in the social field to provide free information. This website contains a wide range of information about institutions, organisations, associations, and self-help groups in public and private welfare. It supports both people in need of care and their relatives.*

Similarly, in Luxembourg, an internet site[95] *is available in four languages in order to inform people about long-term care insurance and the application process for benefits.*

Case and care management can help to guide people in need of long-term care towards the available services, and to co-ordinate healthcare and social care. The Flanders government in Belgium has established an integrated broad reception partnership providing a single entry point in cities and municipalities for questions that are material, psycho-social, legal or more care-related. The primary welfare services are the core actors, responsible for helping people contact social service providers within these partnerships. This can, among other things, ensure that people are not referred unnecessarily and do not have to retell their story in multiple settings. As the emphasis is on the most vulnerable, it is important that the aid and services are closely aligned with their environment. This means that care-givers and aid workers in the primary welfare services adopt a pro-active and outreach approach to help people in need navigate the services they require.

2.5 Conclusion

Long-term care services must be available, accessible, and affordable for people in need of long-term care. On average, 30.9 % of people aged 65 or over living in private households were already in need of long-term care according to 2019 EU-22 data. Furthermore, people in the first (i.e. lowest) income quintile were more likely to be in need of long-term care (37.2 %) than people in the highest income quintile (22.4 %). Population ageing and changing family structures will make the provision of formal long-term care even more important in the future. According to the 2021 Ageing Report (European Commission and EPC, 2021), 31 % of potential dependants aged 65 or over receive homecare, 19 % receive residential care, and 46 % receive cash benefits. However, the availability of formal long-term care services still differs greatly among Member States. In addition, because of gaps in public provision of long-term care, the data show that private providers operate in all the Member States analysed, with an increasing share of private for-profit providers.

[93] https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/vagledning/2016-5-5.pdf
[94] https://www.infoservice.sozialministerium.at
[95] https://aec.gouvernement.lu/fr/l-assurance-dependance.html

The organisation of long-term care varies widely between and also within Member States. There is no single internationally accepted and standardised definition of what constitutes long-term care or even long-term care needs. In many Member States, long-term care systems are characterised by a horizontal fragmentation between the healthcare and social care systems, with very close interaction and interlinking of these systems. There is often also vertical fragmentation between the national, regional, and local levels. As a result, Member States and regions may apply different criteria regarding the entitlement to long-term care, the needs assessment, the depth of social protection, and the services and benefits they offer.

Adequate social protection is crucial to make long-term care affordable. Estimates show that 75.1-76.2 % of older people with any level of long-term care needs (low, moderate or severe) would be below the poverty threshold (after paying for long-term care and before other expenditure) in 19 Member States analysed, should they choose to purchase homecare services at full cost from their income alone. This is an additional burden for an already vulnerable group, as older people with any level of long-term care needs are 28-50 % more likely to be at risk of poverty, even before incurring any out-of-pocket expenses for long-term care. However, even when available, social protection for long-term care would not be sufficient in many cases. At least 47.9-49 % of older people would be at risk of poverty after paying for homecare for severe needs, and after receiving support. Social protection support covers an important share of the costs in most Member States and tends to be more generous for older people with more severe long-term care needs and lower incomes, and less generous for those with assets. Insufficient and unaffordable access to formal long-term care may imply a greater reliance on informal care or unmet needs for long-term care. Nevertheless, the social protection coverage varies widely across and within Member States.

Despite the provision of social protection, a problem of take-up exists. Some people do not apply for the long-term care services and benefits which they are entitled to. Objective barriers and subjective motives for non-take-up may include a lack awareness and a lack of information about eligibility or application procedures, along with a fear of stigma associated with receiving a benefit. In particular, non-take-up of services is generally more common among the more vulnerable groups of society. The application process and the benefits themselves should therefore be designed to make them easily accessible.

Data collection on access and affordability in long-term care remains patchy. In order to strengthen evidence-based policy-making, it will be crucial to improve the availability of comparable data on: long-term care needs; access to, and the provision of, long-term care; and social protection for long-term care. More evidence is also needed regarding possible disparities between rural and urban settings.

3 QUALITY OF LONG-TERM CARE

Quality in long-term care matters, and the Pillar puts a special emphasis on it. From the individual perspective, high-quality long-term care is seen as important to ensure personal dignity, enable personal choice, and improve or maintain personal well-being. Furthermore, it can help protect vulnerable people from potential neglect or abuse. From the economic perspective, high-quality long-term care could help avoid unnecessary hospital admissions or could slow down the deterioration in the recipient's physical condition, thus potentially alleviating the pressure on resources. At the same time, adequate funding and staffing are key to ensuring quality, implying the need for careful strategies to maintain and improve quality while responding to the increasing demand for care. Although there is consensus that it is important to ensure quality, there is no common understanding of what high-quality long-term care means and how it can be achieved.

This chapter will explore the concept of long-term care quality. It will review different approaches to conceptualising, defining (Section 3.1), and measuring (Section 3.2) long-term care quality, look at key factors affecting it, and provide an overview of policy measures and tools to ensure it (Section 3.3). The discussion will be mainly based on residential care rather than informal care, as information on quality assurance in home-based and community-based care is limited.

3.1 Understanding long-term care quality

The quality of long-term care is difficult to define, as it can be approached from various angles, each providing a unique combination of the health and social aspects of care. Relevant dimensions may include: the quality of life that the receiver of long-term care services would be satisfied with; supporting people to have lives that are as empowered and independent as possible; improving, or limiting the deterioration in, medical conditions; protecting people's human rights (e.g. dignity and privacy, non-discrimination, choice, adequate standard of living); or a mixture of all these different elements. Furthermore, an understanding of quality needs to be shared by the numerous relevant stakeholders; these include, in addition to the users of long-term care services themselves, formal service providers, public authorities in charge of organising service provision, and both formal and informal carers.

Person-centred approaches to looking at long-term care quality are receiving increasing attention. These approaches put the needs and preferences of a person at the core, and focus on principles such as: user participation in care decisions; accountability and transparency of service providers; non-discrimination and equality; and the bond between carers and care recipients. However, although breaking down the concept of quality into a number of principles helps to build a more comprehensive picture and to better target policy tools, a challenge presents itself in the form of potentially conflicting principles.[96] For example, concerns about the well-being and safety of service users may be in conflict with the need for services to respect personal preferences. These different perspectives especially come to light

[96] Zigante and King, 2019.

during unexpected situations or times of crisis, as demonstrated by measures taken to confine the COVID-19 outbreak in 2020 (see Chapter 7 on the COVID-19 impact on long-term care quality).

There is no formal national definition of long-term care quality in any Member State.[97] Instead, most Member States use the existing broad quality definitions applicable to healthcare and social care services. These, however, may be rather general. For example, legislation regulating healthcare and social care services might underline the importance of the quality of services without giving a precise definition of what this might be. Only a few Member States have a broad official definition of quality in the healthcare sector (e.g. BE, SI) or social services (e.g. BG). In other Member States, in the absence of an official definition of quality, some quality principles can be derived from specific legislation, accreditation procedures for care-providers or other sources that address particular aspects of long-term care (e.g. the official objectives or standards on certain quality aspects[98]). The situation is particularly complex when it comes to Member States with decentralised responsibilities for long-term care. For example, since care regulations in Estonia are independently set at subnational level by local authorities, there are no common minimum criteria established for social care providers. In Denmark, local authorities are responsible for organising the provision of long-term care services, including defining quality standards and monitoring quality, which can result in significant variations in approaches to quality in practice. To address this, Denmark is developing common indicators of care quality for older people to assess the results of the services provided by municipalities. The indicators should be developed in 2021 and will cover three topics: functionality; quality of life; and coherence and predictability. They will be based on either register data or data from a national survey on satisfaction.

The above approaches to defining quality, however limited, usually apply to formal long-term care, while the quality of informal long-term care is even less researched and addressed. This might be due to the private nature of the relationship between the informal carer and the user. However, this relationship becomes more formal when cash-for-care schemes and other cash benefits make informal care publicly funded, and in some cases regulated (Zigante, 2018). This therefore makes it even more important to address quality in informal care (see more on informal care in Chapter 4).

3.2 Measuring long-term care quality

Because the concept of long-term care quality is so multifaceted and lacks a common definition, finding the right set of indicators to measure it is challenging. One way to operationalise the concept is by using the Donabedian model,[99] which originally examined the quality of healthcare. The model looks at *structure* (inputs and resources: e.g. physical facilities, equipment, and human resources including training, working conditions, and pay); *process* (the way care is delivered: e.g. diagnosis, treatment, preventive care, patient

[97] National examples are taken from: Cès and Coster, 2019.

[98] Such as preventing pressure ulcers or falls, or building a relationship with people with dementia in professional care.

[99] Donabedian, 1980.

education, obtaining information from medical records, interviews with patients and doctors, or direct observations); and *outcomes* (the effects of care on patients: e.g. changes to their health status/functionality, behaviour, knowledge, satisfaction, and quality of life). However, to make inferences about quality, there has to be a relationship between the three dimensions, which is not easy to establish. For instance, improvements in structures or processes may not always translate into better outcomes. In addition, although structure and process indicators may be defined relatively easily, establishing consensus on what could be considered relevant outcomes as indicators of quality may not be so straightforward.

There seems to be some consensus on looking at aspects of the quality of life of the individual as an indicator of long-term care quality outcomes. Quality of life is a very broad concept. The World Health Organization (WHO) defines it as an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns.[100 / 101] There are other instruments that are based on the user perspective. For example, the adult social care outcomes toolkit (ASCOT),[102] used in the UK, measures outcomes by comparing users' perceived outcomes after receiving care with the outcomes they would expect in the absence of care. It collects information on eight dimensions of quality of life: control over daily life; personal cleanliness and comfort; meals and nutrition; accommodation cleanliness and comfort; safety; social participation; occupation; and dignity. Similarly, patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs), used for example in Germany and Denmark, assess outcomes and experiences in relation to healthcare by collecting information directly from users.[103] A more general attempt to capture user experiences across the EU comes from the 2016 European Quality of Life Survey (EQLS).[104] A set of variables to rate the satisfaction of health and care service users was used, with four specific quality dimensions in relation to those services (quality of the facilities; expertise and professionalism of staff; personal attention given; being informed or consulted about care). All the indicators based on self-reported experiences and perceptions of quality reflect a certain degree of subjectivity.

More recently, some attempts to assess and monitor long-term care quality have emerged in line with a human rights-based approach to long-term care. For example, a

[100] World Health Organization, *WHOQOL: Measuring Quality of Life*, https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en

[101] The instrument developed by WHO to measure the quality of life (WHOQOL-100) contains 24 items within six domains: physical health (energy and fatigue; pain and discomfort; sleep and rest); psychological (bodily image and appearance; negative feelings; positive feelings; self-esteem; thinking, learning, memory, and concentration); level of independence (mobility; activities of daily living; dependence on medicinal substances and medical aids; work capacity); social relations (personal relationships; social support; sexual activity); environment (financial resources; freedom, physical safety and security; health and social care; accessibility and quality; home environment; opportunities for acquiring new information and skills; participation in and opportunities for recreation/leisure; physical environment (pollution/noise/traffic/climate; transport); and spirituality/religion/personal beliefs (as a single item).

[102] See: https://www.pssru.ac.uk/ascot

[103] The OECD PaRIS (patient-reported indicator surveys) project is developing new ways to collect data on PREMS and PROMS. http://www.oecd.org/health/paris

[104] Eurofound, 2019b.

tool has been developed[105] for older people with long-term care needs in residential and home-based care settings, which is designed to raise awareness about their rights and help assess and monitor policies and outcomes in upholding them. The Rights of Older People Index (ROPI) is a policy index based on structure and process indicators, complemented by a scoreboard to capture related policy outcomes.[106] Although such an approach looks promising, the relevant data might be difficult to obtain, especially at subnational levels, where policies matter most. More generally, promoting the human rights of older people in long-term care alone is not enough for a comprehensive measure of quality, without also promoting their biological/psychological/social well-being and maximising their access to services and social integration.

The availability of data, and the ease of access to it, are key considerations for developing quality indicators. Having a very detailed list of regularly updated indicators might be counterproductive, if the collection of data increases the administrative burden and the workload on care staff, forcing them to reduce the time they devote to the care user. It is therefore useful to check the design of quality indicators against the extra administrative burden created, as well as making use of digital technologies for data collection and analysis.

As with the definition of quality, there are no common EU-level indicators relating to long-term care quality. The ongoing work in the **SPC ISG** on developing common EU-level indicators for long-term care will contribute to progress in this field, while possibly highlighting data gaps and the need for further statistical and analytical work.

Member States use a number of indicators to monitor care quality, which are usually not specific to long-term care. These indicators are often generic to all residential healthcare facilities (e.g. involuntary weight loss, use of restraints or isolation measures, number of problems with medicine) **(**Cès and Coster, 2019). A few Member States have mandatory, systematic routine data collection in relation to incidents (e.g. falls, pressure ulcers) or safety-related indicators for residential facilities. However, such indicators refer to clinical outcomes and are thus unlikely to fully capture the quality of long-term care. Some Member States use indicators on processes, for example on the number of care receivers for whom a pain assessment was carried out, and how the pain levels have evolved. Another example is regular weight measurements (and how they evolve over time). Those Member States that have in place quality frameworks or minimum standards for long-term care collect specific data that help assess compliance with these quality requirements. Use is also made of user surveys (for instance on quality of life or satisfaction, examining issues such as privacy[107] or autonomy[108]), online quality reviews by care users, and data on user complaints. However, such surveys

[105] Birtha et al., 2019.

[106] The index has been tested in 11 Member States (AT, CZ, ES, FI, IE, IT, PL, PT, SE, SI, SK) plus the UK. It includes 35 indicators in 10 domains: (1) equal access and affordability in relation to care and support; (2) choice, legal capacity, and decision-making capacity; (3) freedom from abuse and mistreatment; (4) life, liberty, freedom of movement, and freedom from restraint; (5) privacy and family life; (6) participation and social inclusion; (7) freedom of expression, thought, conscience, beliefs, culture, and religion; (8) highest standard of health; (9) adequate standard of living; and (10) remedy and redress. The indicators are based on statistical information collected from comparable European datasets.

[107] Percentage of residents who feel that their privacy is safeguarded.

[108] Percentage of residents or representatives who feel that they have a say in the care and guidance they receive.

typically have low response rates and their results need to be interpreted with caution (e.g. people may give only good marks, or not file a complaint, because they fear losing access to services).

3.3 Ensuring long-term care quality

The quality of long-term care is affected by a number of factors, including funding, workforce, organisation, and technology. Funding is one of the most important ingredients that can help ensure the adequate level of physical and human resources (see Chapter 5). However, the availability of those resources and how they are organised also play a significant role. Long-term care services are highly interpersonal. As a result, their quality very much depends on the quality of the workforce. This highlights the role of carers' skills, but also the importance of good and sustainable working conditions to ensure sufficient levels of staff and to avoid high staff turnover (see Chapter 4). The way long-term care is governed and organised may also affect its quality, with vertical (e.g. central vs local) and horizontal (e.g. social care vs healthcare) fragmentation adding to the complexity of the debate. New models of integrated care have started to emerge, which include new payment structures, the use of performance-related incentives, and different structures for commissioning and providing services.[109] The aim of such models is to structure care services around personal needs, which could improve user satisfaction, psychological health, and well-being. This is particularly important for all people with long-term care needs who wish to remain at home for as long as possible. In addition, there may be differences in quality between private and public long-term care provision, although more evidence is needed on the existence and extent of such differences. For example, the differences might not be significant in the Member States where quality requirements (when they exist as such) are the same for all long-term care providers, whether private or public (e.g. in DE). Technology can help improve the quality of long-term care. There are, however, limits and challenges in relation to its use (see Box 5).

Box 5: Role of technology in improving the quality of long-term care[110]

There are undoubtedly benefits to using technology in long-term care. *Technology can improve the quality of services provided, for example by: ensuring timely visits; freeing up carers to spend more time socialising with users; making services more personalised; and increasing users' independence. It can also support quality-assurance efforts through monitoring of service provision. Issues such as the timing and duration of visits, or logging of medication, can all be done electronically and be monitored for quality-assurance purposes. Remote care management (e.g. smart home applications and virtual medical visits) can improve health outcomes by replacing physical visits to clinics and hospitals. Visits in person are often tiring and can expose the user to additional infection. Assistive technologies (e.g. electronic devices, touch-screen technology) can be particularly beneficial for older people, including people with dementia, both in their own homes and in residential care. Care*

[109] The European network on long-term care quality and cost-effectiveness and dependency prevention is a project funded with financial support from the EU. https://www.cequa.org/

[110] Based on: Zigante, 2020.

robots have the potential to enhance the quality of life, though their use in long-term care needs further research.

On the other hand, there are several challenges linked to technology use in long-term care. *They include the risk that reduced human contact leads to increased loneliness, and issues related to practical usage and malfunctioning of technical solutions, which is also linked to the level of trust users may have in the device or software. Insufficient digital skills among older people and their care-givers are a challenge, although as time passes this may become less of an issue as digital skills spread through the population. Data protection remains a challenging issue and this is likely to accentuate over time. There are particular challenges when using technology in dementia care where the progression of the disease, often unpredictable, demands agile and flexible technological solutions. If long-term care technology is to have a positive impact on quality, a key requirement is that the technology works as intended and is available when needed. However, assistive technology provision is fragmented and it may be difficult to access.*

Consumer choice can often create pressure to improve the quality of services, though this may not be a sufficient strategy for long-term care services[111]. First, some long-term care users may lack capacity to consider and express preferences. Second, the idea that quality is improved through competition on the basis that 'consumers vote with their feet' does not fully apply to the long-term care environment, as for example long-term care users are less likely to move from one nursing home to another. The choice of the initial (and often permanent) provider is often carried out at a time of stress and by users who generally already having significant needs. In addition, in many cases, financial constraints and the limited availability of services (as evidenced by long waiting lists) play a more important role than quality preferences. This means that the link between personal choice, competition, and quality is not straightforward in long-term care. On the other hand, if the availability of services or financial considerations are not a problem, quality reports in respect of long-term care providers, if underpinned by common indicators, can be a helpful tool in choosing the right service.

Member States employ a mix of policies and practices to improve the quality of long-term care, but policies focus mainly on residential care. A few Member States have quality frameworks dedicated specifically to long-term care (Cès and Coster, 2019)**.** A long-term care quality framework is here understood as a document setting out quality principles that long-term care services should fulfil, as well as indicators for monitoring, which serves as a reference point for defining, assuring, evaluating, and improving the quality of these services. In the few Member States that have such specific quality frameworks (e.g. DE, LU, PT), they are applicable to all types of facilities and providers (both public and private, residential and home-based, settings). Monitoring may be done by several bodies, based on a wide range of evaluation criteria regarding the structure, processes, and outcomes of long-term care services. For example, Germany launched a new quality-assurance system in residential long-term care facilities (nursing homes) in 2019. Nursing homes have to collect quality-related data for all residents based on 10 indicators (e.g. maintained mobility, maintained ability to

[111] Zigante and King, 2019

independently perform ADLs), which is the basis for mandatory external quality audits that indicate where there is potential for improvement. The new system puts special emphasis on in-house quality assurance, external quality assessments, and public quality reporting.

A key instrument for ensuring long-term care quality is the setting of minimum standards and requirements (Cès and Coster, 2019). These standards are reinforced via registration and accreditation, monitoring, inspections, and sanctions. The minimum requirements usually involve structure-oriented standards, covering standards for infrastructure and buildings, safety, hygiene, nutrition, and workforce (ratio of staff and qualifications of staff), and are often compulsory. Less commonly used are process-oriented standards (e.g. quality of co-ordination between professionals and services; compliance with health and safety standards; rules to ensure the respect of patients' rights; care protocols for different types of long-term care needs; risk-management procedures) or outcomes-oriented standards (e.g. in relation to: the number of falls; the frequency of infections; user-satisfaction surveys). Member States usually have a stronger set of regulations and standards applicable to residential care than homecare. However, some have also developed requirements for homecare services (e.g. BE, DE, ES, FR, IT, MT, NL, PL, PT). To ensure adherence to the quality standards and requirements, a number of quality-control measures are used. They range from self-assessment by care-providers for internal quality improvement to external assessments by independent government bodies, with the latter usually using (either planned or unannounced) on-site inspections. In the event of non-compliance, sanctions may go as far as withdrawal of accreditation, loss of funding or fines. Minimum standards and requirements represent a systematic approach to improving quality. However, the effectiveness of this approach may be undermined by: a lack of resources (e.g. for carrying out inspections); insufficient harmonisation and transparency in the inspection process; or an absence of mechanisms to compel providers to ultimately comply with quality standards.

Financial incentives, as well as increased transparency and information provision, can also play a role in ensuring long-term care quality[112]. However, while negative financial incentives (e.g. fines in the case of non-compliance with quality standards) may be found in a number of Member States, positive financial incentives to improve the quality of long-term care are scarce and usually come in the form of public subsidies to implement quality-improvement programmes (e.g. BG, ES, NL). Nevertheless, other innovative ways to promote quality are also being considered, such as rewarding providers based on the evaluation of results (PT).

Special acknowledgement of long-term care providers' performance may help them achieve a better market standing. Providers can, on a voluntary basis, obtain certification based on either the ISO standards[113] (e.g. PL, SK), the European Quality in Social Services (EQUASS) framework[114], various national-level quality labels (e.g. FR, NL) or voluntary accreditations (e.g. BE, LT, PT). For example, the Swedish Dementia Centre, a non-profit

[112] Cès and Coster, 2019

[113] International Organization for Standardization (ISO), https://www.iso.org/

[114] The EQUASS certification process is an initiative of the European Platform for Rehabilitation, designed to develop continuous learning and enhance quality in the social services sector. https://www.equass.be/

organisation, has developed a training model leading to certification using a star symbol. The star is valid for one year and shows that at least 80 % of the staff have undergone various courses to increase their competence in dealing with dementia patients.

Ensuring the quality of informal care, which represents a large share of all long-term care provided, is particularly challenging (Cès and Coster, 2019). This is largely because it is difficult to identify informal carers. They are often not formally acknowledged and are thus likely to remain unknown to public authorities. In addition, family members helping their relatives with daily life activities may not self-identify as informal carers, since they may see the help they provide as part of their family role. Without formal identification of informal carers it is therefore difficult to systematically support and guide them in providing quality care.

Member States have a number of measures to help informal carers provide high-quality care. Some try to reach out to them via a systematic assessment of their situation (e.g. AT, BE, DE, IT, LU), which is often linked to the legally regulated support measures for informal carers (cash benefits or care leave) or care recipients (cash benefits), sometimes with the explicit objective of assisting informal carers in fulfilling their role. For example, in Germany, there are mandatory consultancy and assistance visits for people receiving informal care, designed to guarantee a certain quality of care and to assist informal carers. A few Member States have formal assessments focusing more on the needs of informal carers (e.g. IT), rather than on their capacity to provide care. However, such assessments are not regular and are often undermined by the limited availability of professionals, such as case managers and social workers. Other relevant support to informal carers comes in the form of training to develop their caring skills (e.g. in Malta specific training for informal carers of people with dementia is provided at the island's largest long-term care facility), counselling, participation in collective groups of carers, psycho-social support, individual follow-up, involvement in drawing up the care plan, etc. Opportunities provided by digitalisation are also available in the form of online tutorials and training, peer support, and virtual supervision. Having dedicated strategies can help ensure a comprehensive approach to supporting informal carers. The Swedish government is working on developing a strategy with the aim of contributing to the support of relatives who care for or support an older person. Further information on informal care can be found in Chapter 0.

There is no specific long-term care-quality framework at the EU level, but the voluntary EQUASS framework, approved by the SPC in 2010, could also be applied to long-term care services. The EQUASS framework is aimed at developing a common understanding of the quality of social services and identifies principles that these services should fulfil. It is meant as a reference tool for public authorities in charge of organising social services. Although the framework applies to social services in general, there have been attempts to

adapt it to specific social services, including long-term care.[115] The framework may be revisited to see how it fits the current realities of long-term care.

3.4 Conclusion

The quality of long-term care is gaining attention across the EU. The Pillar recognises the right of everyone concerned to have access to long-term care of good quality. Although some work is ongoing at national and subnational levels on improving long-term care quality, more needs to be done to build up a common understanding of quality in long-term care across the EU. In this respect, the ongoing joint work of the European Commission and the SPC on developing indicators for long-term care may pave the way forward.

There are a number of approaches to conceptualise long-term care quality. A person-centred approach, based on the needs and preferences of a person in need of care, seems to be gaining attention across the EU. However, efforts to conceptualise and ensure quality mainly focus on residential care, while more work needs to be done on the quality of homecare and informal care. The impact of growing privatisation on long-term care and its quality also needs to be further analysed.

The quality of long-term care could be measured from different angles. Indicators could be developed along the axes of structure (inputs and resources), process (care delivery) and outcomes (impacts on the quality of life, functionality and/or independent living). In addition, in line with a person-centred approach, quality could be measured by capturing users' perceptions of their experience with care or services across a number of dimensions (e.g. waiting times, control over daily life, personal cleanliness and comfort, meals and nutrition, dignity).

Key factors affecting quality are funding, workforce, organisation, and technology. Funding is key to ensuring an adequate level of physical and human resources conducive to long-term care quality. As long-term care services are highly interpersonal, their quality very much depends on the availability and quality of the workforce, working conditions, and on how care delivery is organised. However, the increasing demand for long-term care and the pressure on human resources may accentuate the difficult trade-off between access and quality. Technology could help to improve care quality, including by making services more personalised and increasing users' independence. However, beyond cost considerations, there are also challenges such as: the risk of reducing human contact; the insufficient availability, accessibility, reliability, and acceptance of new technologies; and concerns about the protection of personal data.

Member States employ a mix of policies and practices to improve the quality of long-term care, focusing mainly on residential care. A few have quality frameworks dedicated specifically to long-term care, setting out the quality principles that long-term care services should fulfil. More often, minimum standards and requirements usually operate through

[115] See, for example, the EU quality framework for long-term care services developed by the WeDO project: *Principles and guidelines for the wellbeing and dignity of older people in need of care and assistance*. https://www.age-platform.eu/sites/default/files/EU_Quality_Framework_for_LTC-Summary-EN.pdf

registration and accreditation processes. They are reinforced via monitoring, inspections, and sanctions. Other tools include financial incentives and increased transparency and information provision. To support informal carers in providing high-quality care, some Member States use systematic assessments of their situation, sometimes with the explicit objective of assisting them in fulfilling their role.

4 WORKFORCE IN THE LONG-TERM CARE SECTOR AND INFORMAL CARERS

Long-term care is provided by a mix of formal and informal carers, mainly women. Formal long-term care is provided by professionals, whereas informal care is typically provided by someone from the care recipient's family or social environment. Ensuring that there is a sufficient number of adequately skilled formal carers and providing support to informal carers are thus two key challenges across the EU. In addition, there is a strong gender dimension in long-term care, as almost 90 % of formal long-term care workers in the EU are women, and women are also over-represented among informal carers and care recipients.

This chapter will explore the challenges in relation to the long-term care workforce as well as the prevalence of informal care across the EU and its consequences. The chapter will analyse the numbers, characteristics, and situation of long-term care workers in the *formal* care sector (Section 4.1), looking at its job-creation potential and workforce shortages and underlying drivers, in particular challenging working conditions and comparatively low salaries. It will also analyse the tasks, training, and qualification requirements of long-term care workers and will discuss challenges of specific groups of care workers. The chapter will then analyse the extent of *informal* long-term care across the EU (Section 4.2) and will explore the impact of informal care on carers' health, well-being, and labour market participation, as well as the broader implications for equality between women and men.

4.1 Workforce in the formal long-term care sector

4.1.1 Characteristics of formal long-term care workers

The long-term care workforce includes a variety of professionals from different backgrounds, who collaborate with each other and other actors, both in the community and within an institutional set-up. It includes social care workers (such as personal care workers or counsellors) and healthcare workers (such as geriatric nurses or other nurses) as well as specific groups such as live-in carers[116] (workers living in the household of the care recipient and providing care support: see more information in Box 6). Long-term care workers often have to collaborate with other professionals, in particular other healthcare professionals and social workers, and with informal carers (see Section 4.2). However, the division of tasks is not always clear-cut and responsibilities sometimes overlap. Good co-ordination between communities, institutions, professionals, and agencies is therefore needed to ensure integration of services.

The large majority of long-term care workers are personal carers, and the bulk of the workforce is employed in residential care. While acknowledging the diversity in the long-term care workforce, and its importance to both care provision and the quality of life of

[116] Live-in carers are paid professionals, with or without formal care training, whose work primarily involves long-term care provision while living in a private residence with the care receiver. They should be distinguished from informal carers, who provide care to someone in their family or social environment.

beneficiaries, due to limited data availability the analysis in this chapter will focus on the two groups – personal care workers[117] and nurses[118] – that account for the majority of care workers in formal long-term care provision. In 2019, 67 % of long-term care workers were personal care workers, compared with 33 % who were nurses.[119] In several Member States, more than 8 out of 10 long-term care workers were personal care workers (BG, CY, CZ, DK, EE, ES, FI, HR, IT, LV, PT, RO, SE, SK). There are also, however, Member States where nurses are in the majority (DE, EL, IE). Most long-term care workers across the EU work in residential care (65 % in the EU-27 in 2019), as against 29 % working in non-residential care.

The overwhelming majority of long-term care workers are women. In 2019 according to the LFS, 88 % of long-term care workers in the EU were women. Only in a few Member States (DE, IT, MT, SE) did men account for more than 15 % of the long-term care workforce.

The long-term care workforce is ageing. Most long-term care workers are middle-aged: in 2016, the median age of long-term care workers was 45 across Member States (overall workforce: 42[120]). The share of workers in the long-term care sector[121] aged 50 or over was close to 38 % in 2019 (4.7 p.p. higher than for the entire workforce). It had increased by almost 10 p.p. from 28 % in 2009 (7.3 p.p. for the entire workforce[122]). This age profile and trend may exacerbate labour shortages in the sector over the coming years.

One fifth of the long-term care workforce is foreign-born, with substantial variation across Member States. In 2019, the share of foreign-born long-term care workers (from within and outside the EU) was close to 20 %. This share ranged from close to zero (e.g. HR, SK) to more than 45 % (LU, MT).[123] As these statistics do not always include specific groups such as (often foreign-born) live-in carers, they may even under-represent the actual number of foreign-born long-term care workers. In 2016,[124] 5 % of personal care workers[125] in the EU were mobile workers (workers from another Member State),[126] close to the share of mobile workers among the total EU labour force (4 % in 2016). Romanians were by far the largest group of mobile personal care workers.

[117] Personal care workers (in this analysis defined per ISCO-08, falling under codes 5321 and 5332) are formal workers providing mostly social-related long-term care services at home or in residential care homes and who are not qualified or certified as nurses, but may have other qualifications or training in providing care for older people with long-term care need.
[118] Nurses (in this analysis defined per the international standard classification of occupations ISCO-08, falling under codes 2221 and 3221) include people who have completed their studies/education and training in nursing, are licensed to practice and deliver, among other things, health-related long-term care services at home or in residential care.
[119] EU Labour Force Survey (LFS). Data are based on ISCO 4 digit (3 digit for BG, DK, EL, ES, LV, PT) and nomenclature of economic activities (NACE) 2 digit.
[120] LFS.
[121] As defined by NACE 87 and 88.1.
[122] LFS and Eurofound, 2020b.
[123] LFS. Data are based on ISCO 4 digit (3 digit for BG, DK, EL, ES, LV, PT) and NACE 2 digit.
[124] European Commission, 2021a.
[125] ISCO 3 digit code 532.
[126] Across all sectors, not only long-term care.

4.1.2 Potential for job creation and workforce shortages

There is a large potential for job growth in the sector, given the projected increase in the demand for long-term care, but actual job growth is slow. The formal care sector already employs about 6.3 million people, which represents 3.2 % of the EU's entire workforce (Eurofound, 2020b).[127/128] According to Cedefop skills forecasts for the EU-27,[129] between 2018 and 2030 there will be 3.2 million job openings for health associate professionals, and 3.8 million for personal care workers. However, so far the increasing number of long-term care workers has been outpaced in many Member States by the increasing number of older people. On average in the EU, the number of long-term care workers per 100 people aged 65 or over declined during 2011-2016, from 4.2 to 3.8.[130/131] As shown in Figure 12, the number of long-term care workers per 100 older people varies greatly across Member States, ranging from 0.1 (EL) to 12.4 (SE) in 2016. In interpreting such headcounts of long-term care workers, it should be kept in mind that part-time work is significant in this sector (more than 40 % in 2019) and its extent differs widely across Member States. For instance, in several Member States (AT, BE, NL, SE), more than half of long-term care workers work part time (see respective section below).

Most Member States experience difficulties attracting a sufficient number of long-term care workers, and this may worsen in the future. A large majority of Member States have reported significant numbers of unfilled vacancies, or have estimated increases in the need for personnel and expected staff shortages in the long-term care sector (Eurofound, 2020b).[132] Shortages concern skilled care personnel (mainly nurses) in particular (Eurofound, 2020b). Nursing professionals were ranked first among the occupations experiencing the highest labour shortages in the EU in 2020.[133] Several factors may contribute to increasing staff shortages in the future, notably the expected increase in demand for formal long-term care due to a larger population of old people, as well as ongoing trends such as the increasing labour market participation by women and the greater mobility of people, which may influence the availability of informal carers. Other factors that may increase labour shortages in the sector include the ageing workforce, and thus many workers retiring over the next decade, as well as competition with other sectors with more attractive employment opportunities and better working conditions.

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[127] When analysing EU datasets, this report focuses on the long-term care sector, regardless of profession, and so also includes workers other than 'carers' (for example, support workers such as cooks, cleaners, and administrators). Long-term care workers are broadly employed in the following NACE Rev. 2 classification categories: residential nursing care activities (NACE 87.1); residential care activities for mental retardation, mental health, and substance abuse (NACE 87.2); residential care activities for older people and people with disabilities (NACE 87.3); other residential care activities (NACE 87.9); and 'social work activities without accommodation for the elderly and disabled' (NACE 88.1).

[128] The Eurofound report also shows the large differences between Member States in terms of the size of the long-term care workforce. The long-term care workforce as a share of the entire workforce ranges from 0.3 % in Greece to 7.1 % in Sweden.

[129] European Centre for the Development of Vocational Training (Cedefop), *Skills Forecast*, https://www.cedefop.europa.eu/en/publications-and-resources/data-visualisations/skills-forecast

[130] Excluding LT and LV, for which data are missing.

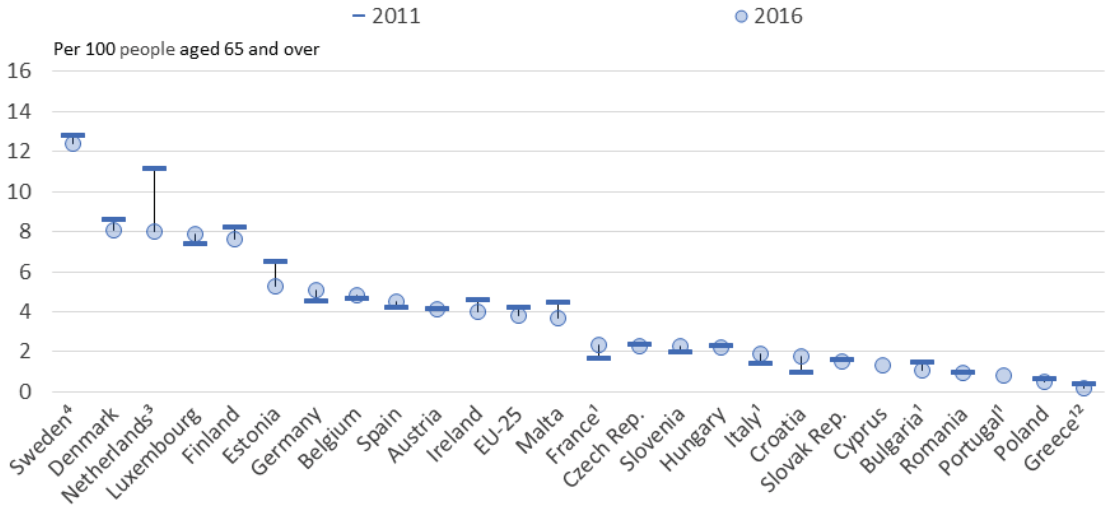
[131] OECD 2020a.

[132] According to country fiches in Annex II, AT, BE, CZ, DE, DK, FI, HR, HU, IE, LT, LU, NL, PL, PT, RO, SE, SI, SK already experience labour shortages; other sources also report labour shortages in many Member States (e.g. OECD, 2020a).

[133] European Commission, 2020a.

Figure 12: Long-term care workers per 100 people aged 65+, 2011 and 2016

The number of long-term care workers per 100 people aged 65+ varies greatly across the EU



Source: OECD analysis.[134]

Several central and eastern Member States are facing the phenomenon of 'care drain'. Many long-term care workers from certain Member States (e.g. BG, HR, HU, RO, SI[135]) are working in other ones, mostly for better salaries and working conditions. Although labour mobility is a key *acquis* of the EU, bringing a wealth of opportunities (e.g. helping to ease shortages in the receiving Member States), the mobility of long-term care workers may entail challenges for the sending Member States. First, it may exacerbate labour shortages in these, especially as they are facing or will face population ageing themselves. Some Member States that export care workers fill the care gap by importing labour themselves, from other EU or non-EU countries. For instance, Hungary attracts care workers from abroad, mostly from the ethnic Hungarian communities of Romania and Ukraine.[136] Demographic change in sending countries and regions may in turn be intensified through the emigration of the working-age population (European Commission, 2020b). Second, sending countries invest in the education and training of care professionals, but then cannot benefit from their skills when these workers decide to work abroad. On the other hand, beyond the overall benefits resulting from the match between workers' talents and demand, there are also clear benefits for sending countries. For instance, many mobile workers send remittances home to their families, who then spend this money in the home country. If eventually mobile care workers return to their home countries to work, they bring their experience acquired abroad, which can help to enrich local practices.

[134] LFS data are based on ISCO 4 digit and NACE 2 digit. 1. Data are based on ISCO 3 digit and NACE 2 digit. 2. Data must be interpreted with caution, as sample sizes are small. 3. The decrease in the Netherlands is partly due to a methodological break in 2012, as well as reforms. 4. Data refer only to the public sector.

[135] According to country fiches of Volume II.

[136] According to HU country fiche of Volume II.

4.1.3 Education and skills levels of long-term care workers

Most long-term care workers[137] have a medium level of educational attainment. The majority of long-term care workers have an upper secondary educational qualification or equivalent (medium education level). Nurses have on average higher educational attainment levels than personal care workers, mirroring their more complex tasks and responsibilities (OECD, 2020). Some professions in the long-term care workforce, in particular nurses, are highly regulated. Although important to ensure the quality of care, this may be a barrier to accessing these professions and thus may contribute to labour shortages. On the other hand, some Member States do not require any minimum qualifications for some categories of personal care and homecare workers (e.g. CZ, RO, SI) (OECD, 2020). Sometimes long-term care workers acquire skills via non-formal channels, for instance through on-the-job training or taking on board more responsibilities. Validation of such non-formal learning could support career progression.

Skills requirements in long-term care are increasingly complex, which may exacerbate the skills gaps in the sector, but may also make the profession more attractive. Long-term care jobs are often more complex than their public image suggests. Skills needs for personal care workers increasingly include soft skills, such as talking about death or managing stressful situations. Nurses often take on case-management tasks and have to manage complex care needs, including age-appropriate care for chronic diseases. Although nurses usually have higher education qualifications, they often do not pursue specialised training in geriatric care and may lack the necessary skills to deal with specific conditions such as dementia, osteoporosis or complex disease-management (OECD, 2020). Although the use of new technologies can support long-term care workers in their jobs, a lack of digital skills has been identified as one of the main barriers to the introduction of technology in the sector (Zigante, 2020). Skills gaps may exacerbate labour shortages and employers may struggle to find suitable workers in the already limited pool of candidates. On the other hand, more complex tasks and higher skills needs may make the profession more attractive and thus increase the demand for nursing education.

Qualifications of personal care workers are not always recognised in other Member States. The EU Directive on the recognition of professional qualifications[138] does not set out harmonised minimum training requirements for long-term care workers[139] (unlike in respect of other health professions[140]) that would allow for automatic recognition throughout the EU. For personal care workers, the general system of recognition applies, which is based on a comparison of training. When substantial differences can be established, the host Member State may require additional measures, such as an aptitude test or a supervised training period,

[137] Defined as personal care workers and nurses.

[138] *Directive 2005/36/EC of the European Parliament and of the Council of 7 September 2005 on the recognition of professional qualifications*. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32005L0036

[139] European Commission, *Single Market Scoreboard*, https://ec.europa.eu/internal_market/scoreboard/performance_per_policy_area/professional_qualifications/index_en.htm

[140] E.g. doctors, nurses responsible for general care, dental practitioners, pharmacists.

which can prolong the recognition process.[141] Recognition of long-term care workers' qualifications varies across the EU, which can be challenging given that a significant share of long-term care workers are foreign-born.

4.1.4 Working conditions and job attractiveness

A large majority of long-term care workers feel that their work is useful, but many are not satisfied with their working conditions. The long-term care sector compares favourably with other sectors when it comes to workers' assessment of the usefulness of their work. According to survey data from 2015 (Eurofound, 2020b), 71 % of long-term care workers always had the feeling that they were doing useful work.[142] However, only a below-average 22 % of long-term care workers stated that they were very satisfied with their working conditions.[143] Job-quality indices by sector based on survey indicators (see Figure 13) single out intensity,[144] monthly earnings, physical and social environment, and working-time quality as challenging compared with healthcare and other sectors. Earnings and the social environment, in particular, score lower in the long-term care sector, again compared with healthcare and other sectors.

Figure 13: Job-quality indices by sector, EU-27 and UK, 2015

The long-term care sector scores higher on job prospects and on skills and discretion, but worse on intensity, monthly earnings, physical and social environment, and working-time quality[145]

Source: Job-quality indices based on European working conditions survey data (EU-27 and UK, 2015). Analysis from Eurofound (2020b).

Non-standard working arrangements[146], as well as irregular working hours, are widespread among the long-term care workforce. As shown in Figure 13, long-term care

[141] European Commission, *Internal Market, Industry, Entrepreneurship and SMEs*, https://ec.europa.eu/growth/single-market/services/free-movement-professionals/qualifications-recognition/general-system_en
[142] Compared with 66 % in the healthcare sector and 52 % for the entire workforce.
[143] Compared with 26 % for the entire workforce.
[144] Long-term care scores more highly on intensity than services other than healthcare and non-service sectors.
[145] The plot shows scores relative to the mean in the overall workforce (z-scores).
[146] For this report, non-standard employment is understood as all forms of work other than full-time, open-ended employment in a subordinate and bilateral employment relationship.

workers score their working-time quality lower than workers in other sectors. Long-term care workers perform their work more commonly in the evening, at night or on weekends and are more exposed to shift work (especially in residential care), compared with other workers (Eurofound, 2020b).[147/148] In 2019, more than 40 % of long-term care workers worked part time across the EU-27,[149] compared with 26 % in the healthcare sector and an overall part-time employment rate of 19 % (Eurofound, 2020b).[150] In several Member States (AT, BE, NL, SE), more than half of long-term care workers worked part time. Although the possibility of working part time may enhance job attractiveness, support work-life balance, and be a bridge to full-time employment in the sector, a significant proportion of long-term care workers work part time first and foremost because they could not find a full-time job (30 % of part-time long-term care workers in homecare and 20 % in residential care work part time, compared with 24 % across all sectors) (Eurofound, 2020b).[151] Around one third of part-time workers in the long-term care sector would like to increase their contractual hours (Eurofound, 2020b). One reason for the high share of part-time work might be that employers only need to cover peak hours during the day (e.g. in the morning when most ADLs need to be carried out) (OECD, 2020). Atypical, irregular, and overlong working hours may contribute to making a career in long-term care unattractive for some.

Long-term care workers are better off with regards to job precariousness. In 2019, the share of permanent contracts among workers in the long-term care sector[152] in the EU-27 was 82 %, which was higher than in the healthcare sector in the EU-27[153] (74 %), and among all workers in the EU-27 (72 %) (Eurofound, 2020b). [154] Self-employment is relatively uncommon in the sector, at 1.9 % (Eurofound, 2020b)[155] compared with 14.2 % in the entire workforce. Self-employment is more common in non-residential long-term care (3.9 %) than in residential long-term care (1.1 %), and it is usually concentrated in subsectors (e.g. live-in carers in AT, homecare nurses and physiotherapists in BE, homecarers in CY) (Eurofound, 2020b). Although zero-hour contracts are common only in a few Member States (FI, SE), online platforms matching individuals in need of (mostly home-based) long-term care with care-providers, based on performing individual tasks rather than continuous employment, have emerged recently in most Member States (Eurofound, 2020b). The impact of these online platforms still needs to be further explored.

Many long-term care workers are exposed to adverse social behaviour. As many as 1 in 3 long-term care workers (33 %) have been exposed to some type of adverse social behaviour

[147] Long-term care (evening: 45 %; night: 20 %; Saturdays: 59 %; Sundays: 55 %); all workers (evening: 33 %; night: 13 %; Saturdays: 24 %; Sundays: 41 %); one-third (33 %) of long-term care workers are involved in shift work, more than in healthcare (28 %), and more than double the proportion in the entire workforce (15 %). Shift work is more common in residential long-term care (39 %) than in non-residential long-term care (20 %).
[148] LFS 2019.
[149] LFS. Data are based on ISCO 4 digit (3 digit for BG, DK, EL, ES, LV, PT) and NACE 2 digit.
[150] European Working Conditions Survey 2015.
[151] European Working Conditions Survey 2015.
[152] As defined by NACE 87 & 88.1.
[153] As defined by NACE 86.
[154] LFS.
[155] Compared with 14.2 % among the entire workforce.

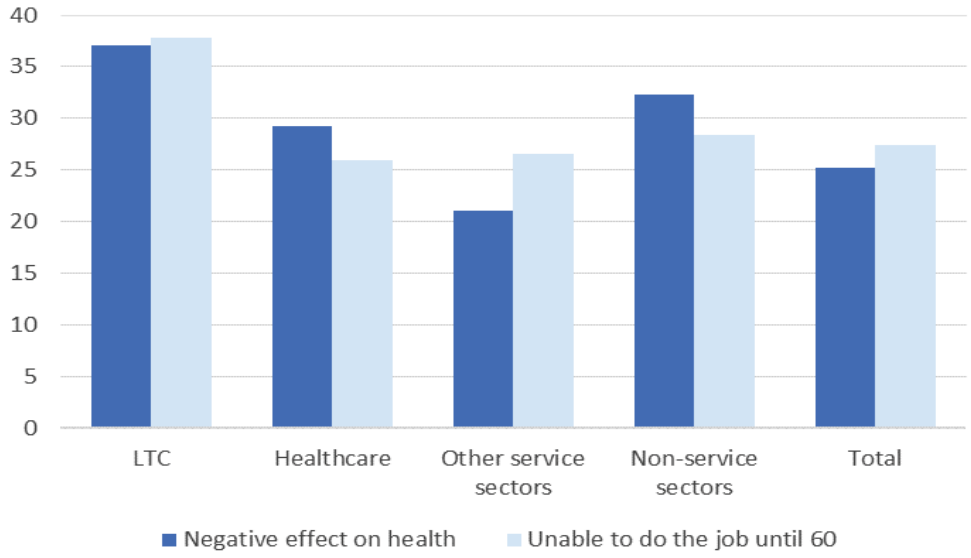
(including verbal abuse, unwanted sexual attention, threats, physical violence, humiliating behaviour, bullying, and sexual harassment) (Eurofound, 2020b). This is substantially higher than in the healthcare sector (23 %) and in the entire workforce (16 %). Adequate training, including in how to provide care for people with dementia, as well as aggression management and appropriate supervision, may help to mitigate the effects of adverse social behaviour (Eurofound, 2020b).

Challenging working conditions are reflected in the significant share of long-term care workers facing work-related health issues. In 2015, 37 % of long-term care workers thought that their job had a negative effect on their health, compared with 25 % among the entire workforce (Figure 14). This may partly reflect the challenging physical environment, where one risk factor that stands out is 'lifting and moving people', which 40 % of long-term care workers are doing more than three quarters of the time.[156] In addition, 23 % of long-term care workers handle, or are in direct contact with, materials that can be infectious, such as waste, bodily fluids or laboratory materials, at least three quarters of the time (Eurofound, 2020b).[157/158] According to data from 2015, long-term care workers also feel less well informed about their health and safety risks at work than healthcare workers (Eurofound, 2020b). These and other challenging working conditions in the long-term care sector have worrying consequences: as shown in Figure 14, 38 % of long-term care workers think they will not be able to continue doing their job until they are 60 years old (Eurofound, 2020b).[159 / 160] Furthermore, job tenure in the long-term care sector is two years lower than the overall workforce average (OECD, 2020). As discussed in Section 4.1.5, appropriate measures to support long-term care workers may contribute to improving their working conditions.

[156] Compared with 23 % in healthcare and 5 % in other sectors.
[157] Compared with 31 % in healthcare and 2 % in other sectors.
[158] European Working Conditions Survey 2015.
[159] Compared with 26 % in healthcare and 27 % among all sectors.
[160] European Working Conditions Survey 2015.

Figure 14: Job and health, EU-27 and UK, 2015

Workers in the long-term care sector experience more negative effects on health, and think it less likely that they could do the job until age of 60



Source: Analysis of European working conditions survey data for 2015 (Eurofound, 2020b).

Digitalisation and new technology can have both positive and negative impacts on working conditions for long-term care workers. The different challenges regarding the long-term care workforce and their working conditions may raise the question of the extent to which technological progress can help ease such health risks or more broadly improve working conditions. On the positive side, telecare and virtual interventions reduce travelling time, are usually shorter than on-site visits, and can be organised more flexibly (KL, 2017). The use of ICT for documentation can reduce the time spent on 'paper work', allowing carers to focus on core care tasks and thus contributing to better working conditions and a higher quality of care. Technology used to monitor patients can reduce the number of workers required during night shifts. Retention rates could be improved by applying technology that supports shift scheduling, effective work allocation, and targeting of users most in need (Zigante, 2020). Long-term care workers felt that when these technologies were introduced, their work was more effective. Care robots can also take over tasks that are physically demanding, such as lifting care recipients (Zigante, 2020). Online platforms matching individuals in need of (mostly home-based) long-term care with care-providers have the potential to facilitate matching supply and demand, when properly managed and if good working conditions are ensured.[161] On the other side, technology used to monitor the activities of long-term care workers raises questions concerning privacy and data protection (Zigante, 2020). The use of technology can also lead to a perceived dehumanisation of care work, leading to additional stress for care recipients[162] (see Chapter 0 for a discussion of the link between technology and quality of care). In order to make full use of the potential benefits of

[161] However, if not properly regulated the services offered through digital platforms can be exposed to undeclared work.
[162] Eurofound, 2020a.

technology for long-term care workers, it is essential to invest in digital skills development, adequate training (including information on the underlying rationale for using the technologies), and good integration into the organisational workflow (Zigante, 2020).

Despite the difficult working conditions, wages in the long-term care sector are relatively low. Only 43 % of long-term care workers have the perception that their earnings are appropriate for their work, compared with 47 % of workers in the healthcare sector and 51 % among the entire workforce (Eurofound, 2020b).[163] Despite efforts by Member States to improve wages,[164] average hourly earnings in the social services sector[165] in 2014 (Eurofound, 2020b)[166] were lower than the average across sectors in all Member States. In 24 of the 27 Member States,[167] average hourly earnings for social services were at least 10 % below national average earnings. They were also lower than average hourly earnings in the healthcare sector[168] in all Member States. In interpreting these data, it is important to take into account the different levels of qualifications and age profiles (regularly coinciding with experience), which may explain at least part of the difference (Eurofound, 2020b).[169] Even the relatively well paid professions[170] in the sector usually do not earn substantially more than the average salary in the country (Eurofound, 2020b). In a number of Member States, personal care workers only earn the minimum wage (OECD, 2020). Wage data often exclude parts of the workforce, in particular live-in carers (often working undeclared or as self-employed), whose salaries tend to be the lowest in the already low-paid long-term care sector (Eurofound, 2020b). Factors contributing to low wages in the sector – beyond the composition effects mentioned above – include a low share of long-term care workers covered by collective agreements, and only partial coverage of long-term care expenditure by public allowances in many Member States (unlike healthcare costs, which are usually fully covered) (OECD, 2020).

The extent to which social dialogue and collective agreements play a role in the long-term care sector differs across Member States. In many cases, long-term care workers are covered by collective agreements for the healthcare sector. In others, some of them may fall under agreements for public sector workers. In both cases, though not specific to long-term care workers, these agreements usually spell out specific conditions for workers in the long-term care sector. In only a small number of Member States are close to 100 % of formally employed long-term care workers covered by collective agreements (AT, BE, DK, ES, FR,

[163] European Working Conditions Survey 2015.

[164] Germany, for instance, has a minimum wage for the long-term care sector, which has increased over recent years and will reach EUR 2600 (gross) by 1 July 2021.

[165] Due to data limitations, the whole social services sector is considered for this analysis – that is, NACE 87 (residential long-term care sector) and NACE 88 (non-residential long-term care but also other social services, such as child daycare).

[166] LFS.

[167] Except for AT, NL, LU.

[168] As defined by NACE 86.

[169] For instance, the healthcare sector includes more medical doctors, who are usually better paid. Indeed, it has been argued that while, overall, the healthcare sector seems to pay better than the long-term care sector, part of this is probably explained by differences in the composition of the workforce. Only a few cases were identified where rules for pay (from collective agreements or public regulation) in the long-term care and healthcare sectors for the same professions and experience differ explicitly.

[170] Such as senior social workers, specialised nurses, and physio/speech/activity therapists.

LU, NL, SI); while in others collective bargaining is almost absent in the long-term care sector (CZ, EL, PL). In some Member States, collective bargaining is limited to (EE, LV), or more common in (DE, MT, SE), the public sector.

Although overall the prevalence of undeclared work in the long-term care sector seems to be limited, it could be substantial in some specific segments. In the case of undeclared work, the carer is in an undeclared employment relation with the care receiver and the work performed is not declared to social security authorities.[171] Although quantitative evidence on the actual size of undeclared work is limited, it seems that undeclared work in the long-term care sector is overall less common compared with other sectors, partly because it is often managed and provided by the public sector or registered social service providers.[172] However, undeclared work could be substantial in certain segments of the sector. For instance, Member States have reported home services (domestic work, cleaning, and personal services), which include homecare, as one of the five sectors among which undeclared work is most common (European Commission, 2016). Undeclared work is also relatively common among live-in carers (Eurofound, 2020b) (for more information on live-in carers, see Box 6). Undeclared work in the long-term care sector seems to be most common in Member States with incomes higher than the EU average, relatively low or unregulated/unconditional long-term care cash benefits, and a high share of live-in care, usually provided by foreign-born workers. Reasons for undeclared work in the sector include expensive declared care, inflexibility of homecare-providers regarding the format of care provided, or complex structures for registering live-in carers (Eurofound, 2020b).

Box 6: The situation of live-in carers

The reliance on live-in care[173] differs among Member States. *In some Member States live-in care is estimated to be relatively common (e.g. AT, CY, DE, EL, ES, IT, MT) (Eurofound, 2020b). In Austria, 60,000 live-in carers were registered in 2016, while in Spain there were an estimated 113,000 domestic care workers (including for childcare) in 2017, and in Italy it is estimated that there were about 160,000 declared live-in carers in 2018 (Eurofound, 2020b). In Germany, it is estimated that around 100,000 households with people in need of care engage live-in carers (Kantar, 2019). In some Member States with a low share of live-in carers, a growing trend towards this form of long-term care can be observed (NL, PL, SI) (Eurofound, 2020b). Overall, data on live-in carers are sparse and there are limitations in data availability. Data gaps may also reflect the potentially substantial share of undeclared work among live-in carers.*

Live-in carers are in many cases mobile or migrant care workers, partly reflecting

[171] There is sometimes a challenge in distinguishing between activities that are clearly fraudulent from those of volunteers or informal carers with very honest intentions.

[172] European Commission, *Special Eurobarometer 498 – Undeclared work in the European Union*, https://data.europa.eu/euodp/en/data/dataset/S2250_92_1_498_ENG#:~:text=Undeclared%20work%20is%20defined%20as,public%20finances%20and%20social%20cohesion.

[173] Live-in carers are paid professionals, with or without formal care training, whose work primarily involves long-term care provision while living in a private residence with the care receiver. They should be distinguished from informal carers, who provide care to someone in their family or social environment.

significant wage differentials between sending and receiving countries. *For instance, in Italy, 75 % of all live-in carers were foreign nationals in 2018, including from eastern Member States and third countries. In Spain, most live-in carers are from Latin America. In Austria and Germany, the vast majority of live-in carers come from eastern Member States (in particular from BG, PL, RO, SK) (Eurofound, 2020b). Due to high demand and low access barriers, live-in care could provide an entry point to the labour market in the host country for some migrant workers (Eurofound, 2020b). Migrant live-in carers may be particularly vulnerable in relation to immigration policies. They often do not file a complaint when their working rights are violated, as in many cases their residency permit is tied to one particular employer (Rogalewski and Florek, 2020).*

Live-in carers work under various employment arrangements, and face difficult working conditions*. Live-in carers are not always directly employed by the care recipient. In some Member States, live-in carers are predominantly self-employed (e.g. AT). In others, they are employed by an intermediary agency (e.g. DE). In Austria and Germany a specific pattern seems to be common, where two or more live-in carers usually alternate to work in interval periods of several weeks (Eurofound, 2020b). In Member States where live-in carers are usually from very distant countries, they tend to live more permanently with the care recipient (e.g. MT, PT). The existing evidence, mostly qualitative, points to several challenges that these carers face (Rogalewski and Florek, 2020). Due to the specific features of their work (living with the care recipient in the same household, working and or being on 'standby' 24/7 for several successive weeks), live-in carers may face social isolation and their employment situation may be in non-compliance with essential labour protection rules. The rights of live-in carers are often not enforced, for reasons including a lack of capacity in labour inspectorates, and limitations on entering and inspecting private households in certain Member States (ILO, 2015). The International Labour Organization (ILO) Convention No 189 on 'decent work for domestic workers'*[174] *is particularly relevant for live-in carers. It lays down rights and principles for domestic workers and requires states to take measures to enhance working conditions of domestic workers.*[175] ***Live-in carers may face low wages and unfavourable working-time arrangements.*** *Some live-in carers do not even receive the minimum wages that are in force in the Member State where they work (Eurofound, 2020b) (Rogalewski and Florek, 2020). Their remuneration conditions are not always clear-cut, as in-kind advantages (such as accommodation and food) may blur the picture. The time during which live-in carers are on stand-by is often excluded from their (paid) working time, even though it is working time according the rulings of the European Court of Justice.*[176] *Generally being in the weakest position of all the stakeholders involved, they are thus required to be available to work for more than the admissible maximum average working time of 48 hours per week, as set out in the Working Time Directive.*[177] *Under standard employment conditions, compliant with labour protection rules, 24/7 care at home would require at least four carers to be employed full time, which would drastically reduce the affordability of the service.*

[174] ILO, *C189 – Domestic Workers Convention,* https://www.ilo.org/dyn/normlex/en/f?p=NORMLEXPUB:12100:0::NO::P12100_ILO_CODE:C189

[175] So far, only seven EU Member States have ratified it (BE, DE, FI, IE, IT, PT, SE).

[176] Cf. e.g. CJEU rulings in C-303/98 (SIMAP, ECLI:EU:C:2000:528) and C-151/02 (Jaeger, ECLI:EU:C:2003:437).

[177] *Directive 2003/88/EC of the European Parliament and of the Council of 4 November 2003 concerning certain aspects of the organisation of working time*. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32003L0088

4.1.5 Measures to address labour shortages in the sector

Increasing the attractiveness of the sector is pursued through various measures. Recent policies[178] include: improving the quality of training (AT, DE, NL); easing the recognition of qualifications acquired in other Member States (AT, DE); validating skills acquired through non-formal and informal learning, and increasing the number of training places for prospective care worker (DE, DK); increasing the wages of care workers (CZ, DE, DK, LV); establishing image campaigns (DE, DK, NL, PT); promoting long-term care jobs among young people (DE, DK, PT); employing migrants and asylum-seekers (HR); providing financial subsidies to people who start education and training in care work (AT, DE); providing funding to finance additional jobs in the sector (DE, SE); and establishing official agreements with third countries to recruit care professionals (DE).

However, many Member States may need to step up their efforts to make the long-term care sector more attractive. One way is to attract a greater inflow of staff by: recruiting a more diverse workforce (including larger numbers of men, thereby tackling gender segregation); improving the image of the long-term care sector; and encouraging the professionalisation of informal carers. Information campaigns promoting the long-term care sector and care ambassador initiatives have proven to be useful in this regard (Eurofound, 2020b). Other measures include: initiatives to reduce legal and language barriers to accessing a profession (e.g. language training for mobile and migrant workers); validating the skills of informal carers or non-professional long-term care workers; and pro-active recruitment from sectors facing high unemployment. Improving carers' working conditions and health and safety at work, as well as promoting social dialogue in the sector, would also help. Although some working conditions (such as working in shifts, especially night shifts, lifting) are intrinsic to the job, they could be eased with more adequate numbers of staff, better working-time arrangements, and greater use of technology and training. Problems of adverse social behaviour could be countered by appropriate supervision, talks with colleagues and supervisors, and comprehensive aggression-management systems (Eurofound, 2020b). Undeclared work could be tackled by providing incentives to declare work (e.g. via voucher schemes, non-bureaucratic registration procedures) and proper regulation of digital platforms. Upgrading wages and benefits can help recruit professional carers, though this needs to be balanced against the sustainability, affordability, and availability challenges. Another way to improve job satisfaction among long-term care workers could be to clarify the tasks and responsibilities of nurses and personal care workers, and to provide nurses in particular with greater autonomy, leadership, and the possibility of delegating tasks to personal care workers. Effective regulation (including ratification of the ILO Convention 189 by all Member States) and its proper enforcement can help to professionalise the live-in care model and give workers greater protection where needed.

Investment in skills and new technologies will be key to improving the efficiency of the long-term care workforce. A renewed focus on the skills and qualifications of carers is needed to ensure a workforce equipped with the necessary skills in the future, including:

[178] According to country fiches of Volume II (see also Chapter 6 for more information on recent policy reforms).

minimum qualification standards; revisited curricula of initial education and training; on-the-job training and vocational training; and mandatory lifelong learning programmes. Although robots and new technologies will hardly replace long-term care workers completely, automation and digitalisation have the potential to enhance labour productivity in the sector, therefore requiring support for digital skills training. Recent research suggests that technology can take over certain tasks of long-term care workers and thus relieve them in their daily work, including lifting patients, electronic documentation, and remote monitoring of homecare recipients (Zigante, 2020). These possibilities will still have to be explored further. Overall, pursuing strategies that increase productivity in the long-term care sector contributes to efficient long-term care systems that are fair, adequate, and sustainable.

4.2 Informal carers

Informal carers carry out a large part of long-term care in the EU, with major implications for them, for the people they care for, and for society at large. Informal care is a key pillar of long-term care in most Member States, but it does not come without consequences or costs both for carers and care recipients as well as the long-term care sector in general. This section discusses the role of informal carers, and the impacts of informal care-giving on gender equality, labour market participation, and the health and well-being of the carers (Van der Ende et al., forthcoming).[179]

4.2.1 Characteristics of informal carers

Informal carers provide care to someone in their family or social environment. Such care may be provided, for instance, to a family member, friend or neighbour. The emotional relationship between the care receiver and care-provider has been identified as one of the most distinctive features of informal care.[180] Roughly half of informal care in the EU is provided to people outside the household. Women provide informal care more often and for longer hours per week than men[181] (Van der Ende et al., forthcoming). Half of informal care is provided to people aged 65 or over (Van der Ende et al., forthcoming). [182]/[183]

Although tasks are often similar to those of formal carers, informal carers are usually not in an employment relationship with the care receiver.[184] Like professional carers, informal carers support care recipients in their ADLs and IADLs.[185] However, they are not hired in a professional capacity. Informal care should furthermore not be confused with

[179] Much of the analysis in this section is based on the study: Van der Ende et al., forthcoming.
[180] Oliva-Moreno et al., 2017.
[181] Van der Ende et al., forthcoming.
[182] Ibid.
[183] EQLS (2016).
[184] In Luxembourg, there exists an easy procedure to put informal carers in an employment relationship, in order to guarantee them access to healthcare insurance; however, they continue to be treated like an informal carer by the long-term care insurance system.
[185] For this report, informal long-term care is defined as long-term care provided by someone from the care receiver's social environment (e.g. a family member, friend or neighbour). The provider is not hired as care professional.

undeclared work[186] (see Section 4.1). Generally, informal carers do not have professional training in caring, although training possibilities for informal carers exist in some Member States (BG, DE, FI, FR, IE, LU, MT, NL, PL, PT). Although some informal carers pursue training, especially for cases of severe care needs, the lack of professional training and qualifications of informal carers could lead to lower quality of care provision than formal care. On the other hand, the social bond between the informal carer and care recipient might enhance the quality of the care provided. More information on quality aspects in informal care can be found in Chapter 3. Although many informal carers may engage in caring activities voluntarily, in some Member States and situations, informal care may also be the only alternative due to the lack of availability or affordability of formal long-term care services (see also Chapter 2).

Most informal care is long-term. Data on the duration of informal care are scarce, but the available information indicates that if people provide informal care, they often do so over a longer time span. In Germany, about 90 % of the people receiving a nursing allowance (*Pflegegeld*) receive it for at least three months before dying and about 75 % for at least one year.[187/188] In France in 2016, the average duration of the 'personal autonomy benefit' was 3.5 years,[189] and in the Netherlands, the average duration of informal care was 4.5 years in 2016.[190]

A substantial number of Europeans provide informal care, especially in Member States where the provision of formal long-term care is low. It is estimated that 12-18 % of the EU population aged 18-75 provide informal long-term care at least once per week (Van der Ende et al., forthcoming). According to Eurofound (2020b), 44 million Europeans are frequent informal long- term care-givers.[191] The number of people providing informal care at least once per week as a percentage of all those aged 18-75 is highest in France (21 %), Latvia (18 %), Denmark (17 %), and Finland (16 %); and lowest in Portugal and Sweden (8 %), and Germany (6 %) (Van der Ende et al., forthcoming).[192] At the EU level, half of informal care is provided to people aged 65 or over (Van der Ende et al., forthcoming).[193] The use of solely informal care varies from 30-40 % (DK, IE)[194] to above 85 % in a number of eastern Member States (BG, EE, HR, LT, LV, PL, RO, SK) (Van der Ende et al., forthcoming).[195] With the

[186] Another common phenomenon of long-term care in certain Member States, where care work is a gainful activity that is not declared to social security authorities.
[187] Jacobs et al., 2017 (see Section 21.2.3, Figure 21.16). Note that only 38 % of the *Pflegegeld* is spent on informal care, according to Table 3.10 in Kantar (2019).
[188] Note that this 75 % applies to all informal care, not to the 90 % that is informal *long-term* care (lasting at least three consecutive months). As a percentage of informal long-term care, the 75 % corresponds to 83 % (= 75 % / 90 %).
[189] See https://drees.solidarites-sante.gouv.fr/IMG/pdf/infographie-apa.pdf.
[190] Based on the Informele Zorg (IZG) 2016 survey. https://www.scp.nl/over-scp/data-en-methoden/onderzoeksbeschrijvingen/informele-zorg-izg
[191] People aged 18+ who care more than twice a week for one or more family members, neighbours or friends, of any age, who are infirm or have a disability.
[192] Based on a combination of EHIS (wave 7, 2013-2015) and EQLS (2016).
[193] EQLS (2016).
[194] The relatively low rate of use of solely informal care in Denmark should be seen in the light of extensive and accessible public welfare services.
[195] Based on EHIS (wave 7, 2013-2015).

exception of Cyprus, Member States with fewer than 5 formal carers per 100 people aged 65 or over have more than 7 full-time equivalent informal carers per 100 people aged 65 or over.[196] At the other extreme, all Member States with more than 7 formal carers per 100 people aged 65 or over have fewer than 8 informal carers per 100 people aged 65 or over. This suggests that the incidence and intensity of informal care are negatively correlated with formal care provision.[197] In some Member States, an obligation to provide informal care to family members is enshrined in legislation.[198]

The majority of informal carers are women, which reinforces gender inequalities. On average in the EU, 59 % of all informal carers (age 18 or over) are women, ranging from 52 % (RO) to 65-66 % (CZ, LT, PL) (Van der Ende et al., forthcoming). In the 18-74 age group, 18 % of women provide informal care compared with 12 % of men (Van der Ende et al., forthcoming).[199] The difference between men and women is greatest in the 45-64 age group, where in most Member States 10-30 % of men and 20-40 % of women provide informal care (Figure 15). The gender difference in this age group is largest in Belgium and Spain (14 p.p., respectively). Most informal carers are middle-aged. 48 % of informal carers are aged 45-64, 33 % are 44 or under, and 22 % are 65 or over (Van der Ende et al., forthcoming).[200]

[196] Although formal carers do not always work full time either, it is more necessary to correct informal care for the intensity of care. It therefore makes sense to compare the sum of full-time equivalents (FTEs) of informal care-givers with people aged 65+ with formal care (also measured in FTEs).

[197] In addition to the lack of formal care provision, there may be also other reasons for the use of informal care, such as cultural or financial reasons.

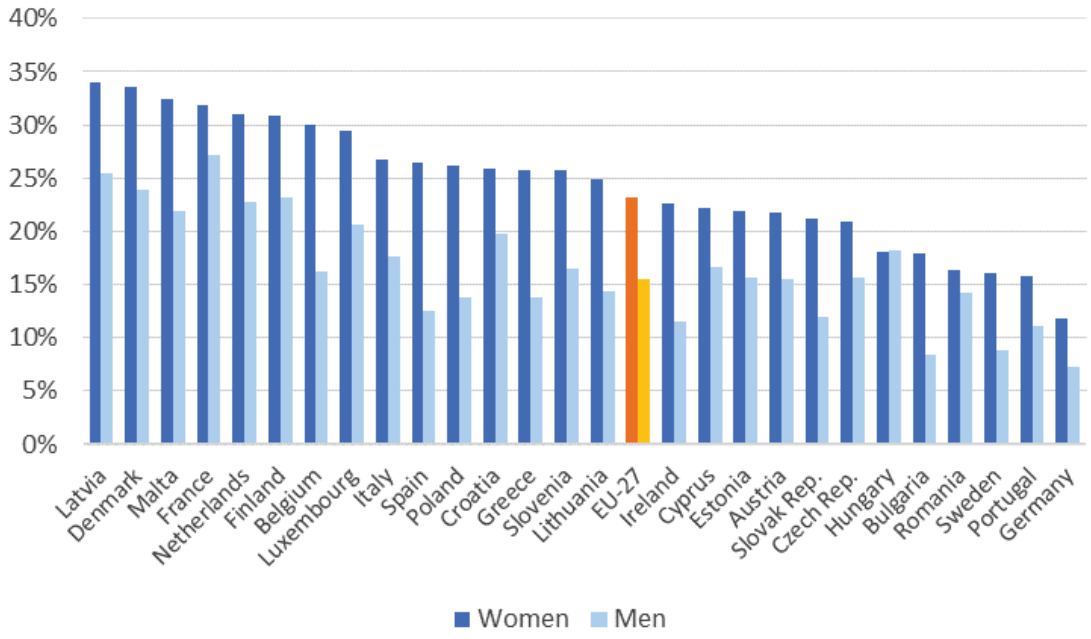
[198] According to the country fiches in Volume II of this report. In Hungary, there is an obligation for individuals to provide informal care to their family members or contribute to the expenses of their formal care. An obligation on children to provide care for their parents also exists in Latvia, while in Poland there is a legal maintenance obligation for adult children towards their parents in need of care and support. There is also a constitutional obligation in Lithuania on adult children to take care of their parents in old age. In some Member States (e.g. BE, PL), children have to pay the costs of residential care, if their parents cannot afford it themselves (and in the case of Belgium, if eligibility for means-tested support does not apply).

[199] Based on combined evidence from EQLS (2016) and EHIS (2013-2015).

[200] Based on EHIS wave 7 (2013-2015) and EQLS (2016).

Figure 15: Share of men and women aged 45-64 providing informal care, per Member State

The share of women aged 45-64 providing informal care is higher, in almost all Member States, than the share of men in the same age group



Source: EHIS, wave 7 (2013-2015) and EQLS (2016). Analysis in: Van der Ende et al. (forthcoming).

Women also provide more intense care than men. Women spend on average 17 hours per week on providing informal care compared with 14 hours for men (see Figure 16). The average hours of informal care are higher in mostly southern and eastern Member States, peaking at 28 for women in Spain, compared with 21 for men in that country.

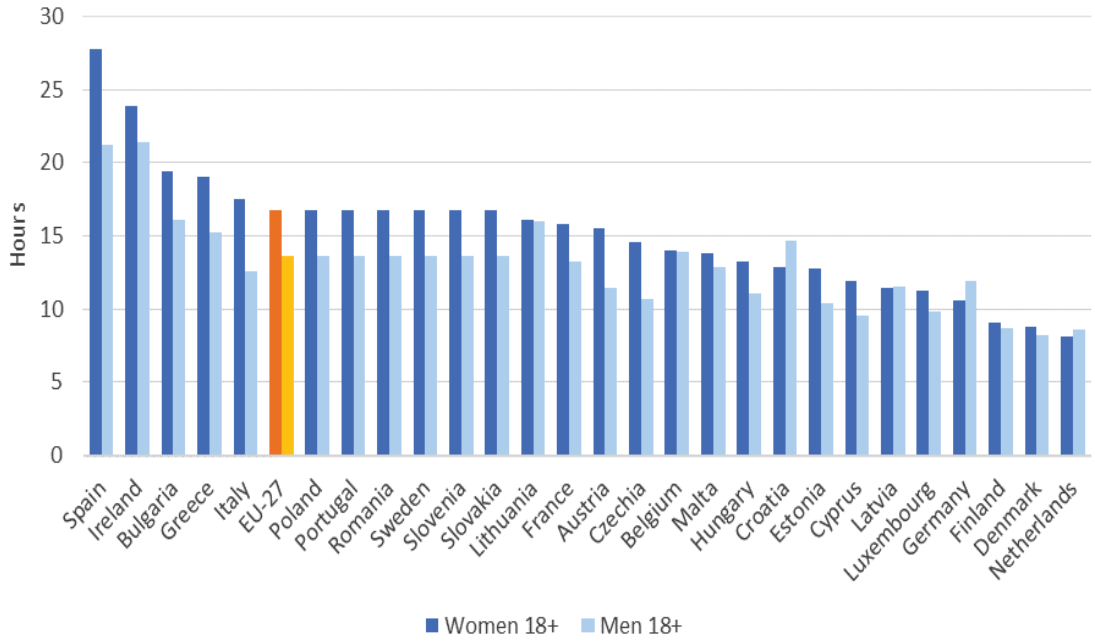
Although many informal carers provide few hours of care, potentially problematic high-intensity care is also prevalent, with women again dominating. On average in the EU, slightly more than half of those providing informal care do so for less than 10 hours per week, and in two Member States this holds for more than 8 out of 10 carers.[201] The analysis of intense care (more than 40 hours per week) is important as it has particularly strong impacts on the carer (e.g. with regards to health or the ability to combine work with caring activities; see below). Among women providing informal care, 12 % provide care for more than 40 hours per week, compared with 7 % for men (

[201] EQLS: 52 % and EHIS: 60 %. In Denmark and the Netherlands as many as around 85 per cent of informal carers do this for less than 10 hours per week according to both databases. Only in Spain do less than half of the informal carers provide care for less than 10 hours per week according to both databases (EQLS: 41 % and EHIS: 35 %).

Figure 17). Here again, the difference between men and women is largest in Spain,[202] followed by Portugal and Greece.[203] Within the working-age population (18-64), the intensity of informal care does not change much by age. However, men, and especially women, aged 65 or over provide substantially more intense informal care, with up to 41 hours per week on average for Spanish older women (Van der Ende et al., forthcoming). The high intensity of informal care past the retirement age is probably driven both by the dependency levels of family members (such as a partner) and by the time availability of the informal carer.

Figure 16: Average hours per week of informal care provision, men and women aged 18+

Women providing informal care spend on average three hours more on doing so than men

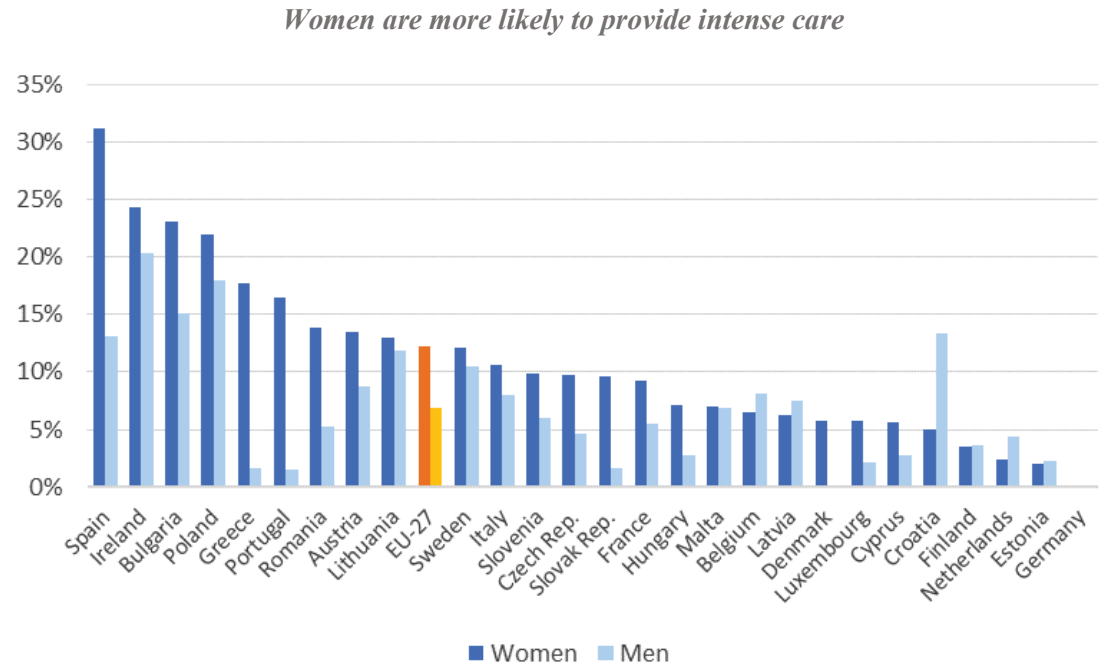


Note: Average hours per person who provides informal care.

Source: EHIS, wave 7 (2013-2015) and EQLS (2016). Analysis in: Van der Ende et al. (forthcoming).

[202] Among informal carers, 31 % of women spend more than 40 hours per week compared with 13 % of men.
[203] 16-18 % for women versus 2 % for men.

Figure 17: Share of informal carers providing more than 40 hours of care per week, men and women aged 18+



Note: In Germany reported hours are capped at 40.

Source: EHIS, wave 7 (2013-2015) and EQLS (2016). Analysis in: Van der Ende et al. (forthcoming).

Despite similar education levels,[204] **low-income earners are slightly over-represented among informal carers**[205]. At the EU level, 46 % of informal carers aged 20-64 live in a household with above-median income compared with 52 % of the general population in the same age bracket.[206] 30 % of informal carers have a household income in the bottom quarter of the income distribution, compared with 26 % of the general population aged 20-64 (Van der Ende et al., forthcoming). One possible reason for a higher incidence of informal care in low-income households is that formal care is too expensive. Another possible reason is that part-time workers and non-employed people, who are over-represented in low-income households, are more likely to start providing informal care. As discussed below, (previously) employed people providing intense informal care face a loss of income, as they cannot participate (fully) in the labour market. As a result, since formal care is rarely free (or fully insured), households face a trade-off between paying for formal care or providing informal care and thus facing an opportunity cost in the form of loss of income.

[204] At EU level, among both the general population aged 20-64 and informal carers in the same age group, 45 % have upper secondary educational level. Compared with the total population, a slightly lower share of informal carers have a lower educational level, while a slightly higher share have tertiary educational attainment. Based on EQLS (2016).

[205] Van der Ende et al., forthcoming.

[206] Based on EQLS (2016).

Box 7: Approximation of informal care within households with EU-SILC data

The EU-SILC ad hoc module of 2016 cannot be matched with longitudinal EU-SILC data*. The EU-SILC data are derived from an annual survey that comes in two versions: cross-section and a longitudinal. The cross-section data contain data of one year, with a core part consisting of questions that are asked every year, and an ad hoc module with additional questions about a certain theme. The core part does not include questions about the provision of informal care, but the 2016 ad hoc module on access to services (need and use) did. As a result, informal carers can be identified in EU-SILC data in 2016 only. Unfortunately, the respondents in the cross-section version cannot be matched with respondents in the longitudinal version, so the history of these informal carers before and after 2016 cannot be observed.*

In the longitudinal EU-SILC data, informal care provision is not observed, but adult household members' need for care can be used as a proxy under certain assumptions. *The longitudinal EU-SILC data follows interviewees for four years, which allows an analysis of what happened to interviewees one year earlier or later. The longitudinal questionnaire does not, however, include a question about informal care. The longitudinal data nevertheless still cover all adults (aged 16 or over) in a household and include a question about having difficulties with daily activities due to reasons of health or old age. Under the assumption that informal care is always provided to other adults in the household with strong limitations in daily activities due to health problems, the presence of a household member with strong health problems indicates an increased likelihood of informal care provision, although the match is not perfect,[207] thus leading to an over-estimation of informal care. By matching with longitudinal data of one year earlier or later, it is also possible to identify household members who needed care in the current year but not one year earlier or later. Informal care given to, for example, parents living in a different household is still unobserved, leading to an under-estimation of informal care. In practice, whenever longitudinal EU-SILC data are used in this report, it should be kept in mind that this only indirectly indicates in-house informal care. Since stronger effects are more likely for intense care, the apparent under-reporting of many informal carers providing less intense care in EU-SILC implies that using EU-SILC may result in over-estimating the average effects of informal care on health status and the likelihood of re-employment. The percentage of informal carers in the EU-SILC 2016 ad hoc module is much lower than in the EHIS/EQLS. To test an assumption that the EU-SILC in particular under-estimates 'light' informal care consisting of only help with household tasks (because other questions in EU-SILC already cover that), the employment rates of informal carers were compared between the EU-SILC 2016 ad hoc module and the EHIS/EQLS, with the idea that a lower employment rate indicates the exclusion of less-intense informal care. The EU-SILC employment rates were indeed lower, such that effects for informal carers providing less-intense care may indeed be over-estimated. Even though they are the only source to compare developments over time between informal carers and other people at EU level, the longitudinal EU-SILC data have proven*

[207] Of course, this likelihood, that someone living with an adult with significant health limitations actually provides informal care, is not 100 % (otherwise there would be no formal homecare); but it is 29 % according to the EU-SILC 2016 ad hoc module, as opposed to 3.3 % of the population aged 18+ providing care to household members (according to the same module). This likelihood is further increased to 34 % by selecting people not in employment or working at most 16 hours per week.

to be very illuminating.

The majority of working-age informal carers combine caring with paid work, but the employment rate decreases with the intensity of care provided. At the EU level, two thirds (64 %) of informal carers of working age (18-64) are employed (Van der Ende et al., forthcoming).[208] This is slightly less than the 67 % employment rate in the total working-age population.[209] The employment rate of low-intensity carers (less than 10 hours of informal care per week) of working age (71 % at the EU level) is higher than for the total working-age population in all Member States (67 %). However, the employment rate decreases with the intensity of informal care, ranging from 71 % (less than 10 hours per week), to 63 % (10-19 hours), 57 % (20-39 hours), and 35 % (40 or more hours) at EU level. Complementary research finds a link with the provision of formal care, namely that in Member States where formal long-term care is least available, the employment rate among frequent carers is 10 p.p. below that of other people. In Member States where formal long-term care is most commonly used, this employment gap is just 3 p.p. (Eurofound, 2019a) When it comes to finding jobs, among people aged 18-64 providing informal care to household members, 21 % of those who searched for work were employed one year later, compared with 24 % for inactive people in general aged 18-64 searching for work (excluding people with a disability) (Van der Ende et al., forthcoming).[210]

Women providing intense informal care and older women providing informal care, regardless of the intensity, are less often employed, resulting in gender inequalities. For younger adults, the provision of informal care is often of short duration and does not affect employment much. However, women aged 18-44 who provide very intense care (40 or more hours per week) work significantly fewer hours per week on average: 29 compared with 38 for women aged 18-44 in the total employed population. When looking at older age groups, among women aged 45-64, the employment rate of informal carers at EU level is 6 p.p. lower than in the general population of women in that age group (Van der Ende et al., forthcoming). Only in two Member States (BE, DK) is the employment rate of women aged 45-64 providing informal care noticeably above the general employment level of women in the same age group. This supports the hypothesis that women aged 45-64 who are informal carers are less often employed than other women in the same age group. [211] When comparing the employment levels of informal carers before and after an adult in the household became dependent on care,[212] analysis shows that around half of the women aged 45-64 had already

[208] Based on combined evidence from EQLS (2016), EHIS (2013-2015) for informal carers, and LFS (2015) for the general population aged 15-74.

[209] The employment gap is particularly pronounced in Ireland (26 p.p.), Malta (17 p.p.), and Greece (13 p.p.).

[210] Based on combined evidence from EQLS (2016) and EHIS (2013-2015).

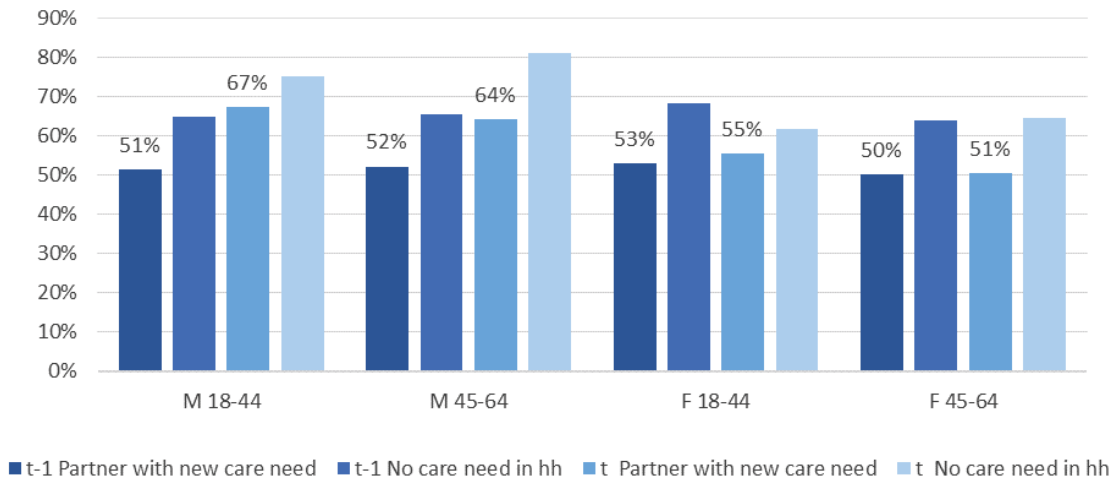
[211] Although a regression with 27 data points (one per Member State) does not indicate a significant relation, a Pearson chi-squared test on 25,000 individual responses of women aged 45-64 indicates a statistically significant difference with a p-value of 0.0004.

[212] The general EU-SILC (2010-2017 data used) offers the indirect possibility of focusing on people providing informal care to other adults in the household. Here, a 'treatment' group can be defined where in the preceding (interview) year people lived with adults without health limitations and in the current (interview) year lived with an adult with health limitations. The

been inactive before becoming an informal carer (see also Figure 18 and Box 7 for methodological explanations). The employment rate was not lower after the partner needed care for the first time than before. For men, on the other hand, the employment levels actually increased once they started providing informal care. This could indicate that women often go from one caring activity to the other, starting with childcare and moving on to care for parents and partners, or even engage in several caring activities at the same time. Another reason why women aged 45-64 who are informal carers participated less in the labour market could be that they provide more intense care. Already existing gender inequalities, such as women often earning less than their partners, might contribute to women dropping out of the labour market to pursue care responsibilities. Overall, informal care-giving and unequal sharing of caring responsibilities between women and men over the life course reinforce and perpetuate gender inequalities, as women participate less in the labour market, contributing to the gender pay gap and gender pension gap.[213]

Figure 18: Employment rate before and after another household member had significant problems for the first time with daily activities due to health, compared with others not living in a household with care needs, by gender and age

Although for men the employment level increases once they provide informal care, around half of the women aged 45-64 were already inactive before becoming an informal carer and continue to be inactive once they provide care



Source: EU-SILC, longitudinal 2010-2017. Analysis in: Van der Ende et al. (forthcoming).

Informal care is also associated with higher rates of part-time work and slightly fewer hours worked. At EU level, 65 % of employed informal carers aged 18-64 work full time, compared with 75 % of all employed people (Van der Ende et al., forthcoming).[214] 77 % of employed men providing informal care work full time compared with 51 % of employed

'control' group is similar, but in the current year no adult household member had health limitations. The 'treatment' group is probably highly correlated with the start of informal care provision to an adult household member ('partner' for short).

[213] Survey evidence from Germany also suggests that problems in reconciling caring responsibilities and paid work often result in the early retirement of women. See: Fischer and Müller, 2020.

[214] Based on EQLS (2016).

women providing informal care (Van der Ende et al., forthcoming). 30 % of employed informal carers work in part-time jobs of 20-36 hours per week, compared with 23 % of all employed people. 7 % of employed informal carers work less than 20 hours per week compared with 4 % of all employed people (Van der Ende et al., forthcoming). The difference in full-time work is largest in Belgium and Germany (Van der Ende et al., forthcoming), where just over 50 % of informal carers aged 18-64 work at least 37 hours per week compared with 70 % in the total working-age population. Even though informal carers on average work part time more often, the difference in the average numbers of working hours between employed informal carers and the general working population is limited at EU level: 39.5 hours on average among employed informal carers compared with 40.6 hours in the total employed population aged 18-64. Although intense carers work less often than others, if they do so it is for similar working hours per week (39.2 hours).[215] Only among women aged 18-44 do intense carers in employment work significantly fewer hours per week at the EU level: 29.2 compared with 37.7 among the total population of employed women aged 18-44.[216]

4.2.2 Impact of providing informal care on the carers' income, health, and well-being

Informal care can have major implications for care-providers. As discussed above, providing (especially intense) informal care may make it difficult for informal carers to reconcile caring with paid work. Reducing their labour market participation has an immediate effect on their current income, but can also have long-term impacts on their old-age income via reduced accrual of pension rights and savings (European Commission and SPC, forthcoming). At the same time, caring responsibilities may have adverse effects on informal carers' health and well-being, as they may be subject to the same kind of risks as formal workers (heavy lifting, stress etc.), but potentially with fewer support measures in place. However, it is difficult to determine the causal effects of providing informal care, mainly due to a lack of data, self-selection (for instance people with bad health may be less likely to provide care to others), and the (often long) duration of informal care (and hence the lack of transitions into and out of informal care provision to analyse pre-existing conditions and persistence of health effects).

Women aged 45-64 who stop working while they provide informal care face a significant average loss in wage income. As shown above, women in the 45-64 age group who provide informal care more often provide intense care, and are less often employed than other women in the same age group. They therefore face an income loss, which is direct (reduced/lost wages while providing informal care), and indirect (a potential difficulty in finding work after the care break, as well as reduced future pensions). The direct wage loss is estimated to

[215] The number of intense carers is too small to affect the overall average number of working hours much. It is also too small to allow comparisons between Member States.

[216] A study also found that (at age 50-70) informal care-giving at low intensity does not significantly affect the probability of being employed or the hours of paid work; but the negative effects of intense care are much stronger for women than for men (see: Ciccarelli and Van Soest, 2018). Another study found (for informal carers aged 50-70) no effect on hours worked, and a negative effect for women on employment in some Member States (see: Heger, 2014). The employment gap is 14 % for people aged 50-70 providing care for their parents, according to: Kolodziej et al., 2018. Care-givers are equally likely to be employed but are more often employed part time in Sweden, according to Stanfors et al., 2019.

amount to[217] EUR 25,800 in gross terms and EUR 17,900 in net terms on average (Van der Ende et al., forthcoming).[218] Men and younger women are less likely to provide intense informal care (more than 40 hours per week) than women aged 45-64. However, if they do and drop out of work, their gross income loss is estimated to amount to EUR 27,000 (men aged 45-64), EUR 23,200 (women aged 18-44), and EUR 30,700 (men aged 18-44).

Women aged 18-44 who provide intense informal care, but continue to work, lose 20-25 % of their income due to reduced working hours. Women aged 18-44 providing intense informal care not only work less often; if they are employed, they work on average eight hours per week less. The loss in associated wage income is 20-25 % for all Member States.[219] It should be further noted that the number of intense informal carers who are employed is too small to affect the overall average number of working hours (for further analysis regarding the cost of care, see also Chapter 5).

Most Member States grant pension credits to informal carers, resulting in a moderately lower pension than with an uninterrupted career. The 2021 Pension Adequacy Report (European Commission and SPC, 2021) provides an analysis of income maintenance after specific career pathways, based on the calculation of theoretical replacement rates.[220] Among other cases, the report models a case where someone worked uninterruptedly for 30 years, left the job for three years to care for a family member, then returned to work for seven years, before retiring in 2019. In most Member States, the period of inactivity due to care provision is (partly) compensated for by the pension system, and the person receives a pension which is not more than 5 % lower than with an uninterrupted career; in some Member States the difference is very small. This implies a less-than-proportional reduction in pension income, as a break of three years corresponds to a reduction in career length of about 8 %.

Informal care can have a negative impact on the health of carers. Data comparing the health status of informal carers with the general population point to a slightly less favourable situation for this group.[221] However, only changes in health status over time can show whether providing informal care has a detrimental effect on the health of the care-provider.

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[217] For an analysis of the (direct) wage loss, wages and applicable tax and social security contributions rates were determined for women aged 45-64 per main occupation (ISCO 1-digit occupations) and per Member State. Limited to organisations with at least 10 workers due to data limitations. Wage levels are not observed in the EHIS and EQLS, so we cannot simply use the observed wages of informal carers. This analysis takes account of the wage distribution for gender and age categories, but does not take account of other differences, for example by educational level. However, as noted earlier, in the working-age population the educational level of informal carers is similar to that of the total population. The gross and net annual wages were weighted per Member State with headcount shares of women aged 45-64 working in those main occupations.

[218] This is the average wage per person (across full-time and part-time employed informal carers), not the full-time wage.

[219] Only in the Netherlands, where about 75 % of employed women across all ages work part time, would a reduction of eight work hours per week result in a larger gross wage loss (30 %). However, people who already work part time may have less need to reduce working hours even further, so the 30 % loss of income probably applies to fewer intense carers in the Netherlands.

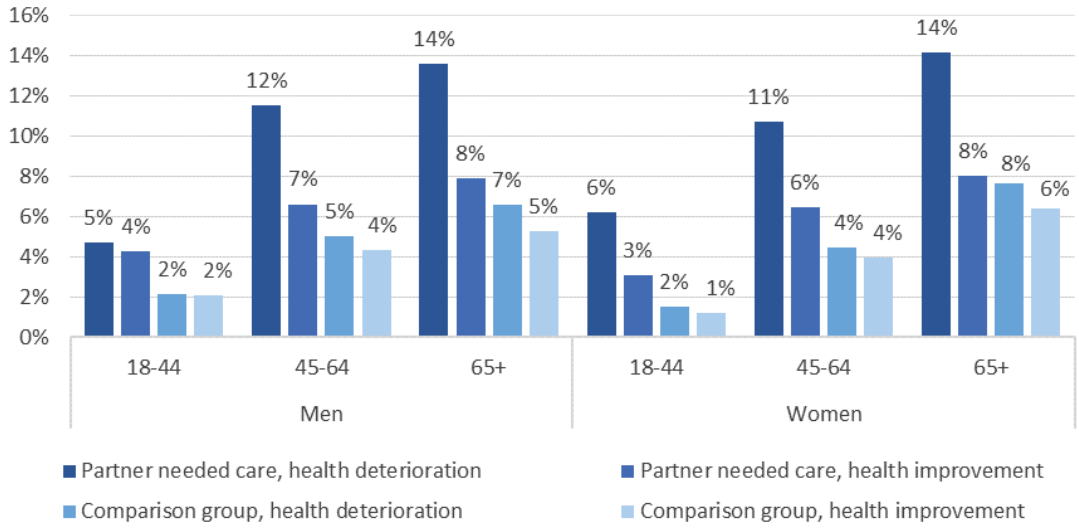
[220] The percentage of their last work income, as an employee in the private sector, a pensioner will receive in the first year of retirement.

[221] At the EU level, 70 % of informal carers aged 18-64 report good or very good health, compared with 76 % in the general working-age population. Informal carers on average are less likely to have health problems (5 %) than non-employed people of working age (where 9 % report bad or very bad health), but more likely than employed people (where 3 % report bad or very bad health).

Except for men aged 18-44, the balance of health changes in consecutive interviews (health improvement minus health deterioration) is more negative for informal carers than for the comparison group[222] according to EU-SILC data.[223] The negative balance is strongest for people providing informal care beyond the age of 65 (Figure 19 and Box 7 for methodological explanations).

Figure 19: Share of people whose health changed to or from bad/very bad: informal carers and comparison group comprised of people who are retired, fulfil domestic tasks or care, or work at most 16 hours per week

Health is more likely to deteriorate if living with an adult who has significant problems with daily activities due to health



Note: The graph shows the share of people whose health changed to or from bad/very bad. Given that the 5 % of informal carers with bad or very bad health is less than the 9 % of non-employed people (including people with a disability) and more than the 3 % among employed people (including full-time workers), a comparison group was created by excluding people with a disability (and students) and people working more than 16 hours per week. Specifically, the control group consists of people with self-reported economic status is retired, 'fulfilling domestic tasks and care responsibilities' or 'other inactive person', as well as those with self-reported part-time work status (as employee or self-employed) and working at most 16 hours per week.

Source: EU-SILC, longitudinal version 2010-2017. Analysis in: Van der Ende et al. (forthcoming).

People providing informal care find what they do in life slightly more worthwhile than the average population, but lack of time and freedom affect their quality of life. 79 % of informal carers in the EU agree or strongly agree that what they do in life is worthwhile, compared with 77 % in the total adult population (Van der Ende et al., forthcoming).[224] Informal carers feel slightly less often that they are free to decide how to live their life and

[222] The control group consists of people whose self-reported economic status is retired, 'fulfilling domestic tasks and care responsibilities' or 'other inactive person', as well as those with self-reported part-time work status (as employee or self-employed) and working at most 16 hours per week.

[223] With longitudinal EU-SILC data (see Box 6), it is possible to analyse the self-reported health status of people between their first interview and their second interview one year later.

[224] Based on EQLS (2016).

that they have some time to really enjoy life, compared with the total adult population.[225] Overall, 82 % of informal carers would rate their happiness a 6 or higher on a scale from 1 to 10, compared with 84 % of the total adult population (Van der Ende et al., forthcoming).[226]

4.2.3 Support to informal carers[227]

Several Member States have introduced financial benefits for informal carers. Nine Member States provide a benefit to informal carers (BE, BG, EE, FI, HU, IE, MT, PL, SK); and 11 provide a benefit to care receivers, who can use it for 'buying' either formal or informal care (AT, CZ, DE, ES, FI, FR, LU, MT, NL, PL, SI).[228] Nevertheless, a large proportion of informal carers still provide care without receiving any monetary remuneration. In some Member States, there is limited control over the purpose for long-term care benefits are used, and they might thus not support the informal carer (e.g. AT). Conditions for the receipt of dedicated benefits differ. For example, in Malta informal care-providers only receive an allowance if they provide full-time care. In Slovakia only informal carers providing care to someone with severe care needs receive cash benefits. In Germany, people needing care may choose to receive a nursing allowance instead of benefits in kind. They get advice about the type of care they need and are free to combine informal and formal care services (Van der Ende et al., forthcoming).[229] In Luxembourg, in order to get cash benefits, an evaluation of the informal carer is done in order to guarantee that the informal carer is able to provide the care needed.

A range of other support measures for informal carers exists, with large differences across the EU. They include counselling measures, such as: hotlines, online platforms or one-stop shops (AT, DE, FR, NL, PT); respite care centres to temporarily relieve informal carers from their caring responsibilities (BE, CY, DE, DK, FI, FR, LT, LU, MT, NL, PL, PT, SE, SK); days off from caring (AT, DE, FI, IT, LU, SK); training possibilities (BG, DE, FI, FR, IE, LU, MT, NL, PL, PT, SI); provision of social security, including pension rights and/or health insurance (DE, ES, FI, LU, NL, PL); municipal benefits, such as parking permits (NL); tax deductions (NL); psychological support (PT); and better collaboration between professional and informal care (PT). In Sweden, municipalities offer support to informal carers with the aim of reducing the burden on them (Socialstyrelsen, 2014). Since the entry into force of the Directive on work-life balance for parents and carers[230] in 2019, Member

[225] With 73 % (75 %) and 39 % (43 %) of informal carers (the total adult population) doing so, respectively. In the second case, the statement was: 'In my daily life, I seldom have time to do the things I really enjoy', and 39 % and 43 % disagree or strongly disagree.

[226] Based on EQLS (2016).

[227] This section is largely based on information available in the country fiches of Volume II of this report, as well as input from Member States' delegates to the SPC working group on long-term care.

[228] Mutual information system on social protection (MISSOC), *Comparative tables*, https://www.missoc.org/missoc-database/comparative-tables/

[229] In Germany, however, if someone chooses to receive combined benefits (meaning that care is provided to a certain extent by informal care-givers and to a certain extent by professional long-term care service providers), the nursing allowance decreases in proportion to the extent to which the ambulatory long-term care benefits in kind are received.

[230] Directive (EU) 2019/1158 of the European Parliament and of the Council of 20 June 2019 on work-life balance for parents and carers and repealing Council Directive 2010/18/EU. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32019L1158

States have three years to adopt the mandatory measures, including a carer's leave of five working days per year and an informal carer's right to request flexible working arrangements for caring purposes.[231]

However, informal carers need better support. Support for informal carers is underdeveloped (mentioned in country fiches for CZ, EL, HU, LT, RO, SI) or lacks a systemic approach (DK, ES, IT). In some Member States, the conditions for receiving care allowances are very stringent (see above). Counselling and training possibilities as well as support to improve the health and safety of informal carers, including psychological support, need to be stepped up. Recognition of skills qualifications may help informal carers to enter the labour market after the end of their care activities, by choosing a career in the formal care sector. There is often no adequate provision of respite care. In some Member States, informal carers need better social protection coverage. Technology could help informal carers in their duties, for example by using mainstream technologies, such as remote monitoring devices, but also other technologies specifically developed for informal carers, such as 'ambient assisted living' (AAL) technologies or assistive technology devices, such as electronic medication dispensers and motion detectors. However, in some cases there might be a need to address a lack of digital skills or a mistrust of new technologies, as well as the focus of assistive technology on an individual- or person-centred model of care rather than family-centred models (Zigante, 2020).[232]

Measures to better support informal carers must go hand in hand with measures to reinforce formal care. Eventually, informal care-giving should become a choice rather than a necessity. Enhanced provision of formal long-term care could relieve the pressure on informal carers, often women, some of whom provide informal care due to a lack of formal care provision, and not entirely voluntarily. Investing in formal long-term care could thus contribute to improving gender equality.

4.3 Conclusion

Member States face several common challenges in their efforts to ensure an adequate long-term care workforce, in terms of numbers and skills. The sector has a potential for job creation, but many Member States already struggle to fill vacancies. The sector employs 6.4 million people and it has been estimated that there will be up to 7 million new job openings for health associate professionals and personal care workers between 2018 and 2030. The number of long-term care workers per 100 people aged 65 or over declined on average in the EU from 4.2 in 2011 to 3.8 in 2016. Furthermore, the number of long-term care workers relative to the older population varies greatly across Member States, ranging from 0.1 to 12.4 (per 100) in 2016. Labour shortages are likely to worsen in the future, as the demand for long-term care grows, while the working-age population shrinks due to population ageing. Important drivers of labour shortages are also difficult working conditions and low salaries. 1 in 3 long-term care workers have been exposed to some type of adverse social behaviour,

[231] Going beyond the right to request, in 2015 Germany introduced a legal claim to partial release from work for up to 24 months.

[232] Sriram, 2019.

while close to 4 in 10 long-term care workers think they will not be able to continue doing their job until they are 60 years old. In 2014, average hourly earnings in the social services sector were lower than in the healthcare sector or the average across sectors in all Member States. Long-term care often involves complex tasks, but not all workers have the necessary skills. Strategies to improve the attractiveness and productivity of the sector, including via investment in technology, skills, and protection of the workforce, are therefore important.

A large part of long-term care is provided by informal carers, who face their own challenges and need to be supported. It is estimated that 12-18 % of the EU population aged 18-75 provide informal long-term care. Half of informal care is provided to people aged 65 or over. The use of solely informal care varies from 30 to 85 % among the Member States. Informal care is more common in Member States where formal care is underdeveloped. Informal carers struggle to balance caring with paid work (especially women who provide intense care), and face negative impacts of caring on their income, future pensions, health, and well-being. Most informal carers of working age combine their caring responsibility with paid work. However, their employment rate decreases with the intensity of care provided, and many informal carers who are employed work part time. Some support measures for informal carers exist, but in many Member States they need to be further developed. Most importantly, investment in formal long-term care systems could help to reduce the care burden on informal carers, thus improving their well-being and allowing those of working age to increase their labour market participation, which is crucial in the context of the shrinking working-age population.

The long-term care workforce, both formal and informal, has a strong gender dimension, as most carers are women. Almost 90 % of the long-term care workforce are women. They are exposed to difficult working conditions and often low pay in formal care, while informal care-giving makes their full participation in the labour market difficult, which contributes to gender gaps in pay and pensions. Addressing the challenges of the long-term care workforce would, therefore, also help to address gender inequalities. Not only do women provide informal care more often than men do, but they also provide more intense care. Most informal carers are working at the same time. However, employment among women aged 45-64, a key group of care-givers, is significantly lower than average (6 p.p. below that of peers without caring responsibilities). Informal carers face negative impacts of caring on their income, future pensions, health, and well-being. Some support measures for informal cares exist, but in many Member States support for informal carers may need to be further developed. Most importantly, investment in formal long-term care systems would also reduce the burden on informal carers.

Given common challenges across the EU, mutual learning and common solutions could help ensure an adequate and resilient long-term care workforce. Mutual learning opportunities arise, in particular, regarding policies to improve the situation of formal and informal carers. Implementing the European skills agenda would also help secure a pool of skilled professionals in the long-term care sector. A common definition of formal carers' profiles, and easing the process for recognising qualifications for professionals in the sector, could help support the free movement of care workers. Supporting sectoral social dialogue at the EU level could contribute to improving working conditions and wages in the sector.

Knowledge-pooling at the EU level would also be beneficial, as a number of common areas of concern need to be further investigated, in particular information on the job creation potential in the sector, better information on informal carers and the situation of live-in carers.

5 LONG-TERM CARE FROM AN EXPENDITURE, FINANCING, AND SUSTAINABILITY PERSPECTIVE

Public spending on long-term care is projected as the fastest rising social public expenditure item compared to healthcare and pensions on average across the EU-27.[233] In order to sustain long-term care spending in the future, many Member States face the challenge of developing sustainable financing systems for long-term care. Although some Member States have a distinct social security branch for long-term care, in many others long-term care for older people is typically funded from different sources and organised at different levels. It is also often financed very differently from other social protection branches and provisions.

This chapter will look at long-term care expenditure, the costs of informal care, financing models, and how to make long-term care more efficient. The chapter will illustrate the current and projected levels of public long-term care expenditure (Section 5.1), before exploring the advantages and drawbacks of possible long-term care financing models. The focus will be on social insurance and tax-based long-term care financing, including hybrid approaches (Section 5.2). It will then highlight the – often neglected – budgetary cost associated with informal care (Section 5.3), and will discuss the role of technologies and prevention to help to reduce the need for long-term care and thus make the provision of long-term care more efficient and sustainable (Section 5.4).

5.1 Expenditure on long-term care

The level of expenditure on long-term care in relation to GDP is highly differentiated in the EU-27. According to the System of Health Accounts (SHA), the current estimated total spending on long-term care[234] as a share of GDP in 2018 ranged from 3.9 % in the Netherlands, 2.1 % in Germany, and 0.9 % in Italy (please note that for Italy this does not include social care expenditure) and Portugal, to 0.01 % in Bulgaria (Figure 20). A detailed analysis of long-term care expenditure is, however, limited by the comparability, completeness, and consistency of the available data.[235] The SHA is the only comprehensive annual data source on long-term care expenditure at the European level. However, while all Member States report data for the health component, only half of them do so for the social component[236] (see Figure 20). The expenditure quoted above and Figure 20 is therefore incomplete as it assumes that expenditure on the social component equals zero for those Member States where it is not reported. As regards public expenditure on long-term care, the triannual Ageing Reports prepared by the European Commission and the Economic Policy

[233] European Commission, 2018.

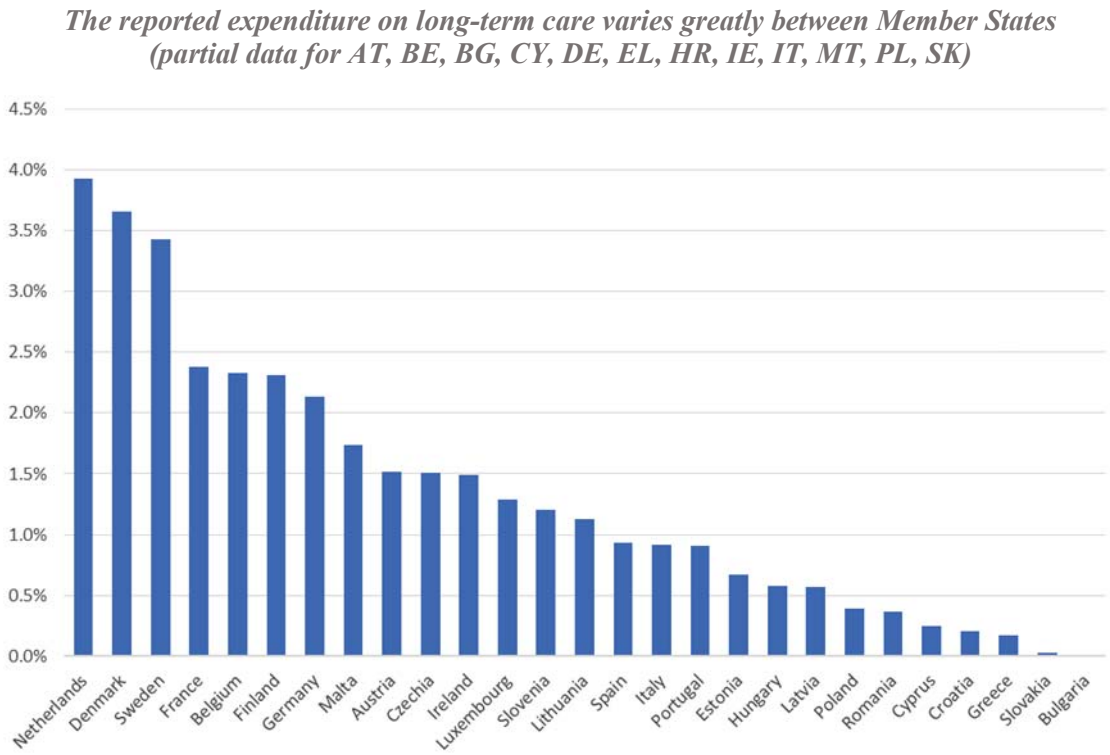
[234] Total spending includes: government and compulsory contributory healthcare-financing schemes; voluntary healthcare-payment schemes; household out-of-pocket payments; and rest of the world financing schemes (non-resident).

[235] Comparability issues still exist regarding the expenditure data on long-term care within the framework of the SHA. All conclusions should therefore be treated with caution. More information can be found in OECD, 2020b.

[236] The SHA 2011 is a statistical reference giving a comprehensive description of the financial flows in healthcare and long-term care. It provides a set of revised classifications of healthcare functions, providers of healthcare goods and services, and financing schemes. The SHA is currently used as a basis for joint data collection by OECD, Eurostat, and WHO on healthcare expenditure.

Committee provide recent data and corresponding projections for Member States. Member States provided some public expenditure data on social long-term care, which are not included in the SHA, directly for the reports. The public expenditure recorded in the EU Ageing Reports will therefore differ significantly from, and will in many cases exceed, the incomplete expenditure recorded in the SHA.

Figure 20: Reported long-term care expenditure as % of GDP



Source: Eurostat, SHA 2018, hlth_sha11_hchf.

Note: Data for the social component of long-term care were not reported in the SHA for AT, BE, BG, CY, DE, EL, HR, IE, IT, MT, PL, SK. For Member States listed above the data presented include only the health component of long-term care, and therefore the total expenditure on long-term care in most of these Member States can be assumed to be higher than presented, in some cases substantially so.

The ageing-related increase in demand for long-term care over the next decades will put upward pressure on public long-term care expenditure. Figure 21 shows the current (2019) public spending on long-term care as a share of GDP and corresponding projections for 2030 and 2050 based on the latest EU Ageing Report (European Commission and EPC, 2021). Out of total current public long-term care expenditure in the EU-27 in 2019, 26 % went on cash benefits, 26 % on homecare, and 48 % on residential care, with marked variations from these averages across the Member States (EU Ageing Report, see data tables in Volume II). Typically, the average cost of residential care per person is higher, but that is also influenced by the fact that the population concerned has a greater degree of dependency. One key element to manage the upward pressure in expenditure is to provide long-term care in the most cost-effective setting, which depends on the specific needs of the care recipient, while also taking into account their preferences.

Figure 21: Public spending on long-term care as % of GDP, current and projections

Public long-term care expenditure is projected to increase significantly across the EU-27

Source: 2021 Ageing Report (European Commission and EPC, 2021); base data for 2019.

Note: Member States ordered according to the 2050 reference scenario. Member States reported some public expenditure data on social long-term care, which are not included in the SHA, directly to the AWG; therefore, the public expenditure recorded in the Ageing Report may exceed the total expenditure recorded by Eurostat.

On average in the EU, public expenditure on long-term care is projected to increase from 1.7 % of GDP in 2019 and 1.9 % in 2030 to 2.5 % of GDP in 2050, with marked variations across the Member States (AWG reference scenario). The projections in this reference scenario are based on the assumption that there is no policy change in relation to the current long-term care systems in Member States and that half of the projected gains in life expectancy are spent without disability (i.e. not demanding care). It thus shows mainly the effects of demographic change (and GDP growth) on expenditure. The underlying assumptions imply that the projected increases in absolute terms are greatest in the Member States that already today provide a high level of public long-term care services and benefits.

An alternative 'risk scenario' additionally assumes an extension of formal care in a number of Member States, implying a doubling of expenditure on average in the EU-27 by 2050. Building on the AWG reference scenario, the scenario is based on the additional assumption that the unit costs of long-term care and the social protection coverage for long-term care will converge upwards to the current EU average, incorporating the effects of such possible key policy changes. The increase in public expenditure on long-term care is therefore projected to be more pronounced in the 'risk scenario' than in the 'reference scenario'. Notably, for the EU-27 as a whole public long-term care expenditure is projected to increase from 1.7 % in 2019 to 2.1 % in 2030 and 3.3 % of GDP in 2050. The projections in the 'risk scenario' are relevant to the policy aim within the open method of coordination, which is to

promote upward convergence among the Member States to adequate levels of social protection, including long-term care. The projections are, of course, only valid within the limits of the specific scenarios and hypotheses used for their calculation,[237] and the limitations of the underlying data[238] imply some uncertainties. Looking at national expenditure paths, the Netherlands, for example, faces the highest projected increase (in p.p.) of public long-term care expenditure, from 3.7 % in 2019 to 4.7 % in 2030 and 6.7 % in 2050 according to the 'risk scenario'. This is also due to a high level of formal care provision. By contrast, public long-term care expenditure in Greece, which currently has a higher use of informal care, is projected to increase from 0.2 % of GDP in 2019 and 0.2 % in 2030 to 0.6 % in 2050, implying a tripling of expenditure by 2050, but from a much lower level. At the same time, the costs of informal care are also expected to increase over this period due to the increase in the ageing of the population, and these also need to be included when looking at current and future expenditure on long-term care (see Section 5.3).

The diversity in the level of public long-term care expenditure seems to be more related to benefit coverage than to different needs of the population. Member States with low current public expenditure (e.g. BG, CY, EL, LV, PL, RO) are among the Member States with a higher-than-average share of people with severe difficulties with personal care and/or household activities (see Chapter 2 Figure 1), while their residents report lower-than-average use of formal home long-term care services (see Chapter 2 Figure 3). These residents also report that they do not use formal homecare services mainly for financial reasons (see Chapter 2 Figure 4). By comparison, in Member States with higher expenditure on long-term care, the social protection coverage for long-term care is also higher (see Chapter 2 Section 2.3). As a result, in Member States that lack adequate publicly funded long-term care systems, it is individuals or households that will have to finance the increased demand for long-term care or provide the corresponding support unless there is any change in policy.

To ensure the availability of long-term care services for current and future generations, public long-term care expenditure has to be managed in line with overall efforts to ensure sustainability of public finances. Most Member States already have high levels of public expenditure and debt, and all of them face strong and growing fiscal pressure to find ways to balance their budget in the medium term against the background of population ageing. This fiscal pressure also affects the public financing of their health, long-term care, and corresponding social protection systems, facing among others demographic pressures under today's revenue structures.[239] Exploring ways to ensure the fiscal sustainability of long-term care systems and to improve their cost-effectiveness becomes particularly important to achieving access to good-quality long-term care services for all. This may include: ensuring that an adequate care setting is used for each recipient; targeting resources towards those who need care the most and can least afford to pay for it; ensuring that long-term care is effectively integrated with healthcare and other social services; and improved governance and

[237] It should be emphasised that the reference scenario and risk scenario are just scenarios, not forecasts or desirable outcomes.

[238] There are uncertainties regarding the projections for the Member States that do not report social long-term care expenditure in the SHA.

[239] European Commission, 2019.

transparency in provision.[240] At the same time, far from being only a burden, public expenditure on formal long-term care will be more efficient if synergies between healthcare and long-term care settings can be enhanced, and long-term care is provided in a dedicated setting. It also generates employment in a growing care sector and may thereby increase GDP. In addition, formal long-term care also facilitates higher employment among older age groups by reducing demand for informal care (see Chapter 4).

5.2 Financing arrangements for public long-term care systems

In most Member States, long-term care for older people has no distinct institutional set-up and is financed from various sources. There are frequent interactions with health systems, and other social protection provision and services; the delimitations are blurred, and not consistent or comparable across different Member States. Long-term care is most often financed very differently from other social protection branches and provisions, depending on the historical and institutional context, and out-of-pocket financing by users and their families may often be a feature. Although the financing arrangement does not affect the level of long-term care expenditure per se, effective and efficient financing can help choose cost-effective settings[241] and promote investment in prevention and technology.

The European public broadly supports the public provision of benefits for long-term care services for the older people.[242] Many Europeans are concerned about sufficient access to good and affordable long-term care for older people and many, especially those aged 50-64, tend to support the idea that the government should provide care for older people. In 2017, international social survey programme (ISSP) data covering 16 Member States showed that around two thirds of all respondents supported the idea that the government should be primarily responsible for providing care for older people. The ISSP 2012 data also revealed that most people in the majority of Member States believed that government or public funding should primarily cover the cost of such care. This was particularly the case in Denmark (77 %), Spain (70 %), Portugal (67 %), and Austria (61 %). On the other hand, the majority of respondents in a few Member States (BG, HR, HU, PL) believed that the family should primarily cover the costs. Few people in Europe (in particular, young people and those on low income) would be more willing to pay additional taxes for this.

Ensuring sustainable long-term care systems requires efficient organisation of risk-sharing and financing arrangements. This could be achieved via different models for financing formal long-term care, which Member States often combine within hybrid approaches. These models pool risks within and across generations, as current cohorts of working-age people finance the benefits of current cohorts of older people, with the expectation of receiving the same treatment from future generations. The three main models of financing are:

a. tax-based (which may imply universal but also means-tested access);

[240] European Commission and EPC, 2016.
[241] For example, long-term care is sometimes provided in expensive hospital settings.
[242] Tóth et al., 2020.

b. social insurance;

c. private insurance (voluntary or compulsory).

The main financing models broadly reflect the typology of different welfare states in Europe.[243/244] Nevertheless, not all Member States fit purely in this theoretical typology and recent reforms imply that approaches may be in flux. Over recent decades, four main types of welfare state models have been identified in the academic literature. The Scandinavian (welfare state) model assumes a high responsibility of the state for the entire population and provides a high level of benefits in kind. They are usually tax-based models of a universalistic nature that promote an equality of high standards. In the Mediterranean model that prevails in southern Member States, by comparison, the primary responsibility and financing for care lies within the family, to which the state is only subsidiary. Mediterranean Member States may be either insurance-based or tax-based, but benefits are usually means-tested with relatively low levels of benefits. The continental models are typically insurance-based, and sit between the Scandinavian and Mediterranean models. Although the state may provide the statutory framework for the care system, its practical organisation and regulation may be outsourced to self-governing bodies. It usually provides comprehensive benefits. In the Anglo-Saxon model, benefits are tax-based: however, the responsibility lies with the individual, and the state only supports in exceptional cases and with a relatively low level of benefits. Strict entitlement rules are often associated with stigma. Eastern Member States seem to be developing into hybrid welfare states, with strong reliance on family support and a tradition of residential care, which, however, is changing. Such a diversity of welfare state models shows on the one hand that there is no unique structure in the Member States, but on the other hand that there will also be no 'one size fits all' solution.

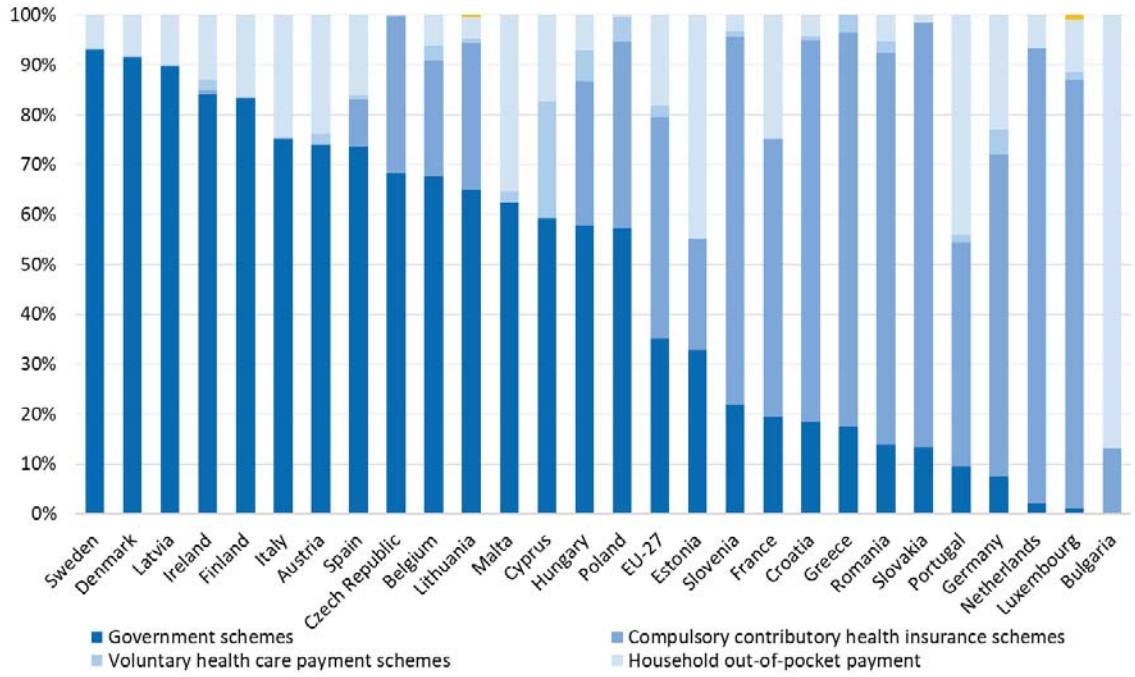
Where no financing via risk-pooling models exists, all payments for long-term care would have to be covered fully by households at the point of service delivery. However, many people in need of long-term care would not be able to afford to pay for the full costs of long-term care (see Chapter 2). As can be seen in Figure 22, the share of reported out-of-pocket payments for health-related long-term care expenditure ranges from 86.8 % in Bulgaria to 0.2 % in the Czech Republic. Except for Cyprus, where voluntary insurance schemes for long-term care account for 23.4 % of expenditure, such schemes only play a minor role. In Cyprus, a general healthcare system was only introduced in 2019 for outpatient care and in 2020 for inpatient care. This may explain the larger reliance of the population on voluntary health insurance schemes, which may also cover long-term care. Chapter 4 of the 2021 Pension Adequacy Report (European Commission and SPC, 2021) analyses how risks and resources are shared in relation to pension systems; it considers alternative and new sources of financing to help ensure sufficient funding to provide adequate benefits and coverage, which is complementary to the analysis in this report.

[243] Esping-Andersen, 1990.

[244] Riedel et al., 2019.

Figure 22: Share of expenditure by financing schemes for the health component of long-term care expenditure

Government schemes are the predominant financing source for long-term care in a majority of Member States



Source: Eurostat, SHA[245] 2018, hlth_sha11_hchf, data for long-term care (health). No information available for: out-of-pocket payments for EL; voluntary healthcare payment schemes for CZ, SK and SE; and rest of the world financing scheme for BE, CY, CZ, DE, ES, FI, FR, HR, IE, IT, MT, PT, RO, SE, SI, and SK (assumed as 0 in figure).

Taxation rather than social insurance is the predominant form of public financing of long-term care in the Member States. Tax-financed systems can be found in some Member States (e.g. AT, CY, DK, FI, IT, SE), as illustrated in Figure 22. Even Member States that have social-insurance based systems rely on general taxation to finance social assistance in relation to long-term care (e.g. DE) or to finance benefits that are provided by local levels of government (e.g. NL). Tax-based systems are financed from taxes levied on a national, regional or local level. The broad tax base is often cited as one of the main advantages, as funding is not solely generated from labour income (wages) as is usually the case for social insurance, but also relies on capital income (e.g. capital gains), thus spreading the cost across production factors. A well-diversified taxation system thus implies a lower cost on labour compared with insurance-based systems, supporting employment and growth. Furthermore,

[245] Government scheme: a healthcare-financing scheme whose characteristics are determined by law or by the government and where a separate budget is set for the programme and a government unit that has an overall responsibility for it;
Compulsory contributory health-insurance scheme, and social health-insurance scheme: a financing arrangement to ensure access to healthcare for specific population groups through mandatory participation determined by law or by the government and eligibility based on the payment of health-insurance contributions by or on behalf of the individuals concerned;
Compulsory private insurance scheme: a financing arrangement to ensure access to healthcare for specific population groups through mandatory participation determined by law or by the government and eligibility based upon the purchase of a health-insurance policy;
Voluntary health-insurance scheme: a scheme based upon the purchase of a health insurance policy, which is not made compulsory by government and where insurance premiums may be directly or indirectly subsidised by the government.

compared with insurance-based systems, (progressive) tax-financing may protect incentives to work for low-income earners. Such systems are also more flexible in generating revenues and in the allocation of resources. However, reduced transparency in the allocation of revenues could affect people's willingness to pay higher taxes, or render tax-based systems more prone to discretionary cuts in times of economic crisis (European Commission and SPC, forthcoming).

Social insurance systems for long-term care rely on social contributions that create an entitlement for long-term care benefits when needed (e.g. DE, LU, NL).[246] The principle of solidarity is employed to calculate the contributions of insured people. Each person insured pays the same percentage of their income into the insurance scheme, while children and unemployed family members are typically free of any contribution. As a disadvantage, such levies on wages may negatively affect the competitiveness of labour-intensive sectors of the economy (as does labour taxation) and some groups may not be sufficiently covered by insurance (e.g. self-employed people, people in non-standard forms of employment, platform workers). At the same time, caps on the contribution basis (income thresholds above which no contributions are paid), and the focus on labour income, limit the redistributive effects within cohorts. However, childless contributors may be required to pay a top-up on their contribution rate (e.g. DE), thereby introducing redistributive effects between people with and without children. The transparency, both in terms of allocation of benefits and financing, implied by social insurance-based models has been highlighted as a key advantage. There are fixed rules relating to the entitlement to long-term care that cannot be changed as easily as in tax-financed systems, and the upfront payment of social insurance contributions implies that all people need to be treated equally via a harmonised assessment of needs, potentially limiting geographical inequalities in benefit generosity (European Commission and SPC, forthcoming).

Compulsory private insurance largely follows the same principles as social insurance systems. Making private long-term care insurance mandatory may help address adverse selection,[247] and myopic behaviour in relation to insurance. Similar to social insurance, compulsory private insurance usually covers only part of the cost. In some cases, premiums may be related to risk profiles. The most prominent example of such insurance schemes is Germany, where people who have private healthcare insurance also have to opt for private long-term care insurance. The social (statutory) and the private long-term care insurance are both designed as compulsory insurances with identical benefits.

Voluntary private long-term care insurance plays only a limited role and is present in only some Member States (e.g. AT, DE, FR).[248] This may reflect the fact that the costs of voluntary private insurance are very high, in part due to problems inherent to long-term care. These include problems of adverse selection, in particular when people buy premiums later in

[246] In addition, earmarked contributions are used to finance long-term care insurance. In the case of Belgium, a lump sum is paid by each adult inhabitant and directly assigned to long-term care insurance.
[247] Only older people with a high risk of developing long-term care needs may opt to enroll, driving insurance premiums up and making the insurance unattractive for younger people and those with a lower risk of needing long-term care.
[248] Comas-Herrera, 2020.

life; and the fact that people may not adequately plan for the risk of long-term care in old age, leaving it too late to take out voluntary private insurance. At the same time, the existence of minimum provisions for long-term care via public funding may reduce incentives for people to invest in voluntary insurance. In addition, private long-term care insurance policies may be regressive in that the premiums may not be affordable to all across the income distribution. The premiums are typically based on a person's age and risk profile[249] rather than income (as is the case of social insurance), limiting redistributive effects. Because of inherent difficulties in calculating a premium that is reasonable based on what the long-term expenditure could be on an aggregate level in 30 years' time, voluntary private insurance usually pays a monthly compensation for long-term care needs, rather than covering the full care costs. In addition, the capital requirements may become prohibitive for insurers when mortality and morbidity rates are taken into account in long-term care insurance in some markets (OECD, forthcoming). Nonetheless, as even the most generous public long-term care systems impose some degree of cost-sharing or fall short of covering all long-term care needs (see Chapter 2), there may be a role for voluntary private long-term care insurance in supplementing them.

5.3 Costs of informal care

Beyond the important societal contribution, informal care comes with opportunity costs and other costs that are not visible in statistics.[250] Many informal carers are of working age and face difficulties in reconciling care and paid work, especially when care is intense. Not being able to maintain paid work or working fewer hours lowers both the current and future income (including pension entitlements) of informal carers and their households, aspects discussed in Chapter 4. These lost hours of work may be considered as an in-kind private contribution from families to the total costs of long-term care (to the extent they receive either no or incomplete income compensation).

Furthermore, informal care also has sizeable direct and indirect fiscal effects at the macroeconomic level. Informal care entails direct and indirect costs for the state that are rarely discussed. These effects are related to fewer hours worked, and hence lower tax revenues and lower social security contributions paid by informal carers, in some cases compensated for by social security contributions paid or credited from the public budget (pension credits). Especially intense informal care (40 or more hours per week) reduces labour supply, lowers incomes, and hence may increase the poverty rate at a later stage – although only about 10 % of informal carers provide intense care at that level. To the extent that informal care displaces formal care, GDP per capita could be lowered.

A recent study aims to capture the full costs of informal care, at both the individual and macro-economic levels (Van der Ende et al., forthcoming). Results relating to the individual costs for informal carers have already been explored in Chapter 4. This section explores two ways of estimating the costs of informal care at the aggregate level. The first way illustrated in this chapter is to put a price or value on all hours of informal care. The 'proxy good'

[249] People with lower incomes have more long-term care needs than people with higher incomes (see Chapter 2).
[250] Only allowances provided by the government to informal carers are included in expenditure statistics.

method, for example, values the hours of informal personal care using the gross wage rate of formal care providers. As such approaches focus on the valuation of time only, and ignore other potential effects of informal care-giving, they lead to results that could be seen as lower-bound valuations of informal care. Second, the analysis in this section estimates the approximate direct and indirect costs for governments connected to a loss in tax revenue and payment of benefits for informal carers. Even excluding future losses associated with informal care (incurred after the care stint), this estimate captures a larger part of the costs of informal care than existing long-term care statistics.

5.3.1 Estimated time value of informal care

The costs or value of the hours providing informal care can be estimated using various methods (Van der Ende et al., forthcoming). The two most commonly used approaches are to value carers' time via the proxy good method and the opportunity costs method.[251/252/253] The proxy good method values the time of informal care-givers using the market price of substitutes for specific care-giving tasks. The opportunity costs method values the time of informal care-givers using the value of the foregone alternative spending of that time. Although these methods value hours of informal care from a substitution perspective (proxy good method) and the informal carer's perspective (opportunity cost method), respectively, they do not indicate the value of informal care to the care recipient. On the one hand, informal care is usually unskilled; but on the other hand, the personal relationship between a family carer and the care recipient, and the fact of always being helped by the same person, could add to the perceived quality of care provided. It has to be noted that these estimates ignore potential other effects of care-giving for informal care-givers such as on health, well-being, and (future) coverage by social protection (Van der Ende et al., forthcoming). In that sense, they could be seen as lower-bound valuations of informal care.

Box 8: Methodology to estimate the time value of informal care provision

The time values of informal care are calculated using the average hours of informal care provision per year based on averaged data from the EHIS and EQLS datasets. *These data capture the average hours of informal care provision per week based on averaged data from the EQLS 2016 and the EHIS wave 2 (2013-2015) datasets. The average reported number of hours of informal care per week are subdivided in five categories: 0-9; 10-19; 20-39; 40-70; and over 70. These categories are used to define a minimum, average, and maximum scenario of actual hours.*

In the base case, hours of informal care per week are based on the average of the minimum and maximum time scenarios. *In all scenarios of actual hours, individuals indicating that they provide 0-9, 10-19 or 20-39 hours of care per week are assumed to provide 4.5, 14.5 or 30 hours, respectively. In the minimum time scenario, individuals providing 40 hours or more of care per week are capped at 40 hours (a full-time working week). In the maximum time scenario, individuals providing 40-70 hours of care are assumed to provide 55 hours, and those providing more than 70*

[251] Hoefman et al., 2013.
[252] Koopmanschap et al., 2008.
[253] Van den Berg et al., 2004.

hours of care are assumed to provide 80 hours.

***Three types of informal care are distinguished**: (a) personal care tasks; (b) household tasks; and (c) paper work. Using SHARE data (2017, respondents aged 50-70 in 10 Member States, the hours per task are assumed to be independent of the age of the care-provider), on average in the EU-27, 57 % of informal care hours are spent on household tasks, 27 % on paper work, and 15 % on personal care tasks.*

***The proxy good method values the time of informal care-givers using the market wage of substitutes for specific care-giving tasks.** In other words, by applying the wages of formal service-providers for each task, the proxy good method values the time of informal care at wage rates for the relevant activities. It should be noted that this approach does not account for potential differences in efficiency and quality of care between formal and informal care-providers. It should also be noted that time is only valued using wages, and does not include the overhead costs of formal care. Additionally, the time valuation does not reflect actual expenditure. In the absence of specific tariffs per task, hours spent on (a) personal care tasks are valued at the gross wage rate of formal long-term care workers (from OECD, 2020);[254] hours spent on (b) household tasks are valued at the gross wage rate of service and sales workers (ISCO code 5, from ILO, 2017[255]); and hours spent on (c) paper work are valued at the gross wage rate of clerical support workers (ISCO 4, from ILO, 2017). Although long-term care workers might perform some household tasks as well, a distinction is made between care tasks and household tasks, as the definition of the wage of formal long-term care workers used by the OECD (2020) focuses on personal care and assistance with ADLs (e.g. bathing, showing, dressing) and hence excludes IADLs (e.g. cooking, cleaning, shopping).*

***The opportunity cost method values the time of informal care-givers using the value of the foregone alternative spending of that time.** Depending on the situation of the care-giver, this may be: the wage rate of the informal carer in the labour market if combining informal care with work; the wage rate of peers (in terms of age, level of education) if not employed but of working age; or the value of (leisure) time if not of working age.[256/257] Ideally, one would use individual-level wages and wage rates of peers to calculate the opportunity cost of informal care. In the absence of the necessary data, informal care hours of employed individuals are valued at the average gross wage rate across ISCO categories of occupations in which people working certain numbers of hours typically work. And instead of wage rates of peers, the value of leisure time is estimated not only for retired informal carers, but for all non-employed informal carers in general.[258] It is important to note that non-employed informal carers do not necessarily start working if they stop providing informal care, so the valuation does not exactly reflect foregone income.*

Because the most recent data in this section are from 2018, all estimated values are converted to

[254] Missing values are imputed based on PPP-corrected GDP per capita.

[255] ILOSTAT database. For all data the latest available latest available value is used and transformed to 2018 Euros (range 2014-2018). https://ilostat.ilo.org/data/

[256] Van den Berg et al., 2006.

[257] Sendi and Brouwer, 2004.

[258] The value of leisure is estimated for all hours of informal care in the maximum scenario. For the minimum scenario the value of leisure is assumed to be zero, and for the average scenario just the average of the minimum and maximum scenarios. The rates of leisure time are derived from the country group estimates in: Verbooy et al., 2018. These country group estimates were converted into estimates for individual Member States by using PPP-corrected GDP per capita.

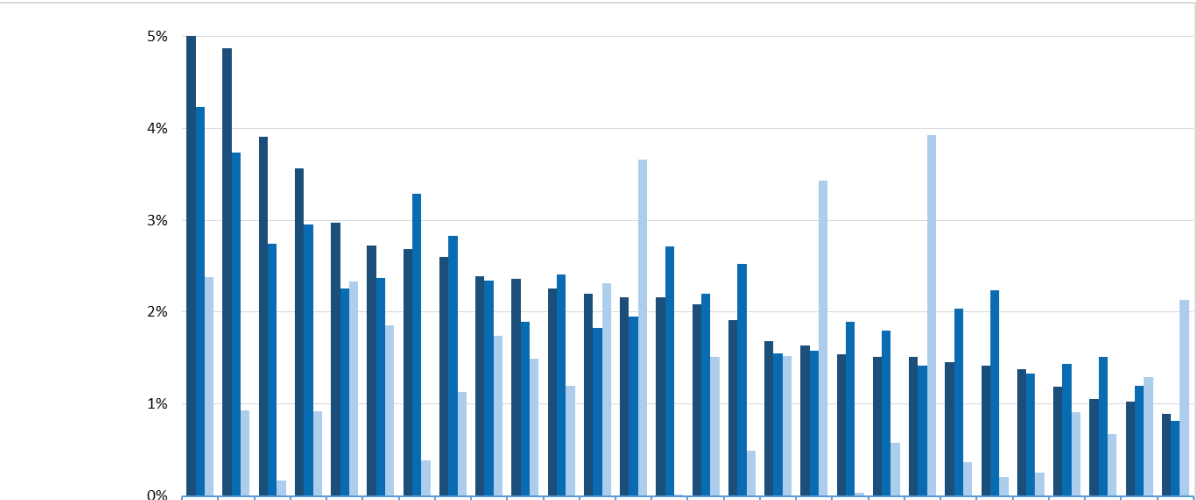
2018 Euro values and presented as a share of 2018 GDP.

An estimated 33-39 billion hours are spent providing informal care annually in the EU-27 (Van der Ende et al., forthcoming). This corresponds to 16.5-19.5 million full-time equivalent workers (assuming 40 hours per week for 50 weeks per year). The Member State with the largest volume of informal care provision is France with more than 9 billion hours of informal care, followed by Italy and Spain with estimates of respectively 5.6 and 5.4 billion hours of informal care.

The annual value of time spent providing informal care in the EU-27 is estimated at 2.7 % of GDP using the proxy good method (Figure 23). This corresponds to an estimated yearly value of informal care of EUR 368 billion (sensitivity range: EUR 338-398 billion) in 2018. The sensitivity range represents the estimated value of informal care when using conservative estimates of actual hours per category of informal care intensity (2.5 % of GDP or EUR 338 billion) and using higher estimates of actual hours per category of informal care intensity (2.9 % of GDP or EUR 398 billion).

Figure 23: Proxy good and opportunity cost time valuations of informal care provision as % of GDP per Member State

The estimated time value of informal care exceeds reported expenditure on (formal) long-term care in most Member States



	FR	ES	EL	IT	BE	EU	PL	LT	MT	IE	SI	FI	DK	BG	CZ	LV	AT	SE	SK	HU	NL	RO	HR	CY	PT	EE	LU	DE
Proxy good	5,0%	4,9%	3,9%	3,6%	3,0%	2,7%	2,7%	2,6%	2,4%	2,4%	2,3%	2,2%	2,2%	2,2%	2,1%	1,9%	1,7%	1,6%	1,5%	1,5%	1,5%	1,5%	1,4%	1,4%	1,2%	1,1%	1,0%	0,9%
Opp. costs	4,2%	3,7%	2,7%	2,9%	2,3%	2,4%	3,3%	2,8%	2,3%	1,9%	2,4%	1,8%	1,9%	2,7%	2,2%	2,5%	1,6%	1,6%	1,9%	1,8%	1,4%	2,0%	2,2%	1,3%	1,4%	1,5%	1,2%	0,8%
Formal care - Eurostat	2,4%	0,9%	0,2%	0,9%	2,3%	1,9%	0,4%	1,1%	1,7%	1,5%	1,2%	2,3%	3,7%	0,0%	1,5%	0,5%	1,5%	3,4%	0,0%	0,6%	3,9%	0,4%	0,2%	0,3%	0,9%	0,7%	1,3%	2,1%

Sources: Van der Ende et al. (forthcoming). Time is valued using the proxy good method and opportunity costs method. Expenditure on formal care: Eurostat, SHA 2018, hlth_sha11_hc, data for long-term care (HC3=health = help with ADLs and HCR1=social = help with IADLs), all financing schemes. Data on the social component are missing for AT, BE, BG, CY, DE, EL, HR, IE, IT, MT, PL, and SK. The value of the social component of the other Member States is included in the EU 27 total. Formal care may include expenditure to support informal care for some Member States. See Box 8 for more information on methodology.

Using the opportunity cost method, the time spent on informal care is valued at 2.4 % of GDP in the EU-27. This corresponds to EUR 320 billion in 2018 (sensitivity range: EUR

190-449 billion). The sensitivity range presents the estimated values of informal care when assigning zero value to the time of care-givers who are retired or not in employment (minimum value of 1.4 % of GDP), or when assigning the value for leisure time (Verbooy et al., 2018) to their time (maximum value of 3.4 % of GDP). The base case (2.4 % of GDP) assigns half the valuation of leisure time to informal care.

The estimated value of the time investment of informal care provision exceeds the cost of formal long-term care expenditure in most Member States. This highlights the fact that the strong reliance on informal care comes with high hidden costs across Member States. The only Member States where the average estimates of the value of informal care using the opportunity cost method do not exceed formal long-term care expenditure[259] are the same as for the proxy good method (DE, DK, FI, LU, NL, SE); and, in addition, Belgium for the opportunity cost method. In the base case, the value of hours of informal care valued using the proxy good method is typically higher than with the opportunity cost method in most Member States, except for mostly eastern ones.[260]

5.3.2 Estimated current costs of informal care for public budgets

Informal care brings costs for public budgets, including losses of tax and social security revenues related to carers' lower labour market participation and to expenditure on benefits for carers – as well as other indirect costs that are difficult to quantify, such as the deteriorating health of informal carers. These overall costs include care allowances, unemployment benefits, and minimum-income support paid to informal carers, pension credits on behalf of informal carers, the costs of deteriorating health among informal carers, and the opportunity cost in terms of lost tax revenues and social security contributions due to lost hours of work. Most costs are associated with lost revenues due to the employment gap, identified with significant confidence for women aged 45-64 (see Chapter 4).[261] Reduced work hours for women aged 18-44 providing intense informal care cause further lost revenues. Some costs are, however, hard to quantify due to a lack of data (pension credits, skills losses, deteriorating health of informal carers) and not included in the subsequent estimates. These estimates therefore provide partial and tentative attempts at quantifying these important costs.

Informal carers may receive a carer's allowance or other benefits that relate to their inactivity in the labour market, such as unemployment benefits and social assistance. In many Member States, informal carers may receive a carer's allowance under certain conditions – for example, relative to the degree of disability of a family member needing care,

[259] Using long-term care expenditure on health for 2018 from Eurostat, https://ec.europa.eu/eurostat/databrowser/view/HLTH_SHA11_HC__custom_114865/settings_1/table?lang=en&bookmarkId=74796c46-9be0-429c-8f5b-5d02db5ad173

[260] Many factors contribute to differences, such as the intensity of care, the type of care, the wage distribution, the profile of informal carers, employment rates, the value of leisure time, and the fact that proxy good rates are assumed to be similar within groups of Member States.

[261] The costs related to the employment gap are (almost by default) zero beyond age 65. Below 45 and for men aged 45-64, an employment gap was only identified for intense carers, but their numbers are too small to affect the average employment rate of informal carers in those groups and therefore no employment gap-related calculations were done for the other gender/age categories.

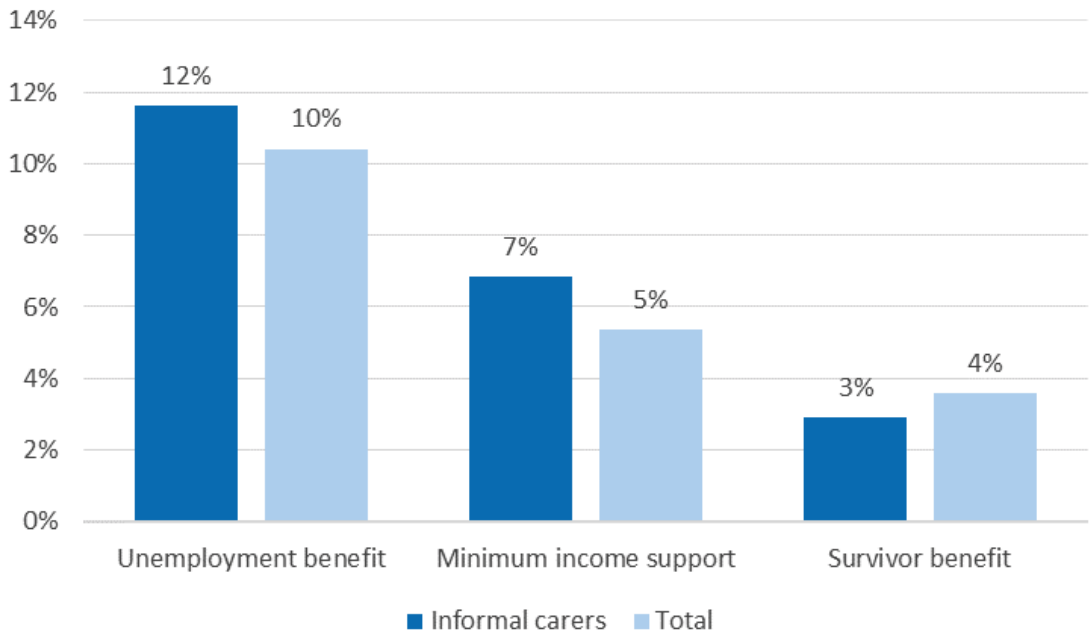
or to a maximum number of work hours per week. Depending on the Member State, this allowance is paid directly to the carer or to the person needing care – in the latter case they may spend it on formal or informal care. Moreover, since women aged 45-64 providing informal care are on average less likely to be employed than other women of that age, they are more likely to receive unemployment benefits or social assistance such as minimum income support, even if they do not qualify for a carer's allowance (Figure 24). The inclusion of such benefits in the cost estimates presented in this chapter is based on whether they are additional to the benefits for non-employed in general.[262] This concerns the following benefits:

- Carer allowances: for all informal carers.
- Unemployment benefits and minimum income support: only in relation to the employment gap.[263]
- Survivor benefits: not included.

Box 9 provides further details on the methodological background.

Figure 24: Share of women aged 45-64 providing informal care who receive unemployment or social assistance benefits, compared with all women aged 45-64

Women aged 45-64 providing informal care are slightly more likely to receive unemployment or minimum-income benefits than women of that age in general



Source: Van der Ende et al. (forthcoming), based on EU-SILC ad hoc module, 2016.

Box 9: Methodology to calculate revenue loss associated with employment gap

[262] The criterion was whether benefits are additional to those for non-employed people in general.

[263] That is, it is applied to 6 % on average across the EU-27 of the women aged 45-64 providing informal care, with the actual percentage varying between Member States.

***Employment gap**. As discussed in Chapter 4, non-employed women aged 45-64 are more likely to provide informal care than employed women of the same age (Van der Ende et al., forthcoming). Hence, the employment gap is at most partially caused by informal care, and the estimated lost revenue associated and benefits paid in connection with the employment gap[264] is arguably an upper bound.*

***Calculation of lost revenues**. To calculate the lost revenues, the average annual income of employed women aged 45-64 was calculated for each Member State and for each of nine main occupations (ISCO). For each Member State and occupation, the OECD rates for income tax, employee social security contributions, and employer social security contributions were used if available; and otherwise PwC information on tax and social security rates were used.[265] Depending on which group of informal carers the lost revenues relate to, the lost revenue per informal carer is multiplied by the relevant number of informal carers: that is, the employment gap (women aged 45-64) for informal carers not working at all; and the number of employed intense informal carers (women aged 18-44 providing 40 or more hours of care per week) for the reduction of weekly working hours.*

The direct annual tax and social security losses related to the employment gap of women aged 45-64 who are informal carers amount to an upper bound of 0.3 % of EU-27 GDP (EUR 48 billion in 2019). A main source of lost tax and social security revenues is that some informal carers stop working completely. However, it is mainly people providing intense informal care (more than 40 hours per week) who stop working. The associated revenue loss has been calculated for women aged 45-64 who are informal carers.[266] As discussed in Chapter 4, the estimated employment gap is negative for four Member States (BE, DK, PL, RO). In those four, among women aged 45-64, the employment rate of informal carers is higher than average for the EU-27: accordingly, informal care is actually estimated to generate additional revenues (negative losses).

In 2019, the annual estimated lost tax and social security revenues related to the care employment gap (as defined above) amounted to 0.3 % of GDP at the EU-27 level, and as much as 0.9 % of GDP in Sweden (Figure 25). The high revenue loss in Sweden is related to the large employment gap, which in turn is related to the high average employment rate of 79 % for women aged 45-64 (the highest in the EU-27). Additional direct annual tax and social security losses may result from the lower employment rates for other groups than women aged 45-64, and from the reduced volume of work of informal carers; these have,

[264] Lost tax and social security contributions being quantified; lost tax and contributions revenues due to difficulties finding work after the care stint not being quantified here; and certain benefits paid: unemployment benefits and minimum-income support being quantified; related notional pension contributions of the state on behalf of these beneficiaries not being quantified here.

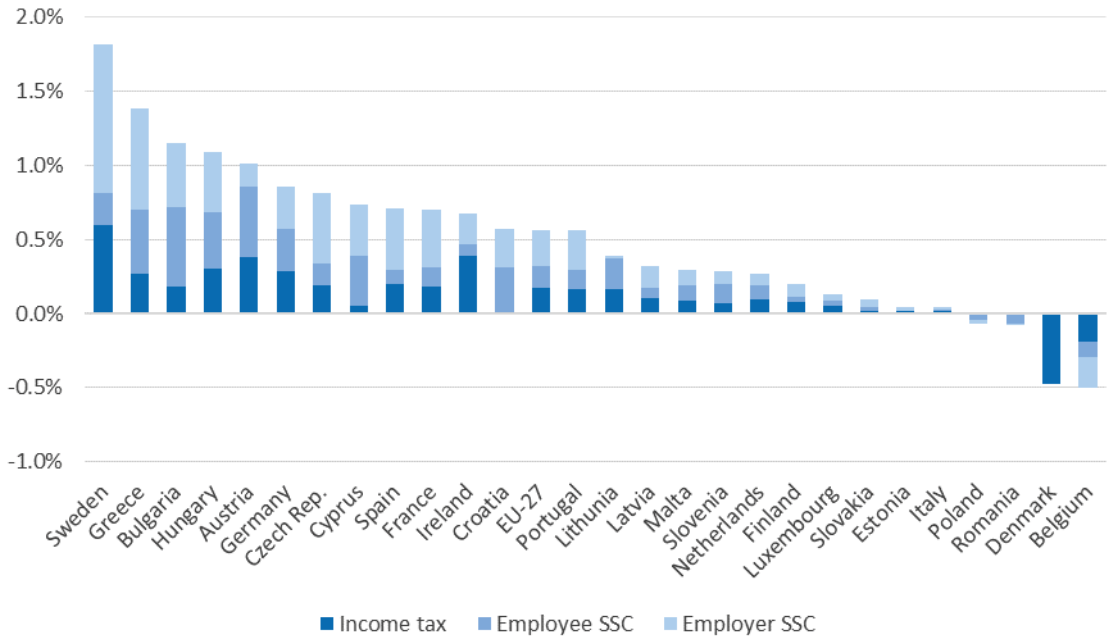
[265] For incomes less than half of the average wage, the OECD rates for half the average wage were applied; for incomes greater than 1.5 times the average wage the OECD rates for 1.5 times the average wage rate were applied; and for incomes in between, a linear combination of rates at 0.5, 1, and 1.5 times the average wage was applied. The revenue losses were then for each Member State averaged across the main occupations, weighted with the proportions in which women aged 45-64 work in those occupations.

[266] Among younger carers and men, their numbers are too few to affect the average employment rate of informal carers in these groups.

however, not been quantified as the difference could not be estimated with a sufficient degree of significance[267] It is therefore important to note that the present estimate of public revenue losses related to the employment gap is a partial one.

Figure 25: Lost tax and social security revenue due to informal care employment gap as % of GDP, women aged 45-64

The tax and social security revenue foregone as a result of the employment gap of informal carers during their care stint (observed for women aged 45-64 alone) amounts to 0.3 % of EU-27 GDP



Source: Van der Ende et al. (forthcoming), based on EHIS (2013-2015), EQLS (2016), EARN SES (2018), LFS (2019), OECD-PwC tax rates (2019).

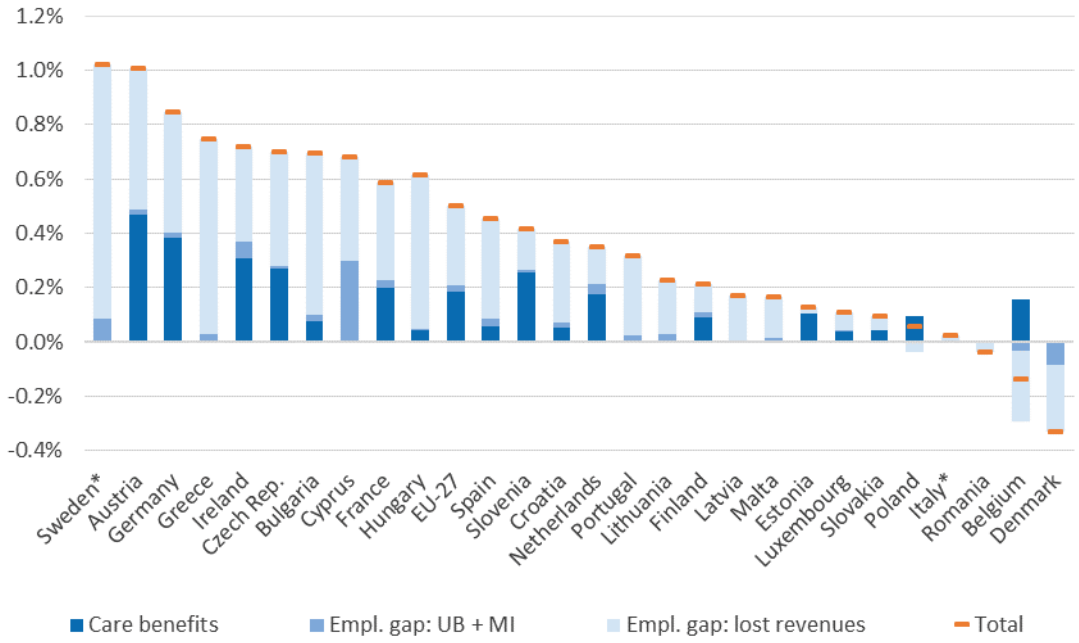
The cost of allowances and benefits to carers is estimated to amount to close to 0.2 % of GDP. The estimated value of informal care allowances (paid directly or through the person needing care) amounts to 0.18 % of EU-27 GDP (Figure 26). Among the 17 Member States with care allowances and available data, it ranges from 0.04 % (HU, LU, SK) to 0.39 % (DE), and 0.47 % (AT). However, it should be noted that these costs are over-estimated in some Member States (e.g. BE)[268] while being under-estimated in others (IT, SE) due to lack of data. Moreover, in relation to the employment gap, unemployment and minimum-income benefits for informal carers not already covered by informal care allowances are also added to the calculation of costs. Those costs are quite small, ranging from -0.08 % (DK) and -0.03 % (BE) (in these cases, women aged 45-64 providing informal care are actually more likely to be employed) to 0.08 % (SE) and even 0.30 % (CY). The reason for the low level of costs is that they are only applied to the employment gap of women aged 45-64 who are informal

[267] Chapter 4 found a difference of about one hour (39.5 hours of work on average among employed informal carers, compared with 40.6 hours in the total employed population aged 18-64); but this result was not found to be significant.
[268] Where expenditure on 'homecare' includes not only informal but also formal homecare.

carers, with a view to capturing only benefits that are additional to support for non-employed people in general.[269]

Figure 26: Estimated cost to the state of informal care, for selected categories

Lost revenues and expenditure on benefits during care stint are estimated to represent 0.5 % of EU GDP



*Note: * Means administrative data on care benefits missing for indicated Member States. New data for Luxembourg on care benefits are still pending.*

Sources: Van der Ende et al. (forthcoming), based on EHIS (2013-2015), EQLS (2016), EARN SES (2018), LFS (2019), OECD-PwC tax rates (2019), EU-SILC 2016 ad hoc module, desk research on care benefits.

Further significant but unquantified costs include those of poorer health, lost revenues due to difficulties in re-entering employment after a care stint, and pension credits for informal carers. In general, people who are non-employed for a longer time are less likely to re-enter employment. Based on the findings in Chapter 4, this is particularly the case for non-employed men aged 45-64 who are informal carers, but to a lesser extent also for younger people providing informal care. In addition, the employment gap of women aged 45-64 providing informal care also carries over to the period after the care stint, when they have the

[269] Care allowances are allocated fully to costs. However, the unemployment and minimum-income benefits (UB+MI) of informal carers are applied only to the employment gap. The reason is that others in the general population may also receive those benefits, unlike care allowances. Technically, the average UB+MI is calculated per non-employed informal carer (women aged 45-64). The assumption is that every non-employed informal carer is equally likely to receive UB+MI and not everyone in the employment gap receives UB+MI: they might have been non-employed prior to starting informal care, or the partner's income might already be above the minimum-income threshold. Unfortunately, care allowances are not observed in the EU-SILC (2016 cross-section data). It is assumed that every non-employed informal carer is also equally likely to receive informal care allowances. Thus, the number of informal carers receiving care allowances is multiplied by the share of women aged 45-64 times their non-employment rate. This result is subtracted from the employment gap if the employment gap is positive (employment is lost) and the result is set to zero if the employment gap was or becomes negative (negative numbers of UB+MI make no sense if employment is lost).

same (low) probability of entering employment as before the care stint (and as their peers not providing care). Informal carers remaining inactive results in further income losses and associated reductions in public revenues. In addition, in many Member States the state credits the years of informal care for their old-age pension if they meet national eligibility criteria. Due to technical difficulties and the need for strong assumptions, these further costs, as well as costs associated with poorer health among informal carers, are not quantified in monetary terms here.

The total cost to the state of informal care is estimated at 0.5 % of EU-27 GDP (EUR 72.4 billion in 2019). These calculations include the partial estimate of annual tax and social security losses resulting from the lower employment rates for women aged 45-64, and the expenditure on allowances and other additional benefits. By contrast, they do not include revenue losses or additional costs resulting from: lower employment rates of other groups; a lower number of hours worked by informal carers; re-employment difficulties after a care stint; and pension credits to which informal carers may be entitled. Although these estimates are therefore only partial, they are a first step towards capturing the cost of informal care. They already indicate their significant magnitude, for instance in relation to total public expenditure on long-term care, which amounted to 1.6 % of GDP in 2016 (see Section 5.1). The estimated public costs are highest in Sweden (1.0 % of GDP due to the large employment gap), Austria (1.0 % of GDP), and Germany (0.8 % of GDP). In some Member States (BE, DK, RO), slight revenue gains (negative costs) arise from the fact that the employment rate among women 45-64 providing informal care is actually higher than among their peers not providing informal care (it also causes low estimated costs in Poland). The main reason why the estimated cost for the state is small in some other Member States (e.g. EE, FI, LU, SK), at 0.2 % of GDP or less, is that the employment gap is small.

5.4 The role of disease prevention and new technologies in improving cost-efficiency of long-term care

The rising demand for long-term care and related increases in expenditure call for improvements in the efficiency and productivity of long-term care. Investment in disease prevention, for example regarding dementia, can help postpone the onset of care needs in the older population, thus contributing to lower expenditure on long-term care. New technologies also have the potential to raise the cost-efficiency of care service delivery and somewhat alleviate workforce shortages.

Active and healthy ageing policies, including health promotion and disease prevention, can help reduce the need for long-term care in old age. People who are fit when they become old and who remain physically and mentally active not only have a better chance of avoiding or postponing frailties,[270] but they are often also better at managing functional

[270] The EU co-funded 'Advantage' project summarises the current state of the art of the different components of frailty and its management, both at a personal and population level, and increases knowledge in the field of frailty to build a common understanding to be used by participating MS. https://www.advantageja.eu/index.php

decline when it occurs.[271] The 2014 joint SPC and European Commission report on adequate social protection for long-term care needs looked in more detail at strategies of prevention, rehabilitation/re-enablement, and age-friendly environments in the Member States (Social Protection Committee and European Commission, 2014). Its key findings, briefly indicated below, remain highly relevant.

Prevention may be 'primary' to avoid a disease, 'secondary' to detect a disease or 'tertiary' to manage life with a disease. Primary prevention refers to actions that avoid the manifestation of a disease.[272] Such actions include the promotion of healthy workplaces, but also healthy lifestyles and health education. Secondary prevention is associated with early detection of a disease, which may result in improved chances for positive health outcomes (e.g. cancer screening). Tertiary prevention is associated with services that promote a better quality of life for those living with disease (e.g. rehabilitation, 're-enabling' care, disease-management programmes).[273] The extent to which these approaches are followed depends on the Member States' policy mix, and the definitions may also slightly vary by Member State.

Certain medical conditions are particularly prevalent in old age and thus need specific attention. They include arthritis, stroke, diabetes mellitus, chronic obstructive pulmonary diseases, cardiovascular diseases or cancers, dementia, and other cognitive impairments and frailties. Some risk factors for these conditions are considered potentially modifiable through primary prevention. For instance, it has been found that 35 % of risk factors for dementia are potentially modifiable; positive outcomes are also shown from an increase in childhood education and exercise, maintaining social engagements, reducing or stopping smoking, and management of hearing loss, depression, diabetes, hypertension, and obesity (Livingston et al., 2017).

The success of a preventive measure is determined by the extent to which the expected onset or course of a disease can be avoided, mitigated or delayed. Generally, prevention is an important investment in health in older age, as it extends healthy life years in the older population. In this regard, prevention may also bring about cost reductions in long-term care. In order to assess cost-effectiveness, an economic evaluation is necessary. However, there is still little evidence available regarding which interventions aimed at keeping older people in good health lead to better pay-offs or are cost-effective. This uncertainty acts as a deterrent to implement potentially valuable initiatives in long-term care systems (OECD, 2011). The economic evaluation of prevention and the establishment of causality is particularly difficult in view of the potentially very long time-lags between preventive measures and the onset of

[271] The EU-funded 'FrailSafe' project aims to delay frailty by developing a set of measures and tools, together with recommendations to reduce its onset. https://frailsafe-project.eu/

[272] Primary prevention is complementary to the concept of health promotion. According to the WHO, '*health promotion enables people to increase control over their own health. It covers a wide range of social and environmental interventions that are designed to benefit and protect individual people's health and quality of life by addressing and preventing the root causes of ill health, not just focusing on treatment and cure*.' https://www.who.int/news-room/q-a-detail/what-is-health-promotion

[273] European Commission, *Health promotion and disease prevention*, https://ec.europa.eu/jrc/en/health-knowledge-gateway/promotion-prevention#prevention

care needs. In addition, factors such as age, sex, and genetics may also play a role in whether or how a person will develop a need for long-term care.

Prevention measures that focus on older people and consider both the person's behaviour and their environment are promising (Riedel et al., 2019). The 2014 SPC and European Commission report identified key components of successful prevention programmes. First, there should be a focus on the main factors listed above which lead to the need for long-term care. Second, as part of a life-course approach, the intervention should start before a need for long-term care arises; and in particular, primary prevention should start at as young an age as possible. Third, those who are most at risk should be identified, taking into account socio-economic, cultural, and geographical factors. Fourth, 'personalised action plans' should be drawn up, so that the most effective form or mix of prevention can be adopted in each case. Fifth, innovative organisational approaches and technical solutions that screen for, identify, and target frail older people for evidence-based interventions should be implemented. Lastly, long-term care recipients should be empowered in order to improve the person-centred dimension of service delivery, but also self-management.[274] In general, successful prevention of diseases, medical conditions, frailty, and functional decline requires more knowledge about the risk factors; this may eventually result in better definitions of risk groups, and in therapies and interventions that can be offered earlier and be more tailored to individuals.

Technology can also help improve long-term care efficiency, for example, by helping older people 'age in place' (Zigante, 2020). This could reduce more expensive residential stays (in hospitals or residential care homes).[275] Different types of technologies could facilitate ageing in place in different ways: telecare and telehealth could enable exchanges between professionals, care users, and informal carers; remote monitoring by qualified staff could provide added safety and prevent unnecessary deterioration and hospitalisation; and 'smart home' technology could offer comfort, access to care, and help ensure users' safety at home. 'Smart home' and other ICT solutions could also help reduce feelings of loneliness and isolation, which may benefit users' mental health.[276/277]

Technologies can also optimise care provided by formal or informal carers. Technological solutions could ensure that, for example, home visits are more productive by enabling carers to provide targeted care, rather than reducing the number of visits overall. Adaptive technologies can provide enhancements or different ways of interacting with already existing technologies or tools in order to help older individuals to accomplish a specific task. Similarly, workforce efficiencies, such as improved recruitment and retention (outlined in

[274] A geriatric assessment can improve this person-centredness of care. A comprehensive geriatric assessment is a multidimensional, multidisciplinary assessment designed to evaluate an older person's functional ability, physical/mental health, and social/environmental circumstances. See: Welsh et al., 2014.
[275] Mosca et al., 2017.
[276] Marikyan et al., 2019.
[277] Satariano et al., 2014.

Chapter 4), but also improved scheduling and better record-keeping through variations of electronic health records, have been reported as beneficial.[278]

Although evidence on the cost-effectiveness of technologies in long-term care is scarce, some efficiency gains can be observed. There is a lack of evaluations of technological interventions in long-term care for older people. Studies are often lacking in robustness (i.e. evaluations of pilot programmes rather than randomised controlled trials) and follow-up times tend to be too short to capture the benefits of complex interventions. Nevertheless, even if cost-effectiveness has not yet been demonstrated, benefits in terms of improved efficiencies and effectiveness have been identified in some cases, most commonly in relation to telecare, where studies report positive findings (Daly Lynn et al., 2019). Outcome improvements have also been identified, for example, from the use of robots for care and company. However, more research is needed to establish whether these represent a cost-effective improvement compared with a real person providing care (Johansson-Pajala et al., 2020). Overall, given the investment costs, it is important to consider the design, implementation, and sustained support needed to ensure that technological products or services can reach their full potential.

5.5 Conclusion

Public long-term care expenditure is projected to increase from 1.7 % of GDP in 2019 to 2.5 % in 2050 across the EU-27. The projected increase shows marked variations across Member States, partly due to varying levels of social protection for long-term care.

This expenditure, however, does not include most of the cost of informal care. An estimated 33-39 billion hours are spent providing informal care annually in the EU-27. The value of the care provided by informal carers has been estimated to amount to 2.7 % (sensitivity range 2.5-2.9 %) or 2.4 % (sensitivity range 1.4-3.4 %) of GDP per year depending on the calculation method. Partial estimates of the cost to the state of informal care amount to 0.5 % of EU-27 GDP (EUR 72.4 billion in 2019). These calculations include a partial estimate of direct annual tax and social security losses resulting from lower employment rates for women aged 45-64, and the expenditure on allowances and other additional benefits. Overall, it is important to pursue long-term care strategies that increase productivity and labour market participation in the formal economy, in order to promote adequate and sustainable long-term care systems.

Sustainable financing for long-term care is, therefore, necessary to ensure adequate long-term care for current and future generations. In many Member States, long-term care for older people is not a distinct policy field and is funded from different sources and organised at different levels, both horizontally and vertically. Most Member States use hybrid forms of tax and contribution-based systems to finance long-term care. Member States that have introduced social insurance for long-term care over recent years usually complement it with tax-based benefits, while other Member States use taxes as the main financing source. Voluntary private insurance plays only a minor role in financing long-term care in Europe.

[278] Czaja, 2016.

To help ensure fiscal sustainability, the efficiency of long-term care should be increased via prevention and use of technology. Investment in active and healthy ageing policies, health promotion, and disease prevention can help to postpone the onset of care needs in the older population. In addition, new technologies have the potential to raise the cost-efficiency of care service delivery. Further evidence will be useful to help determine which interventions aimed at keeping older people in good health lead to the best results in terms of cost-effectiveness, and in how new technologies can enhance care delivery.

Improved data on long-term care expenditure at the EU level are needed to help guide mutual efforts. Current national-level data is not comparable, complete or consistent across the EU. The analysis of long-term care expenditure is subject to many uncertainties and the projections are only valid within the limits of the specific assumptions used. Improvements in the availability of comparable data on all long-term care expenditure would strengthen the basis for evidence-based policy-making and is crucial in order to advance this work further.

6 RECENT REFORMS IN THE AREA OF LONG-TERM CARE

Several Member States have implemented reforms of their long-term care systems in recent years.[279] Four main reform trends can be observed. Reforms have been designed to: (a) improve the situation of informal carers; (b) improve access, affordability, and quality in relation to homecare services; (c) improve access, affordability, and quality in relation to residential care; and (d) improve the situation of the professional long-term care workforce.

This chapter provides an overview of recent Member State actions to address long-term care challenges. It is based on the 27 EU country fiches which are published as Volume II of the present report. The chapter provides a brief overview of the main trends in recent long-term care reforms in the Member States (Section 6.1) and takes a closer look at the scope of the reforms around the key long-term care challenges (Section 6.2). It must, however, be noted that many of the reforms and measures reported are still in their early stages, and there is a need for good policy-evaluation mechanisms that would allow lessons to be drawn on their impact and the need for adjustments in the future. The chapter also presents relevant ongoing legislative processes and recent policy debates in the EU (Section 6.3). The chapter also contains a box on key challenges in long-term care for other age groups (Box 10).

6.1 Recent long-term care reforms: an overview

In recent years, long-term care systems have been mostly subject to parametric reforms – that is, changes only affecting some aspects of the system (see Table 3). Only Bulgaria and Germany have implemented overarching reforms of social services, which are expected to have an impact on many aspects of their long-term care systems. As will be explained below, some of the parametric reforms may, however, have a significant impact on the supply of long-term care services, for service-providers as well as for the recipients of care.

The first, most visible, trend concerns improvements in the situation of informal carers (observed in AT, BE, CZ, DE, EE, FI, FR, HR, IE, LU, MT, NL, PL, PT, SK). These

[279] The period covered in this chapter is between January 2017 and July 2020.

measures include introducing or raising carer's allowances, more favourable social protection conditions, work-life balance measures,[280] and other support measures (e.g. training and respite services) for informal carers.

The second trend relates to improvements in access, affordability, and quality in relation to homecare services (BE, BG, CY, DE, DK, EE, FI, LT, LU, LV, MT, NL, PL, RO, SE, SK). The reforms include establishing new services, as well as measures reinforcing the integrated delivery of care. The latter measures mostly tackle sectoral disparities between healthcare and social care by setting up co-ordination structures. They are also aimed at improving local and regional management and enhancing co-operation between different providers of homecare.

[280] It should be noted that the Directive on work-life balance (https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32019L1158), which aims to improve access to family leave and flexible work arrangements for workers who are parents or carers, entered into force on 1 August 2019. Member States have three years to implement the directive.

Table 3: Long-term care reforms adopted in Member States, 1 January 2017 to 1 July 2020*

Member State	Parameter(s) affected															
	Long-term care cash benefits for the dependent person			Homecare services			Residential (or semi-residential) services			Informal carers				Workforce		
	LTC cash benefits for the dependent person	Access	Affordability	Quality	Financing	Access	Affordability	Quality	Financing	Cash benefits	Leave	Employment conditions	Other support**	Recruitment	Salary and working conditions	Training and up-skilling
Belgium	X	X		X		X		X	X	X	X					
Bulgaria	X	X	X	X	X	X		X					X			X
Czech Republic	X									X	X	X			X	
Denmark				X				X						X		
Germany	X	X	X	X	X	X	X	X	X	X			X	X	X	X
Estonia		X		X	X	X		X	X		X		X		X	X
Ireland										X			X			
Greece		X				X										
Spain											X		X			
France								X		X			X			
Croatia											X			X	X	
Italy	No reforms during the period under examination															
Cyprus			X													
Latvia		X		X	X	X							X			
Lithuania				X				X								
Luxembourg			X	X	X		X	X	X				X		X	

Member State	Parameter(s) affected															
	Long-term care cash benefits for the dependent person			**Homecare services**			**Residential (or semi-residential) services**			**Informal carers**				**Workforce**		
	LTC cash benefits for the dependent person	**Access**	**Affordability**	**Quality**	**Financing**	**Access**	**Affordability**	**Quality**	**Financing**	**Cash benefits**	**Leave**	**Employment conditions**	**Other support****	**Recruitment**	**Salary and working conditions**	**Training and up-skilling**
Hungary						X				X						
Malta	X	X		X		X		X					X			X
The Netherlands		X	X	X	X		X	X	X				X	X	X	X
Austria	X					X	X		X		X					
Poland	X	X	X		X				X	X			X			
Portugal										X	X	X	X			
Romania		X		X	X			X								
Slovenia	No reforms during the period under examination															
Slovakia				X	X	X		X	X	X						
Finland		X	X	X		X	X	X			X		X	X		
Sweden		X			X	X			X					X		X

** This table focuses on reforms improving long-term care. ** Other support may include benefits in kind, respite care, up-skilling and training, psychological support etc.*

Source: ESPN country fiches 2020, SPC Member States' delegates.

The third trend concerns improved access, affordability, and quality in relation to residential care (AT, BE, BG, DE, DK, EE, EL, FI, FR, HU, LT, LU, LV, MT, NL, RO, SE, SK). The main reforms include more favourable eligibility conditions, rules for fees and cost sharing for dependent people and their families, and increasing the availability of places in residential care facilities. Quality of residential care has been addressed by setting up quality assessments, quality-monitoring tools, and ensuring compliance with quality norms.

The fourth trend concerns improvements in the situation of the professional long-term care workforce (CZ, DE, EE, FI, HR, IE, LU, MT, NL, SE). Among the key measures taken in this respect are increased funding to recruit staff, increases in salaries, better access to training, and improved working conditions (e.g. more stable contracts).

The reforms outlined above are likely to continue in the coming years. All-encompassing reforms, expected to change several aspects of the long-term care systems, are being discussed in some Member States (AT, EE, FR). Others have tabled specific measures focusing on access and affordability (CY, DE, FI, IE, PL, SI), quality of care (CY, DE, FI, LU, SI), and strengthening the attractiveness of working conditions (DE). The COVID-19 pandemic – which has hit older people and other vulnerable groups hard, and shed light on significant shortcomings and weaknesses in long-term care systems in many Member States – will, most probably, fuel further discussions on reforms together with the already ongoing debates.

6.2 Reform trends addressing the key challenges in long-term care systems

This section looks more closely at the scope of long-term care reforms, and is structured around the four key challenges faced by long-term care systems: access and affordability, quality, employment, and financing.

6.2.1 Reforms to improve access and affordability in long-term care

Measures affecting access and affordability in long-term care have been among the most prominent ones (AT, BE, BG, CY, CZ, DE, EE, EL, HU, LU, LV, MT, NL, PL, RO, SE, SK). They have mostly been designed to improve the availability and affordability of homecare services and residential care, as well as providing improved access to, and higher levels of, benefits targeted at dependent people.

Reforms of long-term care cash benefits have covered the introduction of new benefits, increases in the level of existing benefits, or an easing of the relevant eligibility conditions (AT, BE, BG, CZ, DE, MT, PL). In 2019, Poland introduced a cash benefit for adults who are unable to live independently. Moreover, a definition of 'inability to live independently' was established, together with new assessment rules. In January 2020, Austria introduced yearly indexation of long-term care cash benefits. This is a major change, as, in the past, long-term care cash benefits were indexed on an ad hoc basis, and thus their real value tended to fall substantially over the medium term. In the Czech Republic, the personal care allowance for the most dependent groups of beneficiaries (apart from those in residential care facilities) has been increased (as of July 2019) by 45 %. More favourable eligibility

conditions for cash benefits have also been implemented in Germany. As of 2017, the legal entitlement to long-term care benefits and the categories of beneficiaries have both been considerably extended (in particular to people with dementia), while the amounts of benefits have been raised substantially as well.

Access and affordability in relation to residential care have been addressed through the extension of supply, as well as through more favourable eligibility conditions, and rules for fees and cost-sharing for dependent people and their families (AT, BE, BG, DE, EE, EL, FI, HU, LV, MT, SK). In Austria, since 2017, the federal provinces can no longer have recourse to the assets[281] of people in residential long-term care, or those of their relatives, heirs or gift-recipients, to cover the costs of care. Previously, those in residential long-term care often lost all their assets.[282] Similarly, since 2019, Germany exempts children – with an annual gross income of less than EUR 100,000 – of people in need of care from the obligation to cover care costs not covered by the care beneficiary, regardless of the care setting. Moreover, since 2017, co-payments for people receiving residential care no longer depend on a person's care grade. All people in a nursing home who need long-term care and have been assigned to higher care grades[283] pay the same care-related co-payment (the amount differs between residential homes).

Other reforms have been designed to improve the infrastructure, and the sectoral and territorial management, of care facilities to provide better access (BE, BG, LU, LV, NL). In 2017, the Belgian federated region of Wallonia reformed the regulation of residential care for older people. This includes rules on daily fees and improved local and regional management, which is expected to improve access.[284]

Reforms targeting homecare services have established new services and benefits for dependent people (BE, BG, DE, EL, LU, MT, NL, PL, RO). Some key reforms have taken place in some Member States with the least developed homecare services (BG, EL, PL, RO). Bulgaria implemented a comprehensive reform of the social services sector involving, among other measures, the setting-up of several new types of community-based social services, benefiting over 2000 users.[285] In 2018, Poland implemented a programme[286] that finances care services in rural areas and smaller towns, locations that are particularly prone to depopulation and ageing due to migration processes. Under the programme, local authorities may be

[281] *Pflegeregress.*

[282] The federal government will compensate the federal provinces for the loss of revenue due to these new measures.

[283] Grades 2 to 5 on a scale from 1 to 5.

[284] Similar legislation was already in place in Flanders.

[285] This number covers the planned number of users of new social services facilities which are under development in accordance with the action plan for 2018-2021 for the implementation of the national long-term care strategy. It envisages the closure of 10 specialised institutions for the most vulnerable people with different type of disabilities, and the development of 100 new social services for 2140 users. The total number of people with disabilities living in specialised institutions is approximately 5000. 'People in need' is very large target group and includes a variety of needs. This number refers only to people in need of social services.

[286] This programme is a part of a larger package of measures, including the 'care services for people with disabilities' programme (2019) targeting people with disabilities aged under 75, as well as the 'social policy towards older people 2030: security-participation-solidarity' scheme (2018). The latter was implemented to foster an ageing-friendly social environment for older people, encouraging them to stay active, providing health education, increasing access to care for people with functional impairments, and investing in the nursing and care professions.

granted a subsidy to enable homecare services to be provided by full-time professional carers. In its first year of implementation, one third of the 900 eligible municipalities took part in the programme. Romania developed a national strategy for promoting active ageing 2014-2020, which gives priority to the development of community-based services for vulnerable older people or those at risk of poverty. Another line of reform is to increase the capacity of public community-level and home-based social services, to help older people stay longer at home. Other Member States with well-developed homecare services have been extending them (BE, DE, LU, MT, NL). In 2018, Malta reinforced homecare by introducing a cash benefit for people employing a full-time carer of their choice to assist them in their daily needs. In Germany, numerous reforms, adopted between 2008 and 2019, have extended benefits to facilitate and provide incentives for informal care as a measure targeting affordability.[287]

Reforms focusing on integrated delivery of care have mostly tackled sectoral disparities between healthcare and social care by setting up co-ordination structures (BE, BG, DE, DK, EL, LU, LV, NL, SE). They are also aimed at improving territorial management and enhancing communication and co-operation between formal long-term care providers, to improve the effectiveness and efficiency of care delivery. The above-mentioned major reform of social services in Bulgaria is also intended to be a complete overhaul of homecare and community care; it establishes an entirely new model for high-quality integrated social services. The reform is expected to increase access, especially for vulnerable people. It is aimed at establishing an integrated network of homecare services for people with disabilities and older people. Over 30,000 people[288] are expected to be supported as a result of the reform.[289] In 2018, Greece implemented a programme to establish 150 'integrated care centres for older people,' operating as branches of the 'community centres' in various municipalities of the country.[290] They provide information and support to homecare services provided exclusively to older people, and co-ordinate the existing care services – namely the open protection centres for older people, daycare centres for older people, and the 'help at home' programme. In Belgium, a federal programme has been implemented to improve care for people with chronic diseases, including older people. Since 2018, 12 projects have been set up at local level, testing a series of measures to improve care integration. One of them, case management at home, aims to improve access to care for people who have lost their autonomy. In addition, in Belgium in 2017, the federated region of Flanders was divided into 'primary care zones' for the purpose of improving the governance of homecare services.

[287] In 2008 cash benefits were increased from EUR 205-665 to EUR 316-901 per month, and side benefits were increased and improved as well (carer leave, daycare, advice etc.). In 2015 a long-term care provident fund for was set up as a collective, capital-covered insurance element, designed to ensure sustainable financing in the face of demographic change; each year until 2034 about EUR 1.5 billion will be transferred into the fund.

[288] This number refers to people who use social services and are potential beneficiaries of the ongoing reform in the social services sector. At the end of October 2020, the total number of people who are using social services was 34,804. The total number of people who were waiting for the use of different (first choice) social services was 4540.

[289] An integrated approach to the provision of long-term care services is set out in the new Social Services Act (enacted as of 1 July 2020).

[290] The 'community centres' are a kind of one-stop-shop, responsible for reception, information, and service provision, and for linking up citizens – and especially vulnerable social groups – with all the social programmes and services available at local level. Currently, there are 241 community centres in operation all over the country. They are run by the municipalities and are funded by the regional operational programmes of the national strategic reference framework 2014-2020 for Greece.

These zones are responsible for co-ordinating the various primary and social care partners within the zone, and are expected to become a central mechanism for organising co-ordination between the various stakeholders in homecare. In Germany, care-support bases offering advice and support are being set up,[291] providing relevant information, application forms, and practical assistance. In 2017, the Netherlands launched several programmes that have clarified how to assess the needs for social support (e.g. loneliness), and have improved integrated delivery of care and the matching of care to needs. In 2018, Finland took steps to improve the sharing of individual social welfare information in the national archive with care institutions at county level, in order to improve care management.

6.2.2 Reforms to improve the quality of long-term care

Reforms addressing the quality of long-term care have mostly focused on enhanced control and monitoring (BE, BG, DE, DK, EE, FI, FR, LT, LU, LV, MT, NL, RO, SK)**.** Some reforms have also implemented new comprehensive quality-assessment procedures or improved administrative procedures, or were linked to investment in residential care facilities.

Reforms implementing new comprehensive quality-assessment procedures have taken place in a few Member States (BG, FI, SK)**.** The reforms have tackled quality assessment in both homecare and residential care. Bulgaria and Slovakia did not have a well-developed set of quality standards for long-term care before. Bulgaria now relies on licensing of social services providers, and has introduced new quality standards. If providers do not meet these, funding will be phased out. The system will be monitored by the newly established Agency for the Quality of Social Services. In addition, a crucial part of the legislation is a focus on person-centredness (i.e. the individual needs of every person are to be assessed in the future, to achieve further improvements in the quality of services). Finland issued a quality recommendation in 2017, which is designed to guarantee high-quality ageing and effective services for those older people in need of them[292]; it has also addressed the quality of care, making the InterRAI assessment system[293] obligatory for all long-term care institutions by 2023.[294] In 2019, Slovakia[295] developed the national 'quality of social services' project, a methodology for implementing quality requirements for the quality-assessment process. The aim is to provide methodological support and guidance to public and private providers of social services as well as to the evaluators.

Measures strengthening quality control and monitoring have also been on the reform agenda of several Member States (BE, BG, DE, DK, LU, NL, SK). This was true in the Member States that have well established and long-standing sets of standards in the field of

[291] These are being set up by the health insurance and long-term care insurance funds on the initiative of the federal state. As of 2017, the role of the municipalities in setting up care support bases was strengthened.
[292] The recommendation was renewed and issued on 1 October 2020.
[293] InterRAI is an international collaborative project to improve the quality of life of vulnerable people through a comprehensive assessment system.
[294] According to the new act which came into force on 1 October 2020.
[295] Slovakia had received country specific recommendations in the context of the European semester on the quality of long-term care. Although quality standards for social services were defined in 2008, regular assessment of quality has been postponed several times.

residential care, reinforcing control and monitoring, and improving the regulation of providers. In 2018, Denmark introduced external audits in municipalities, following a debate in which it was claimed that internal audits by municipalities could be biased. In Bulgaria, the new Social Services Act establishes and regulates new quality and control mechanisms at all levels of governance. For the first time, monitoring of the efficiency of social services has been introduced. In Belgium (Flanders), a new decree (2019) defines the different components and functions of long-term care (and homecare). It is designed to clarify the prices of services and to set out clear quality criteria. In 2019, the Belgian federated region of Wallonia also improved standards for residential facilities for older people, and strengthened regulation mechanisms such as sanctions.[296] Germany, which is one of the few Member States with a well-developed long-term care-quality framework, has enhanced in-house quality assurance, external quality assessments, and quality reporting. Twice a year, all residential care facilities in Germany are obliged to collect quality-related data on all residents, based on a total of ten outcome quality indicators.[297] The Netherlands has taken measures to ensure a reasonable price-quality ratio in the care sector; these involve closer monitoring of private insurers and providers of both homecare services and residential care, as well as stricter conditions (e.g. a prohibition of profit distribution or specific requirements for public procurement).

Extensive investment to comply with quality norms has also been designed to improve the quality of care (DE, MT, NL). In the Netherlands, there are several ambitious plans for improving the quality of residential care, and large-scale government investment is taking place to facilitate compliance with quality norms. In addition to the drive to employ highly qualified care professionals, organisational changes (e.g. small scale, demand-, and thus user-, centred organisation) have been stressed. Other reforms have attempted to reduce administrative burdens and accelerate administrative procedures (BG, DE, NL).

6.2.3 Reforms to address the challenges of formal and informal carers

Several Member States have made legislative reforms aimed at improving the situation of the long-term care professional workforce (BG, CZ, DE, DK, EE, FI, HR, LU, MT, NL, SE).

Several measures have focused on the recruitment of care staff, in order to reduce staff shortages in the sector (DE, DK, FI, HR, NL, SE). Measures concerning the recruitment of additional long-term care staff in both homecare and residential care have mostly involved increasing the financial resources dedicated to staffing, as well as innovative measures to make the care profession more attractive. In Sweden, for instance, during 2015-2018 the government increased resources to hire new staff within the long-term care sector, leading to an increase of around 19,000 jobs.[298] In the Netherlands, in order to counteract the workforce

[296] Similar standards and regulation mechanisms existed in Flanders before.

[297] The newly designed mandatory external quality audits conducted by the Health Insurance Medical Service (MDK) and the auditing service of the private health insurance system build on these quality-related data, which indicate where there is potential for improvement. The new definition of public quality consists of several pillars: outcome quality data collected by the facilities; external audit results; and quality-relevant information from licensed long-term care service providers.

[298] The long-term care sector had just over 250,000 employees in 2015.

shortage, the 'labour market agenda 2023', as well as two targeted programmes,[299] were aimed at increasing the availability of skilled care professionals working for older people. These programmes focus on improving the attractiveness of the sector via image campaigns and several other measures linked to working conditions and training. In 2017, Germany adopted legislation[300] which makes the care profession more attractive for trainees by abolishing apprenticeship fees and stipulating that trainees are entitled to appropriate remuneration. In 2019, the relevant stakeholders in the care sector agreed comprehensive measures to: increase workforce training; improve working conditions and pay; introduce new ways to increase efficiency and relieve the administrative burden on professional carers; and promote recruitment of care professionals in third countries.[301] In a first step to raise staffing, following the Care Staff Strengthening Act,[302] up to 13,000 additional posts for qualified long-term care workers[303] were created in the field of medical treatment in nursing homes.[304] Furthermore, the funding of 20,000 additional positions for nursing assistants was secured within the framework of the 'Act to Improve Healthcare and Nursing' (GPVG).[305] Further steps to prepare the establishment of new and substantially increased staffing standards will follow in 2020/2021. Public efforts to co-operate with third countries in the area of vocational training and recruitment of long-term care professionals have also been intensified, especially with Mexico, the Philippines, and Kosovo. Costs will be borne by the statutory health insurance funds. In Croatia in 2017, the government launched a programme,[306] using EU funding, which was intended to encourage the employment of disadvantaged women (especially aged 50 or over) to provide support and care for older and disadvantaged people in their communities. In 2020, this programme was serving around 30,000 people, and employed 6,000 women.

Measures have been taken to improve the attractiveness of the long-term care sector, through higher salaries and improved working conditions (CZ, DE, HR, LU, NL). Germany raised salaries in the long-term care sector, and the application of collective agreements to more employment relationships in long-term care facilities may contribute to better working conditions. The Care Wages Improvement Act[307] of 2019 created a legal basis to improve wage conditions for care workers. In consequence, minimum wages for qualified care workers have been introduced and the minimum wages for nursing assistance staff were raised (and previously disparate regional rates were aligned). In addition, homecare-providers as well as residential care facilities can receive partial funding through the long-term care insurance funds for the acquisition of digital and technical innovations to improve the

[299] 'Working for the elderly' (2017) and 'working in healthcare' (2018).
[300] *Pflegeberufegesetz (Gesetz über die Pflegeberufe)*.
[301] 'Concerted action for the care workforce' (*Konzertierte Aktion Pflege* – KAP).
[302] *Pflegepersonal-Stärkungsgesetz* (which came into effect on 1 January 2019).
[303] Total number of professional care workers in residential care facilities is more than 250,000.
[304] Funding for these additional posts is mainly provided through a yearly lump-sum payment of EUR 640 million from the statutory healthcare-insurance funds to the statutory long-term care insurance funds. The private long-term care insurance companies bear a part of the costs as well.
[305] *Gesetz zur Verbesserung der Gesundheitsversorgung und Pflege* (*Gesundheitsversorgungs- und Pflegeverbesserungsgesetz* – GPVG) (which came into effect on 1 January 2021).
[306] The 'Wish for – women's employment programme'.
[307] *Pflegepersonal-Stärkungsgesetz*.

working conditions of professional long-term care staff over the period 2019 to 2021. Another programme makes grants available up to 2024 for measures to improve the work-life balance of professional carers.[308] In the Czech Republic, the government has repeatedly and significantly increased the salaries of workers in the long-term care social sector over the last three years.[309] The clear upward trend in salaries in the social services sector since 2014 is likely to have made the profession more attractive. The Netherlands implemented a battery of measures in 2017, including: improved the working conditions; better protected contracts (e.g. open-ended contracts, flexible working time, leave); reorganisation of work through (inter) sectoral co-operation; innovation in work practices; and better matching of supply and demand. Finland has taken measures requiring higher staffing ratios,[310] which could also help improve working conditions.

Some Member States have implemented measures to increase up-skilling opportunities for long-term care workers (BG, DE, EE, MT, NL, SE). In Bulgaria, the new social services law introduces the right to participate in training for long-term care workers and employees providing social services, and the right to supervision. In Malta, jobs in the sector are being made more attractive through new training opportunities at tertiary level, with the launch of certified training programmes for potential carers. In Sweden in 2020 (partly because of the COVID-19 crisis), the government presented a reform specific to the long-term care workforce.[311] Long-term care employees will be offered paid training to become, for example, assistant nurses. Local authorities and the relevant trade union have supplemented this by agreeing to offer a permanent full-time job for those who participate in this training. The programme is expected to create 10,000 new permanent jobs for assistant nurses and other care professionals, and to make the care profession more attractive.

Although the reforms are an important step towards improving the situation of care professionals, they have mostly taken place in a few Member States with generally well developed homecare and residential care sectors. No reforms were reported in the majority of Member States that have serious shortages of care professionals and far less developed formal care sectors (e.g. some southern and eastern Member States).

Improving the situation of informal carers is among the key trends of recent reforms (AT, BE, CZ, EE, ES, DE, FI, FR, HR, HU, IE, LT, LU, MT, NL, PL, PT, SK)**.** Such reforms have focused on: improving the social protection of informal carers, by introducing carer's allowances and care leave from work; providing better work-life balance arrangements (e.g. flexible employment); and enhancing training, psychological support, and respite care. In 2019, Portugal introduced a major reform establishing a formal status for informal carers, which establishes the right for 'principal carers', who provide care on a permanent basis, to receive a carer's allowance. This is, however, conditional on: the carer being a family member

[308] Eligible for funding are, for example, childcare services that are aligned to the specific working hours of care staff, and additional education and training courses.
[309] By 23 % in July 2017, by 10 % in November 2017, and by 10.8 % in 2018.
[310] From 1 October 2020, the ratio should be 0.5 nurses per care recipient, and from 1 April 2023 it should be at least 0.7. The law will increase the number of personnel in 24/7 services by about 4400 by 2023. However, due to retirements, there will be a constant need to increase staffing numbers in the coming years: hence 4400 additional workers is not a constant number.
[311] *Äldreomsorgslyftet*.

and living in the same household as the care recipient; not receiving any remuneration (for instance from work, pension or unemployment benefits); and the household in which the principal carer lives having an income below a certain threshold.[312] The reform also establishes a set of rights for both principal and non-principal carers,[313] including the rights to: accumulate social security credits; receive training; receive follow-up, information, and psychological support; be consulted about public policies aimed at informal carers; and respite periods. The new law also contains rules to facilitate the work-life balance of 'non-principal informal carers'. The new measures reinforce the Portuguese social protection system's reliance on informal care. Although it promotes carers' work-life balance and social protection, the new status for informal carers only covers family members, thus excluding, for example, care provided by friends or neighbours. The above-mentioned eligibility conditions to receive a carer's allowance, including restrictive means-testing, may prove quite restrictive, hindering take-up of the allowance.

A carer's allowance to support carers' activity has been introduced in several Member States (CZ, FR, PL, PT, SK). In 2019, France introduced an allowance for people entitled to carer's leave. Its purpose is to encourage carers to make use of the leave, which, at that point, was rarely taken up. In 2019, Slovakia introduced a new social benefit for long-term carers for a sick relative. This benefit will be implemented as of 2021; it supplements a similar social benefit (benefit for caring for a sick relative) that is already in place, and allows people to care for relatives who leave hospital in bad health or in need of palliative care for a maximum of 90 days.[314] Moreover, Slovakia repeatedly increased the amount of the 'attendance service benefit',[315] which in 2018 reached the level of the minimum wage. In the Czech Republic, a new cash benefit was introduced in June 2018 to improve the financial situation of family members providing long-term care for their relatives ('long-term care-giver's allowance'). The carer, whether employed or self-employed, is compensated for the loss of income from work due to taking care of a family member discharged from hospital and requiring at least 30 days of further care (up to a maximum of 90 days).[316] Carers are also protected against dismissal.

Introducing carer's leave in line with the work-life balance Directive[317], and improving social protection for informal carers, have been on the agenda of some Member States (AT, BE, CZ, EE, ES, HR, PT). From 2019, Belgium has provided extended leave for workers to provide informal care under specific conditions (including provision of at least 50 hours care per month or 600 hours per year). In 2019, Austria introduced a legal entitlement to care leave, which applies in companies with more than five employees (previously the

[312] Lower than 1.2 times the social support index (EUR 526.57 per month in 2020).
[313] A principal informal carer is a family member living in the same household as the person being cared for, providing care on a permanent basis without remuneration. A non-principal carer is a family member caring on a regular but non-permanent basis, with or without remuneration.
[314] It is expected that 400 people per month will claim this new benefit.
[315] *Príspevok na opatrovanie,* aimed at carers of long-term dependent relatives.
[316] In the first year, there were close to 1500 beneficiaries.
[317] Directive (EU) 2019/1158 of the European Parliament and of the Council of 20 June 2019 on work-life balance for parents and carers and repealing Council Directive 2010/18/EU. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=celex%3A32019L1158

employer had to agree to it, which resulted in rather low take-up). In May 2020, Croatia increased the parent care-giver compensation by 62 %.[318] In 2019, Spain reinstated the payment of social protection credits by the state for informal carers who were recognised as care-givers in an individualised care plan.

Respite periods, training and other services for informal carers have also been among recent reforms in some Member States (BG, DE, EE, FI, FR, IE, LT, LU, PL, PT). In Bulgaria, the new social services law introduces support and training services for family members who provide informal care at home. Moreover, for the first time, the carer is given the right to respite periods. In Poland, a respite care[319] programme was implemented in 2019. Local authorities can apply for financial resources to improve access to respite-care services, which previously were almost non-existent. Besides respite care, health education and training are envisaged for carers of children or adults with disabilities, including older people. In 2017, Ireland implemented a programme of training and support for family carers. This programme is funded from unused funds in dormant accounts in credit institutions and unclaimed life-assurance policies. In 2016, Finland increased the number of holidays for informal carers who enter into an informal care agreement with the municipality to at least two or three days off per month. The well-being of carers is also supported by providing welfare and health checks. Since January 2018, informal carers also have the right to coaching and training organised by the municipality.

6.2.4 Reforms to address the financing of long-term care

Changes in the sources, or the conditions for, long-term care financing have occurred in a few Member States (BE, DE, EE, PL, RO, SK).[320] In Slovakia, the conditions linked to the financing of social services, including long-term care services, were partially changed in 2018. The financial contribution paid by the state to social service providers, granted according to the degree of dependency of each service-user, has been significantly increased, and providers must use this amount to pay the salaries of employees. The measure is estimated to have provided considerable financial support for the supply of social services (in particular, long-term care services) and has also made these services more easily affordable. In Germany, the contribution rates for long-term care insurance increased between 2008 and 2018, mainly to finance the extension of benefits and the increasing numbers of people in need of care.[321] In 2020, Romania adopted new cost standards for all social services, including residential and homecare services for both public and private service-providers. The

[318] In accordance with the Croatian Social Welfare Act, the status of care-giver can also be obtained by a spouse or common-law partner, as well as a formal or informal life partner of a person with a disability (a person who is completely dependent on the care of another person, including children and adults). Exceptionally, it can also be obtained by one of the family members with whom the person with a disability lives. The right to the status of parent care-giver / care-giver can be recognised up to age 65, and exceptionally for longer if the assistance cannot be provided in any other way and the status was obtained before that age.

[319] *Opieka wytchnieniowa*.

[320] This section refers only to changes in the financing mode of long-term care systems, whereas the columns on financing in Table 1 also refer to additional resources allocated for long-term care systems. The information on the latter has been streamlined in the previous sections.

[321] In 2020, they stood at 3.05 % for people with children, and 3.30 % for childless people.

Belgian federated region of Wallonia reformed the financing mechanism for residential care facilities and established a regulation for the daily fee.

6.3 Planned reforms and ongoing debates

Some Member States have announced plans for comprehensive reforms affecting several aspects of their long-term care systems. These include access, quality, financing, and the workforce (AT, DE, EE, FI, FR, SK). A key example is the French reform plan, which – in response to the COVID-19 crisis – was confirmed as a policy priority by the government in May 2020.[322] The plan proposes 175 measures regarding long-term care, structured along three strands: establishing a new financing mix for the supply of long-term care (e.g. merging healthcare and social care expenditure in residential homes to reduce the remaining amount payable by residents); overhauling the existing financial support system (e.g. a new cash benefit for homecare); establishing new homecare and residential services; and boosting resources to further improve the status of informal carers. In Austria, the government has announced a thorough reform of long-term care to improve nationwide planning and co-ordination, and to reform financing structures. The specific ideas and measures to be discussed are still at an embryonic stage. Similarly, in 2021, Estonia plans an overarching reform of the long-term care system, establishing an integrated long-term care framework to reduce the care burden and to ensure the cross-sectoral supply, availability, and quality of human and family-oriented services. In Slovakia, according to the government's programme statement, an allowance is planned for people needing to purchase care services: the allowance would be paid direct to users, and would vary according to their degree of dependency. More ambitiously, the plan is to establish a new system of long-term healthcare and social care, including financing arrangements, in order to promote integrated care for older people and for people with severe disabilities. Similar reforms are under preparation in Germany and Finland (development of homecare).

Other Member States intend to implement reforms focusing on access and affordability (CY, FI, IE, PL, SI) **and on quality of care** (CY, FI, SI). In Cyprus, two new pieces of legislation on home and community care, as well as residential and day-care are underway; they are expected to define more clearly the criteria for inclusion on the professional register of formal care-givers, as well as reforming qualifications so as to make them both more comprehensive and more relevant to the modern requirements for homecare and residential care. In Ireland, the introduction of a 'statutory basis' – the establishment of a formal status of 'carer' for homecare – has been under discussion, in response to a major review of health and care services.[323] The statutory basis would lead to incremental increases in the funding and volume of homecare services, as well as some ad hoc training and support initiatives for informal carers. Finland has launched a development programme for health and social services centres of the future, which will be implemented in 2020-2022. At such centres, patients will have access to all services under one roof, such as primary healthcare, local social work, and homecare services. The programme also includes the development of user

[322] The major features of this in-depth reform were presented in the Libault report (2019).
[323] The *Sláintecare* reform programme.

and service guidance to ensure the co-ordination of the appropriate services and help users deal with the various authorities involved. In a broader context, responsibility for organising health and social services will be transferred from the municipalities to 22 regional authorities (counties) with the aim of providing better access to long-term care in rural areas.

Box 10: Key challenges in long-term care for other age groups

The current long-term care systems may also present disparities in coverage, access, and adequacy of benefits/services for age groups other than older people, who are the focus of this report. *The relevant groups are working-age adults with disabilities or mental illness, and children with disabilities. Although a comprehensive analysis is beyond the scope of this report, this box summarises the key corresponding findings of the country profiles in Vol. II. Some of the most prominent challenges for long-term care for age groups other than older people (while potentially also relevant for older people) are: difficulty in accessing cash benefits (due to lack of information and overcomplicated bureaucratic procedures); the transition from residential care to homecare and community-based services; long waiting times; a shortage of qualified professionals; and reductions in care budgets.*

The situation of adults with disabilities is challenging in several Member States, and in particular in some eastern ones. *In several, the most serious challenges relate to: difficulties in the transition from residential care to homecare and community-based services (EL, FR, HR, LT, MT, RO, SI, SK), reflecting inter alia limited financing and low coverage by non-residential services; and encouraging the employment of people with disabilities in the public and private sectors (FR). Moreover, reduced financial resources result in a high risk of non-take-up as people in need of care would face considerable expenses (BE, FR, IE), long waiting times (CY, EE), and a lack of places in residential care homes (EE, LT). Vulnerable people may have to use the cash benefits allocated for other purposes, and to incur out-of-pocket payments, to cover the costs of rehabilitation services or a stay in a care facility (CY, RO, SK).*

The provision of long-term care for children with disabilities has many weaknesses. *These notably include service access and availability (mostly rehabilitation services in CY, DE, FR); the transition from residential to community-based services (EL, FR); and weak co-ordination and interaction between health professionals and the families of children with disabilities (CY). In Cyprus, for example, inadequacies in access are related to long waiting times, the shortage of qualified healthcare professionals, and a gap identified in help for specific age groups (1-5 years). In the Netherlands, the long waiting lists for residential youth care are a key issue, especially for children in need of psychiatric care and children with developmental issues, as is the 18- to 18+ transition. National experiences also underline the need for transparency and accessibility.*

The situation of working-age adults with mental illness is still precarious in some Member States, with underfinancing being one of the main challenges. *Mental care often relies on psychiatric institutions. In several Member States there are problems of coverage (EE, ES, PO), affordability (FI), and independent living (BE, CZ, FI, LV, MT). Other difficulties include the lack of a common vision linking projects, stigmatisation, and low involvement of experts outside the mental health sector. Several Member States have begun the transition from residential to community-based services (HR, LV, PL) to facilitate independent living and relieve the pressure on institutions including psychiatric hospitals.*

6.4 Conclusion

In recent years, several Member States have implemented reforms of their long-term care systems. The reforms have mostly been parametric – that is, only affecting some aspects of the system. The main trends concern reforms to: improve the situation of informal carers; facilitate access, affordability, and quality in relation to both homecare services and residential care; and improve the situation of the professional long-term care workforce. Member States also have also taken measures to respond to the COVID-19 pandemic by introducing mainly ad hoc measures, and to a lesser extent structural changes (for more information on the implications of COVID-19 for long-term care systems, see Chapter 7).

7 IMPLICATIONS OF COVID-19 FOR LONG-TERM CARE SYSTEMS

The COVID-19 crisis has had a significant impact on long-term care systems and Member States have had to urgently take measures, notably to protect care recipients and providers of long-term care. The pandemic is still ongoing and Member States have faced second, and in some cases even third, waves. Although one of the biggest obstacles for providing targeted support to long-term care systems during the first wave of the crisis was the limited availability of data, available information sources[324] have shown that long-term care systems have been strongly affected by the pandemic, due to their users' high vulnerability to the sickness. Figures about high mortality rates in care homes[325] in the first wave raised serious concern about the capacity of long-term care systems to cope with the crisis. In general, it appears that in most Member States, residential care providers were largely unprepared for the epidemiological threat: insufficient sanitary procedures related to isolation of potentially infected people, shortages of personal protective equipment particularly in the social sector, staff shortages and insufficient testing. While entailing these new challenges, the crisis has also brought to the fore already existing structural challenges many long-term care systems are facing in view of population ageing, affecting the access and affordability, quality, workforce and informal carers and sustainability of long-term care. Member States have acted swiftly and implemented a number of policy responses to counter the negative effects of COVID-19 in the long-term care sector. Measures such as preventive testing therefore have been organised with a strong priority for the long-term care sector.

7.1 Ad hoc measures during the first wave of COVID-19 pandemic

This section reflects the state of play in the first wave of the COVID-19 pandemic in the EU, during the period from March to July 2020.

Although COVID-19 and corresponding policy responses have affected access to long-term care, the effect on affordability is less clear

Several Member States have limited access to long-term care services during the crisis. The nature of long-term care services, which mostly involve close physical contact, has made service delivery increasingly challenging in times of social distancing measures. In order to reduce the risk of spreading COVID-19, daycare centres were temporarily closed or made subject to limited access in a number of the Member States (CZ, DE, HR, HU, LU, NL, PL, RO, SI, SK) during the first wave of the pandemic. Similarly, access to homecare was reduced in several Member States (FR, LU, NL, SI). Some Member States (e.g. BE, CY, FR, NL) limited homecare services to strictly necessary visits. In Austria during the initial phase of the pandemic, problems in homecare arose especially regarding live-in care at home, provided by privately employed carers mostly from central and eastern Member States. For a

[324] This section is based on: Member States' responses to a dedicated questionnaire (replies received by summer 2020) in the context of preparing this report; Member States' responses collected by the Croatian Presidency; OECD health policy tracker; Comas-Herrera et al., 2020; Dawson et al., 2020.

[325] Different counting methods and definitions used by Member States.

time, travel bans prevented carers from travelling between their place of work and their home in a usually biweekly cycle. In addition to homecare, residential care has also been more difficult to access during the crisis. In several Member States (BG, EE, HR, LU, PL), the placement of new residents in residential care was temporarily restricted. In Poland, people had to provide a negative COVID-19 test before admission to residential care. In Bulgaria, exceptions were only granted as a last resort where people were in extreme need of accommodation.

In order to ensure access to long-term care, several Member States have reinforced care-giving via telecommunication (CY, ES, FR, NL, PL, RO)**.** In Cyprus, for instance, there has been extensive use of telephone communications and teleconsultations between care-givers and both patients and health professionals. Romania has established a national emergency phone line. In many Member States, greater attention has been paid to pro-active identification of crisis situations, provision of telephone and internet services, and local volunteering groups to help with groceries. Informal care is likely to have compensated for a significant share of the care that was previously provided by professionals. In addition, anecdotal evidence suggests that people in need of long-term care sometimes chose to reduce or not use informal or formal long-term care in order to minimise their risk of contracting COVID-19. This suggests that, during the first months of the crisis, unmet long-term care needs may have increased.

The effect of the crisis on the affordability of long-term care services is as yet unclear. Formal long-term care could become more expensive in the medium term due to higher costs related to measures against COVID-19, while some people in need may be less able to afford long-term care due to the economic downturn. Some Member States have introduced temporary support or even reinforced financing. Bulgaria, for example, exempted users of certain social services from the payment of fees during the first lockdown, and Germany increased the monthly allowance for personal hygiene equipment for people in need of care. At the time of writing, there is, however, no formal evidence yet of the impact the COVID-19 crisis may have on the affordability of formal long-term care. Member States have not yet reported changes to long-term care insurance benefits or to their social protection coverage for long-term care due to the crisis, either.

Protecting long-term care recipients and carers from COVID-19 was essential, and required innovative solutions, while some necessary measures negatively affected their well-being

COVID-19 has challenged the capacity of long-term care systems to provide good-quality care, as it brought into focus the need to balance patient well-being with patient survival. Many measures taken by Member States during the first wave of the pandemic focused on protecting vulnerable groups, including older people receiving care, from exposure to the virus – often with the side-effect of limiting their rights. To stop the infection spreading through care homes, external visits were banned, residents were often isolated from one another, and visits from carers were limited to attending to their basic needs. This was psychologically difficult, especially for people in residential care facilities suffering from dementia or other psychological pathologies or terminal disease.

Member States have taken a number of measures to limit the negative effects of the pandemic on the well-being of care-home residents. Soon after the start of the pandemic, special meeting areas were designed (DE), contacts with visitors were carried out using telephones or video tools (CY, BG, DE, FR, HR, HU, LU, SK) or, when visits were allowed, their rules were revised to make sure that visitors did not display COVID-related symptoms (DK, HR). Guidance, training, and information measures were stepped up (AT, CZ, DE, SI). Residents in need of regular hospital treatment (e.g. chemotherapy) were provided with hospital accommodation (HR). Creative solutions were deployed to help residents cope with isolation, such as 'corridor-games', music broadcasting, and entertainment events (FR, LU). The pandemic also had an impact on the quality-assurance process itself. For example, in Germany regular quality inspections were temporarily stopped during the first phase of the pandemic, though it was still possible to conduct single quality inspections (e.g. when complaints were raised or serious quality deficits were suspected).

People in need of long-term care living at home also experienced loneliness and anxiety. To help them, community-based social services were provided by phone, e-mail or internet communication technologies (BG). Civil society organisations and the private sector stepped in too. For example, in France civil society organisations and city services used administrative data to identify and contact older people in need; several pharmacies offered free delivery for older people; one organisation provided free-of-charge nursing care; and some radios broadcasted family messages to older people. Sweden allocated funds to civil society associations to enable them to help counteract loneliness among older people through outreach activities by telephone or digital meetings, and to help with food purchases.

The pandemic negatively affected the working conditions of long-term care workers and is likely to have led to a more difficult situation for informal carers

COVID-19 has negatively affected the working conditions of the long-term care workforce. Although working conditions were already challenging in the long-term care sector before the outbreak of the pandemic, COVID-19 has put even more pressure on long-term care workers. Workers have in many cases been exposed to higher stress levels, due to high uncertainty regarding the evolution of the crisis, pressure to protect their care recipients, and anxiety over getting infected themselves. At the beginning of the crisis, in particular, the long-term care sector faced shortages in personal protective equipment and tests to adequately protect employees and users (BE, DE, EE, FR, PL, SE). Shortages of workers worsened during the crisis, as infected carers or carers at risk of having been infected had to quarantine and were unavailable to perform their job (EE, PL, SI).

Member States have introduced a wide range of measures to support long-term care workers during the crisis. Most Member States have provided personal protective equipment and prioritised long-term care workers for testing.[326] Additional measures taken to protect employees during the first period of the pandemic included special accommodation and transport for long-term care workers (FR, HR, RO) and weekly or other types of shifts (BG, HR, PL, RO). Member States have also focused on providing guidance, training, and

[326] At a later stage, long-term care staff were also prioritised for vaccination against COVID-19 in many Member States.

information to long-term care workers. A few Member States reported providing psychological support to long-term carers (FR, LU). Many Member States made efforts to increase the pool of available staff in the first part of the pandemic, either by mobilising workers from other sectors, including the healthcare sector (BE, DE, FR, HR, PL), or recruiting volunteers, medical students, and retirees (CZ, DE, IE, LU, PL, RO). Other measures to accommodate the increased pressure on and demand for long-term care workers included bans on firing long-term care workers (ES) and relaxed working-time regulations (LU). Member States with a high number of foreign workers eased the entry of long-term care workers and live-in carers from other Member States (AT, LU). Some Member States introduced measures to acknowledge the difficult situation of long-term care staff by issuing bonus payments for long-term care workers (CZ, DE, PL, RO, SK) or live-in carers (AT).

COVID-19 may also have put additional strain on informal carers. Although information about the situation of informal carers during this crisis is limited, reductions in the availability of formal care services, in particular daycare centres, would entail more people having to step in to provide informal care to someone in their family or social environment, and an increasing workload for people already providing informal care. Several Member States have reported increased reliance on informal care during the first period of the pandemic (HR, LU, SI, SK). Anecdotal evidence points to informal carers having faced increased social isolation due to precautions designed to avoid transmitting the virus to the care recipient. A number of Member States have introduced support measures for informal carers during the pandemic, including: special care leave (AT, BE, LU); the right to receive a care-giver allowance as a wage replacement benefit for an extended period of up to 20 working days (instead of 10 days) to provide or organise care in situations caused by the pandemic (DE); psychological support (AT, SI); and a toll-free number to receive advice and support (FR).

Member States have provided financial support to strengthen long-term care systems during the pandemic and to implement measures to protect long-term care recipients

Member States have made additional funding available to support long-term care systems during the pandemic. Although it is too early to assess any long-term impact on the sustainability of long-term care systems, most Member States have provided additional financial support to the long-term care system as result of the crisis (e.g. AT, BE, BG, CZ, DE, DK, EE, FR, HR, IE, LT, LU, NL, PL, RO, SE, SI, SK). In systems with regional competences (e.g. AT, BG, CZ, DK, SE), the state (or federal state in some Member States) in most cases makes available grants to regions and municipalities to finance the extraordinary burden of care. The additional costs for long-term care systems have largely been caused by the introduction of new hygiene measures (such as purchasing personal protective equipment, providing tests, adaptations to buildings) and by premiums for staff working during the crisis.[327/328] At the same time, residential care facilities, and to a lesser extent homecare

[327] In France, for example, EUR 506 million of the total budget increase of EUR 981 million was dedicated to a bonus payment for staff, while the Czech Republic dedicated around EUR 80 million of EUR 200 million additional long-term care financing support to bonus payments.

services, suffered from a loss in revenue, as there was less demand for formal care services. Some Member States (e.g. BE, DE, FR, LU) therefore also compensated services for their lost income. France estimated, for example, that half of the extra financial needs of long-term care services during the crisis are caused by additional expenditure and half by lost revenues.

The crisis strongly affected long-term care systems and laid bare structural weaknesses in the sector

To conclude, the pandemic has affected long-term care systems in many ways. It put long-term care recipients, a very vulnerable population group, at health risk, affected their well-being, and limited their access to formal long-term care services. The pandemic had strong implications for long-term care workers and possibly also for informal carers. Member States have made great efforts to implement measures to protect long-term care recipients and support long-term care workers and informal carers. In order to do so, they have made significant additional funding available.

The first period of the crisis has already shown that more investment and reforms are needed to tackle structural weaknesses in the long-term care sector. These weaknesses include staff shortages and a lack of physical resources in residential care. It is worth noting that the problems in long-term care systems that have arisen during the pandemic were caused not only by a lack of financial resources but also by insufficient organisation, management or co-ordination of long-term care services. Although the full effects on long-term care systems are not clear at the time of writing this report, it is not to be excluded that the COVID-19 crisis will have long-lasting impacts on the long-term care sector. The crisis may require a review of the provision of long-term care services, and of the organisation and financing of long-term care systems, influencing choices on the social and financial sustainability of current long-term care provision.

7.2 The impact of COVID-19 on long-term care reforms

This section reflects on the impact of COVID-19 on long-term care reforms which go beyond the ad hoc measures taken during the crisis.

In addition to ad hoc measures, the crisis spurred a public debate on the shortcomings and weaknesses in the system in most of the Member States, and may influence planned or ongoing reforms (DE, IE). Germany plans to present further measures relating to the efficiency, financing, and staffing of long-term care. In Ireland, reform of health and long-term care services is high on the political agenda, and the government formed in June 2020 has committed to delivering a commission to examine care and support for older people. Included in the new government's priorities were learning from and mitigating the impact of COVID-19 on the delivery of care, and accelerating the introduction of the *Sláintecare* programme. In addition, a nursing home expert panel has made a number of recommendations for reforms of the nursing home sector which are currently under examination.

[328] In addition, some Member States provided additional funds for diverse measures, including to fight loneliness (mostly by investing in telephone helplines). In Denmark, for example, funds were also directly allocated to organisations that should help deal with the crisis (e.g. an Alzheimer's organisation or a telephone counselling service for older people).

Some Member States started to introduce structural changes to the long-term care system in response to COVID-19 that remain in place after the crisis (FR, LU, NL, SI, SK). In France, the law of 7 August 2020 on social debt and autonomy created a fifth sector of the National Health System, dedicated to the loss of autonomy of older people and people with disabilities, with EUR 1 billion funding. It is the first step in a global reform of the French organisation. Luxembourg has taken measures to ensure the continuity of care in residential care facilities during evenings, weekends, and public holidays (e.g. by establishing an on-call system for general practitioners, and establishing stocks of medications in care homes). Discussions on the need to reform the training of health professionals have been reopened. The Netherlands intends to strengthen the connection and collaboration between long-term care and healthcare, and to focus research on pandemic-related issues. Slovenia's new draft long-term care act aims to facilitate and ensure the implementation of long-term care as the new pillar of social security: this will take the form of integrated activities, allowing people to enjoy independence and security for as long as possible. Slovakia is preparing a proposal for a comprehensive reform, aimed at providing affordable and high-quality long-term social care and healthcare. The government of Slovakia has committed itself to a comprehensive reform of long-term and palliative care. The main aim of the proposed reform is to strengthen the integration of social care and healthcare, which is a prerequisite for ensuring quality and affordable long-term care for all age groups. Other Member States have not decided or formally started preparing structural changes so far, as it is very early to draw lessons from the COVID-19 crisis.

The COVID-19 emergency has put on hold or delayed reforms of long-term care systems in some Member States. Belgium has postponed planned cost-saving measures, which will be scrutinised and subject to revision after the crisis. In Finland, the preparation of many of the measures included in the government programme, such as legislative reform, the quality recommendation for older people, and the age strategy, were delayed by several months due to the epidemic.

It is too early to assess how deep and lasting the effect of the COVID-19 crisis on long-term care will be, as the crisis is still ongoing. As discussed, a few Member States have introduced structural changes to their long-term care systems that may remain in place after the crisis. However, as many Member States are still in a phase where short-term crisis management is the priority, it is too early to assess the feasibility or likelihood of making some of the temporary measures permanent. Although likely to be significant, it is also too early to assess how deep and long-term the effect will be of the COVID-19 crisis on long-term care systems, and how it may also affect the mind-sets of policy-makers and people in general with regards to the design of long-term care systems. It will thus be important to draw lessons from the crisis to improve long-term systems on a structural basis and make them more resilient in the future.

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ANNEX 1 KEY DEFINITIONS AND ABBREVIATIONS

Key word	Definition
Access (to long-term care)	Possibility of using long-term care services, encompassing the dimensions of cost/affordability, availability, awareness (about the existence of a particular service), and physical accessibility.
Accessibility (of long-term care)	Degree to which people with limitations in (instrumental) activities of daily living have access to products, services, and infrastructure on an equal basis with others.
Activities of daily living (ADLs)	Personal care activities such as bathing, dressing, eating, getting in and out of bed or a chair, moving around, using the toilet, and/or controlling bladder and bowel functions.
Affordability (of long-term care)	Degree to which people in need of long-term care are able to meet the out-of-pocket costs (after social protection or security) associated with the use of long-term care.
Availability (of long-term care)	Degree to which long-term care goods or services are available for purchase or reach people in need of them.
Cash benefits for long-term care	Monetary transfers to a person in need of long-term care and/or their family to buy long-term care services (as opposed to in-kind benefits).
Community-based care	Long-term care provided and organised at community level, for example in the form of adult day services or respite care.
Formal homecare	Long-term care provided in an individual recipient's home, by a professional long-term care worker.
Informal carer	Person providing informal long-term care to someone in their social environment – most often a partner, parent or other relative – who is not hired as a care professional.
Informal long-term care	Long-term care provided by an informal carer.
In-kind benefits	Social transfers in kind from government or other authorities, including goods and services purchased on behalf of individuals. The goods and services may be the output of these institutions as non-market producers, or may have been purchased by these institutions from market producers for onward transmission to households for free or at prices that are not economically significant. These benefits may also take the form of reimbursement of the cost of goods or services purchased by individuals.
Instrumental activities of daily living (IADLs)	Household activities such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone.
Live-in carer	Long-term care worker who lives in the care recipient's household

	and provides long-term care.
Long-term care	A range of healthcare and social care services and assistance, for people who, as a result of mental and/or physical frailty and/or disability and/or old age, over an extended period of time depend on help with daily living activities, and/or need some permanent nursing care.
Long-term care recipient	A person in need of long-term care who receives any kind of long-term care (formal and/or informal long-term care).
Out-of-pocket payment	Direct payment for long-term care goods and services from primary income or savings, where the payment is made by the user at the time of the purchase of goods or use of services; or the part not reimbursed by a third party.
Residential care	Long-term care provided to people staying in a residential long-term care setting.
Semi-residential care	Intermediate cases of long-term care combining formal homecare with specific elements of residential care, for instance day or night care, respite care, and short-stay services.
Social protection	All interventions from public or private bodies intended to relieve households and individuals of the burden of a defined set of risks or needs, provided that there is neither a simultaneous reciprocal nor an individual arrangement involved. The list of risks or needs that may give rise to social protection is, by convention, as follows: 1. Sickness/healthcare 2. Disability 3. Old age 4. Survivors 5. Family/children 6. Unemployment 7. Housing 8. Social exclusion not elsewhere classified.

Abbreviations

AAL	Ambient Assisted Living
ADLs	Activities of daily living
AROP	At risk of poverty
ASCOT	Adult social care outcomes toolkit
AWG	Ageing Working Group of the Economic Policy Committee
Cedefop	European Centre for the Development of Vocational Training
CJEU	Court of Justice of the European Union
EHIS	European Health Interview Survey
EPC	Economic Policy Committee
EQLS	European Quality of Life Survey
EQUASS	European quality in social services framework
ESF+	European Social Fund Plus
ESPN	European Social Policy Network
EU	European Union
EU-SILC	European Union Statistics on Income and Living Conditions
EUROFOUND	European Foundation for the Improvement of Living and Working
FTE	Full-time equivalent
GALI	Global activity limitation indicator
IADLs	Instrumental activities of daily living
ILO	International Labour Organization
ISCO	International standard classification of occupations
LFS	European Union labour force survey
LTC	Long-term care
NACE	Nomenclature of economic activities
OECD	Organisation for Economic Co-operation and Development
PREMs	Patient-reported experience measures
PROMs	Patient-reported outcome measures
ROPI	The Rights of Older People Index
SHA	System of Health Accounts
SHARE	Survey of Health, Ageing and Retirement in Europe
SMEs	Small and medium-sized enterprises
SPC	Social Protection Committee
SPC ISG	Indicators Sub-Group of the Social Protection Committee
TILDA	Irish longitudinal study on ageing
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization

Member States

BE	Belgium
BG	Bulgaria
CZ	Czech Republic
DK	Denmark
DE	Germany
EE	Estonia
IE	Ireland
EL	Greece
ES	Spain
FR	France
HR	Croatia
IT	Italy
CY	Cyprus
LV	Latvia
LT	Lithuania
LU	Luxembourg
HU	Hungary
MT	Malta
NL	Netherlands
AT	Austria
PL	Poland
PT	Portugal
RO	Romania
SI	Slovenia
SK	Slovakia
FI	Finland
SE	Sweden