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Accompanying the document

Commission proposal for a Council Recommendation
on access to affordable high-quality long-term care

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# 1. INTRODUCTION

'For nights on end [during the pandemic], we all stood at our windows and doors to applaud critical workers. We felt how much we relied on all those women and men who work for lower wages, fewer protections and less security. The applause may have faded away, but the strength of feeling cannot. This is why the implementation of the European Pillar of Social Rights is so important — to ensure decent jobs, fairer working conditions, better healthcare and better balance in people's lives. [...]

We will come forward with a new European care strategy to support men and women in finding the best care and the best life balance for them.'

President Ursula von der Leyen, 2021 State of the Union speech<sup>1</sup>

In her 2021 State of the Union speech, Commission President Ursula von der Leyen announced a European care strategy to support both carers and care receivers, from childcare to long-term care (LTC). The strategy sets out a holistic and lifelong vision for care that enables everyone to access and afford the high-quality care they need. It also aims to help improve working conditions in the care sector, close the gender employment gap, increase women's empowerment, and make the most of the benefits of the 'silver economy' and digitalisation.

The initiative will support the implementation of the European Pillar of Social Rights<sup>2</sup>, notably principle 18 that states that 'Everyone has the right to affordable long-term care services of good quality, in particular home care and community-based services'. It follows up on the European Pillar of Social Rights action plan, the gender equality strategy<sup>3</sup>, and the Green Paper on Ageing<sup>4</sup>, which highlighted the need for integrated and person-centred long-term care that is accessible, affordable and of high quality. It also respects the United Nations Convention on the Rights of Persons with Disabilities<sup>5</sup>, which recognises the equal right of all persons with disabilities to live independently in the community, with choices equal to others.

The preparatory work for the initiative built on the 2021 Joint Report on Long-Term Care prepared by the Social Protection Committee (SPC) and the Commission (Directorate-General for Employment, Social Affairs and Inclusion). This report analysed the common challenges in related to the provision of long-term care and set out key messages on the way forward. In addition, several studies (e.g. Social protection in long-term care (by the OECD)) and EU publications (e.g. long-term care workforce (by Eurofound)) as well as European statistics provide the analytical underpinning for this staff working document. A range of collaborative processes in the context of the European Semester process and the social Open Method of Coordination enriched the knowledge base for the initiative. To complement this input, the

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<sup>&</sup>lt;sup>1</sup> European Commission, 2021, State of the Union Address by President von der Leyen.

<sup>&</sup>lt;sup>2</sup> Commission (COM/2021/102 final), The European Pillar of Social Rights Action Plan.

<sup>&</sup>lt;sup>3</sup> Commission (COM/2020/152 final), <u>A Union of Equality: Gender Equality Strategy 2020-2025.</u>

<sup>&</sup>lt;sup>4</sup> Commission (COM/2021/50 final), Green Paper on Ageing.

<sup>&</sup>lt;sup>5</sup> UN, 2006, Convention on the Rights of Persons with Disabilities.

Commission published a call for evidence and a targeted stakeholder consultation between February and April 2022.<sup>6</sup> The initiative consists of a Commission Communication on the European care strategy<sup>7</sup>, a Commission proposal for a Council Recommendation on access to affordable high-quality long-term care <sup>8</sup>, and a Commission proposal for a Council Recommendation on the revision of the Barcelona targets on early childhood education and care <sup>9</sup>. On long-term care, the aim is to address the common challenges and structural weaknesses<sup>10</sup> that were highlighted by the COVID-19 pandemic. To do so, the Commission sets out a framework for policy reform to ensure better and more affordable access to high-quality long-term care services and improve working conditions in the sector.

This staff working document provides the analysis and evidence underpinning the Commission's proposal for a Council Recommendation on long-term care. It also illustrates the policy narrative on long-term care as formulated in the Commission Communication on the European care strategy. For the purposes of this document, long-term care means 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, 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, such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone)<sup>11</sup>.

Following the introduction, chapter 2 gives the wider socio-economic and political context of the initiative. Chapter 3 summarises the common challenges of long-term care at Member State level and the *status quo* underpinning the initiative. Chapter 4 describes the current support and initiatives available at EU level. Chapter 5 identifies different policy scenarios and practical examples of policy responses to address the common challenges of long-term care.

#### 2. CONTEXT OF THE INITIATIVE

Care is one of the foundations of a social Europe. Policy developments in this regard are deeply inter-linked with demographic, social and labour market trends, as well as with the digital and green transition. Against the **background of population ageing**, geographic mobility, increased share of single person households and increasing women participation on the labour market, Member States are confronted with significant challenges to meet the

<sup>&</sup>lt;sup>6</sup> Commission staff working document (SWD/2022/440 final), Summary of consultation activities.

<sup>&</sup>lt;sup>7</sup> Commission Communication (COM/2022/440 final), The European care strategy.

<sup>&</sup>lt;sup>8</sup> Commission (COM/2022/441 final), Proposal for a Council Recommendation on access to affordable high-quality long-

<sup>&</sup>lt;sup>9</sup> Commission (COM/2022/442 final), Proposal for a Council Recommendation on the Revision of the Barcelona Targets on early childhood education and care.

<sup>&</sup>lt;sup>10</sup> Council (9144/21), Endorsement – Key conclusions on 2021 long-term care report of the Social Protection Committee and the European Commission.

<sup>&</sup>lt;sup>11</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities in an ageing society</u>, Volume I, Publications Office of the European Union, Luxembourg.

increasing demand for long-term care. The **COVID-19 pandemic** has further exposed the structural weaknesses of long-term care systems.

# 2.1. Demographic trends

Consistently **low birth rates and higher life expectancy** are transforming the shape of the EU's age pyramid. Europe is transitioning to a population structure with more older people, a development which is already apparent in several EU Member States today. As a result of demographic change, the proportion of people of working age in the EU is shrinking, while the relative number of those retired is expanding. In 2021, more than one fifth (20.8%) of the EU's population was 65 years and over, while young people (0 to 14 years old) made up 15.1 % and people of working age 64.1%. The share of people aged 65-79 years and over is projected to increase by 23% over the next 30 years 13, while the share of people aged 80 or over of the total population is projected to almost double. As a consequence, the **old-age-dependency ratio** is projected to increase significantly from 32.5% in 2021 to 52.0% in 2050.

Despite progress in healthy life years, as well as in preventive approaches and use of digital technologies, the ageing of the population will lead to a **growing need for long-term care**. 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.

Although there is no single internationally accepted and standardised definition of what constitutes long-term care needs, Member States usually take into account the presence and extent of difficulties with personal care (ADLs) and household activities (IADLs). Thus, data from the European Health Interview Survey (EHIS) can be a proxy for the number of people in need of long-term care.<sup>17</sup>

On average, 26.6 % of people aged 65 or over and 39.4% aged 75 or over living in private households were in need of long-term care, according to 2019 data for the EU-27. These self-reported long-term care needs ranged from 11.6 % in Luxembourg to 56.5 % in Romania (see Figure 1). In the first (i.e. lowest) income quintile, 35.9 % were in need of long-term care, compared with 17.2 % in the fifth income quintile across the EU-27. Comparing data for 2019 and 2014 shows that self-reported needs for long-term care among people aged 65 or over slightly decreased from 27.2 % in 2014.

<sup>&</sup>lt;sup>12</sup> Eurostat, 2022, <u>Population Structure and Ageing</u>.

<sup>&</sup>lt;sup>13</sup> From 14.8% in 2021 to 18.2% in 2050.

<sup>&</sup>lt;sup>14</sup> From 6.0 % in 2021 to 11.3% in 2050. The population aged 65+ is projected to be 30.3% in 2070, while the population aged 80+ is projected to be 13.2% of the total population.

<sup>&</sup>lt;sup>15</sup> The number of people aged 65+ (the age when they are generally economically inactive) for every 100 of people of working age (15-64).

<sup>&</sup>lt;sup>16</sup> Eurostat, 2022, <u>Population Structure and Ageing</u>.

<sup>&</sup>lt;sup>17</sup> 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'.

<sup>&</sup>lt;sup>18</sup> 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.

<sup>&</sup>lt;sup>19</sup> EHIS, 2019, indicator hlth ehis tadli.

70% 60% 50% 40% 30% 20% 10% 0% Cleck Republic Netherlands Lithuania Poland CABLIS Bulgaria Austria ■ Women 65+ ■ Men 65+ ♦ Total 65+

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

Source: EHIS wave 3, 2019, hlth\_ehis\_tadle.

Across the EU, according to the **projections**<sup>20</sup> **from the 2021 Ageing Report**<sup>21</sup>, the number of potential dependants of all ages, defined as people with a disability, 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%. In 2019, 17.0 million of those dependents (10.8 million women and 6.1 million men) were above 65 years old, a share of 55% of all dependants; however, this age group accounts for only 4% of the general population.<sup>22</sup> Therefore, while acknowledging that people of all ages may require long-term care services, most of the statistical data in this document linked to long-term care concerns the group of older people 65 years and over.

The **demographic profiles of EU regions** vary widely, notably between urban and rural areas, with some places ageing significantly and others expanding their working age population. However, the demographic projections of the Atlas of Demography<sup>23</sup> show that patterns of ageing do not necessarily follow the urban-rural classification of territories (see Figure 2). Although rural areas have a higher share of older adults, there is no clear-cut pattern where rural areas would be ageing faster. The population is ageing faster in the areas affected by depopulation, including in some small towns and cities. In rural areas, the share of older people is projected to increase from 19% in 2011 to 30% in 2050. During that same time period, the share of older people would proportionally even increase more in towns (from 17% to 29%)

<sup>&</sup>lt;sup>20</sup> Ageing Working Group (AWG) reference scenario assumes that half of the expected gains in life expectancy are spent without disability (i.e. not demanding care).

<sup>&</sup>lt;sup>21</sup> European Commission and Economic Policy Committee, 2021, <u>The 2021 Ageing Report</u> – Economic and budgetary projections for the EU Member States (2019-2070), Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>22</sup> As an underlying difficulty in the analysis of all aspects of long-term care is the limited availability of comparable data, a variety of data sources, including national and non-harmonised data, are used in this document.

<sup>&</sup>lt;sup>23</sup> European Commission, 2022, <u>Atlas of Demography</u>, Interactive tool.

and cities (from 15% to 27%). Consequently, the difference between the share of older people in rural areas and in cities could become smaller in several Member States over the next decades.

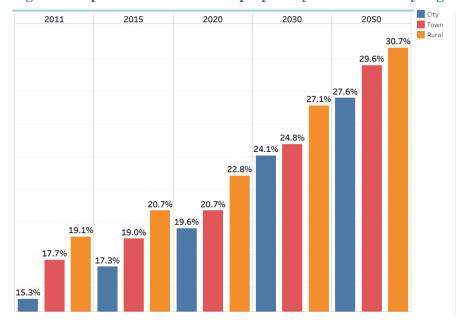


Figure 2: Expected median share of people 65 years and older by degree of urbanisation

Source: JRC Atlas of Demography

#### 2.2. Social and labour market trends

Old-age poverty or social exclusion slightly increased since the mid-2010s. Almost 20.2 % (18.1 million) of people aged 65 and above in the EU-27 in 2020 were at risk of poverty or social exclusion, while in some countries the share is much higher. The monetary poverty risks among older people have slightly risen over the past three years, while severe material and social deprivation has continued decreasing and inequalities become more pronounced in old age. In the EU-27, the gender gap in old-age poverty is larger than in working age, and more so among those aged 75 and above (almost 1.4 pps, i.e. 16.8% among men, 18.2% among women). The gender pension gap caused by the aggregated impact of labour market inequalities remains significant (27.7 % in 2020 among those aged 65-79) despite a slight decrease (from 31.9 % in 2016).

More older women than older men are in need of long-term care, while being less able to afford it. Women live longer than men<sup>29</sup>, and men tend to spend a greater proportion of their

<sup>&</sup>lt;sup>24</sup> EU-SILC, 2020, Persons at risk of poverty or social exclusion (AROPE) by age and sex, ilc\_peps01n. Please note that the AROPE indicator is flagged with break in series for EU-27, DK, DE, IE, FR, LU.

<sup>&</sup>lt;sup>25</sup> EU-SILC, At-risk-of-poverty rate (AROP), ilc\_li02.

<sup>&</sup>lt;sup>26</sup> EU-SILC, Severe material and social deprivation rate, ilc\_mdsd11.

<sup>&</sup>lt;sup>27</sup> EU-SILC, 2020, Relative at risk of poverty gap by poverty threshold, ilc\_li11.

<sup>&</sup>lt;sup>28</sup> EU-SILC, 2020, Gender pension gap by age group, indicator ilc\_pnp13. Please note that the indicator is flagged with break in series for EU-27, DK, DE, IE, FR, LU.

<sup>&</sup>lt;sup>29</sup> Eurostat, 2020, Life expectancy at birth, indicator SDG 03 10, men 77.5 years and women 83.2 years in 2020.

somewhat shorter lives in good health.<sup>30</sup> In addition, women have lower earnings (including pensions) across the EU and are exposed to a higher risk of poverty or social exclusion in all Member States. At the same time, older women<sup>31</sup> are more likely to live alone and thus may not be able to rely on support from other household members.

Old-age poverty and social exclusion also aggravate older people's **loneliness** and isolation, affecting their well-being and social engagement. This is often linked to poor access to social care and healthcare, transport and housing services. Loneliness increases the likelihood of admission to long-term care facilities and sometimes affects older people in need of long-term care, despite social activities, potential company with peers and the care provided.<sup>32</sup>

Women are increasingly participating in the labour market – a positive development in the context of the increasing importance of equality of opportunities, ageing societies and a decreasing working-age population<sup>33</sup>. However, women also carry the bulk of informal caring activities (and almost 90 % of workers in the formal long-term care sector are women). Therefore, in 2020, 6.3 % of women aged 50-64 wanting to work **did not seek employment** due to caring responsibilities, compared to only 2.5 % of men in this age group.<sup>34</sup> Informal carers play an important role in long-term care, as they provide an estimated 33-39 billion hours of care worth around 2.7% of GDP across the EU-27 (compared to public long-term care expenditure of 1.7% of GDP, see chapter 3).

While older people were severely impacted by the COVID-19 crisis in general, the **recovery** on the labour market was more dynamic for older workers after the COVID-19 crisis than for the economy as a whole. After a dramatic contraction in 2020, the EU economy rebounded strongly in 2021 with an 1.4 pps increase of the employment rate after the earlier drop of 1 pps. Older workers aged 50-64 weathered the crisis better than average, as their employment rate only grew less fast, by 0.6 pps in 2020, than it did earlier during the 2010s (by a yearly 1.4-2.2 pps). As a result, their employment rate reached 60.5% in 2021 against 46.6% in 2012. Although the recovery was stronger for men than for women in this age group, **employment rates of women grew more**, by 37% over this period (vs 24% for men) reducing the gender employment gap from 14.2 pps to 12.7 pps.

Changing and more diverse family structures and more individuals and couples remaining childless also lead to increased need for formal care services, as the traditional capacity of the family to provide informal care is decreasing. In 2020, 40 % of older women were living alone, double the share for men.<sup>35</sup> While the total number of households rose by 7.2% between 2010 and 2020, single adult households without children grew by 20.3% across the EU. Moreover, households with two or more adults not being a couple (e.g. older person living with other

<sup>&</sup>lt;sup>30</sup> Eurostat, 2020, Healthy life years at birth, indicator SDG\_03\_1, men 63.5 years; women 64.5 years in 2020.

<sup>&</sup>lt;sup>31</sup> In 2019, 40 % of older women were living alone, double the share for men. See Eurostat, <u>4 in 10 women aged 65 or over live alone</u> (press release of 23 June 2020).

<sup>&</sup>lt;sup>32</sup> Casabianca, E. and Kovacic, M., 2022, <u>Loneliness among older adults - A European perspective</u>, JRC Policy brief.

<sup>&</sup>lt;sup>33</sup> The employment rate of women increased from 60.7% in 2010 to 66.2 % in 2020 (Employment rate by sex, indicator SDG\_08\_30).

<sup>&</sup>lt;sup>34</sup> EU-LFS, 2020, indicator, lfsa\_igar.

<sup>&</sup>lt;sup>35</sup> EU-LFS, 2020, indicator lfst\_hhindws.

members of the family, economically independent roommates), decreased by 7.4 % over the 2010-2020 period in the EU<sup>36</sup>.

Increased labour 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. While increasing retirement ages grant higher pensions and allow providing better support, they also keep people busy working for longer. Adequate and affordable formal long-term care services and policies helping to **reconcile paid employment with caring/familial responsibilities** help meeting the rising demand for care and sustaining the growth in women's labour market participation, while keeping in mind work-life balance and the health of all involved.

# 2.3. The digital transition

**Digital technologies**, especially artificial intelligence, are **transforming the world** at an unprecedented speed and **present manifold opportunities**. They have changed our societies and our economies and are increasingly changing the way long-term care is provided. This includes fostering independent living, improving access to high-quality and affordable care, while tapping into the potential of the Single Market and facilitating upscaling of digital solutions for the benefit of people in need of care and their caregivers. Effective deployment of new technologies may also boost the efficiency of long-term care expenditure. The way the digital transition impacts the care economy is documented in recent research. The global market for ICT solutions for healthcare monitoring in private homes was projected to grow from nearly EUR 11 billion in 2016 to roughly EUR 32 billion by 2021, while the European market for robots and other devices assisting older people is estimated to be worth about EUR 13 million in 2016, with clear prospects for further growth<sup>37</sup>.

The **growth of the platform economy** in the recent years brought forth the development of digital care platforms, such as in private household childcare or care for older people. The size of the EU platform economy in the domestic and home services sector has grown to an amount of EUR 1.5 billion in 2020 from EUR 0.8 billion in 2016<sup>38</sup>, and is expected to continue to expand in size<sup>39</sup>. Digital labour platforms in the care sector provide a digital infrastructure to match supply and demand in the field of private household care. They provide a flexible and easily accessible way to access work in this field and facilitate access to care for consumers. Digital labour platforms can play an important part in formalising work in this sector<sup>40</sup>.

<sup>&</sup>lt;sup>36</sup> Eurostat, 2021, <u>Household composition statistics</u>.

<sup>&</sup>lt;sup>37</sup> Technopolis Group and Oxford Economics, 2018, The Silver Economy, study prepared for the European Commission DG Communications Networks, Content & Technology.

<sup>&</sup>lt;sup>38</sup> PPMI, 2021, Study to support the impact assessment of an EU initiative on improving working conditions in platform work, p.81.

<sup>&</sup>lt;sup>39</sup> Ibid.

 $<sup>^{40}</sup>$  Ticona, J., and Mateescu, A., 2018, Trusted strangers: Carework platforms' cultural entrepreneurship in the on-demand economy, New Media & Society, 20(11), 4384, 4385.

# 3. STATE OF PLAY OF LONG-TERM CARE – CHALLENGES IN MEMBER STATES

Member States face similar challenges and structural weaknesses of care systems, which have been brought to the fore by the pandemic. The analysis in this chapter describes the status quo in Member States structured in five sub-sections: organisation and financing of long-term care systems, social protection for long-term care, availability and accessibility of long-term care, quality of long-term care workforce and informal carers. Subsequently, chapter 5 builds on these identified common challenges by showcasing examples and opportunities how to address them.

# 3.1. Organisation and financing of long-term care

There are substantial differences across the EU in terms of how long-term care is funded, organised, delivered and monitored. Member States are at different maturity levels with regard to long-term care policy and the organisational framework. Some Member States currently allocate relatively low levels of expenditure to long-term care, which might be indicative of long-term care being a low policy priority or of a heavy reliance on informal care (sometimes expressed as a legal obligation for family members to take care of their dependent relatives). Few Member States have long responded to the need to address long-term care as an important social risk by mitigating individual needs either through universal or at least partial coverage and public support in cash or in-kind. In these countries, long-term care is integrated into social security systems (next to health, accident/disability, retirement and unemployment) and/or an important part of social assistance schemes.

#### 3.1.1. Organisation of long-term care systems

Long-term care is organised in an often **complex system of services across health and social care** and sometimes other types of support, such as housing and local activities (e.g. volunteering). According to a recent report by the ESPN<sup>41</sup>, only 10 out of 27 Member States (AT, BE, DE, DK, ES, FI, FR, LU, NL, SE) have an 'integrated' public system, (i.e. having a dedicated public social protection branch for long-term care) while out of these 10 countries, at least two feature either not totally integrated systems (AT) or a division of responsibilities among subnational levels (BE). The other 17 Member States<sup>42</sup> have a public system usually split between social care/social assistance and healthcare and between authorities in charge of providing cash benefits and authorities in charge of providing in-kind services.

There are differences in terms of the **territorial level** at which long-term care is organised. In most of the Member States (AT, DE, LU, NL, IE, MT, CY), the national level plays a pivotal role in the organisation of long-term care. Here, an important complementary role is played by local and regional authorities running services. Belgium, being a federal state, is a specific case where long-term care organisation has been mostly devolved to the regions (federated entities).

<sup>&</sup>lt;sup>41</sup> Pavolini, E., 2021, <u>Long-term care social protection models in the EU</u>, European Social Policy Network (ESPN), Luxembourg: Publications Office of the European Union.

<sup>&</sup>lt;sup>42</sup> Recently, in May 2022, Estonia changed its legislation to introduce a definition of long-term care that includes healthcare services, care services and support services for everyday coping.

In France, regional administrations implement national health policies defined centrally by the government, whereas the decentralised local authorities are responsible for social policy. In the Nordic countries (DK, FI, and SE) municipalities are in charge of ensuring an integrated healthcare and social care long-term care system. In 15 Member States (BG, CZ, EE, EL, ES, HR, IT, LV, LT, HU, PL, PT, RO, SI, SK), long-term care organisation responsibilities are allocated to **different layers of government depending on the type of provision** (healthcare services, social care services, and cash allowances). <sup>43</sup>

This **horizontal fragmentation** between the healthcare and social care systems, as well as the **vertical fragmentation** between the national, regional, and local levels implies different organisational structures and conditions of services not only across, but also within different Member States. As a consequence, the **comparability of administrative data are limited**, and sometimes data are even **not available** at national level.

Formal long-term care services are organised as home, community-based or residential care. **Home care** means long-term care provided in the recipient's private home, by professional long-term care workers. **Community-based care** means long-term care provided and organised at community level, for example, in the form of adult day services or respite care (semi-residential care), meaning that people in need of long-term care continue to live in their private homes but receive long-term care services outside of their home in a building within their community. By comparison, **residential care** is provided to people staying in a residential long-term care setting. In practice, these services are available in all Member States, alongside other in-kind contributions (e.g. house adaptations) or technological devices, but to a different extent. Home care is for example the main setting in a number of Member States (AT, CZ, DE, EE, EL, FI, IT, SE), while in others (FR, RO) most recipients of formal care are cared for in a residential care setting.<sup>44</sup>

Long-term care services provided by the national and/ or local authorities and associations are primarily considered as **social services of general interest**<sup>45</sup>, as they have a clear social function: facilitate social inclusion and safeguard fundamental rights of older people; complement and support the role of families in caring for the oldest members of the society; provide assistance for people in permanent or temporal need etc.

Member States provide **long-term care services in-kind and via cash benefits**. An important distinction among these schemes is between 'bound' cash benefits (beneficiaries have to document how the resources that they received are spent) or 'unbound' benefits (beneficiaries are free to use the resources as they prefer without any form of accountability). Most countries with cash benefits (12 out of 19) use 'unbound' cash benefits (AT, BE, BG, CY, CZ, DE, FI, HR, IT, PL, PT, SI). Only 7 (ES, FR, LT, LU, LV, NL, SK) use 'bound' ones. Schemes based on **'bound' cash benefits usually ensure coordination** between the beneficiary and the long-

<sup>&</sup>lt;sup>43</sup> Pavolini, E., 2021, <u>Long-term care social protection models in the EU</u>, European Social Policy Network (ESPN), Luxembourg: Publications Office of the European Union.

<sup>&</sup>lt;sup>44</sup> KPMG, 2021, Study on the long-term care supply and market in EU Member States.

<sup>&</sup>lt;sup>45</sup> Commission Communication (COM/2006/177 final), <u>Implementing the Community Lisbon programme: Social services of</u> general interest in the European Union.

term care public system (in terms of social workers and health professionals' supervision, and in terms of integration with the provision of long-term care services). Schemes based on **'unbound' cash benefits leave more freedom of choice** and flexibility to beneficiaries, but they do not often foster coordination and there is less leverage for public intervention for quality assurance of the care received.<sup>46</sup>

Across the EU, significant differences exist also in the **market structure for long-term care services**. A recent study<sup>47</sup> covering 16 Member States<sup>48</sup> showed significant changes in the supply structure with more market-based provision through private actors (both for-profit and non-profit) over the last three decades in the countries studied. The quantitative data from five countries showed a trend towards privatisation in the market, with an increasing number of private for-profit and private non-profit providers – 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). Marketization and privatisation can affect different dimensions of long-term care, including the supply and affordability of care as well as the quality of care provided and working conditions for care workers.

Whereas formal 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. 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. Also, the shares of residential care, community care, and home care in the long-term care market differ significantly between the Member States analysed.

Long-term care stakeholders are manifold. They include people in need of long-term care, their family members and organisations representing them, relevant authorities (national, regional, local), social partners, civil society organisations, social economy actors, providers of different long-term services (residential, home care, community-based care) and with various legal status (public, private for-profit, private non-profit), as well as bodies responsible for promoting social inclusion and integration and protection of fundamental rights, including national equality bodies.

#### 3.1.2. Public expenditure on long-term care

Population ageing will significantly increase demand for long-term care over the next decades. On average in the EU, public expenditure on long-term care is projected to increase from 1.7 % of GDP in 2019 to 1.9 % in 2030 and 2.5 % of GDP in 2050, with marked variations

<sup>&</sup>lt;sup>46</sup> Pavolini, E., 2021, <u>Long-term care social protection models in the EU</u>, European Social Policy Network (ESPN), Luxembourg: Publications Office of the European Union.

<sup>&</sup>lt;sup>47</sup> KPMG, 2021, Study on the long-term care supply and market in EU Member States.

<sup>&</sup>lt;sup>48</sup> AT, BE, BG, CZ, DE, EE, EL, ES, FI, FR, IE, IT, NL, PL, RO, SE

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). Figure 3 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<sup>49</sup>.

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 with public long-term care expenditure increasing from 1.7 % in 2019 to 2.1 % in 2030 and 3.3 % of GDP in 2050 for the EU-27 as a whole.

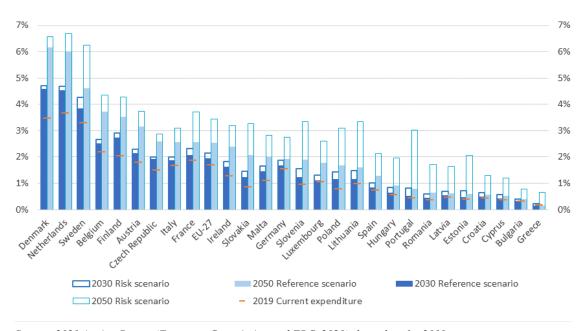


Figure 3: Public spending on long-term care as % of GDP, current and projections

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

Out of total current public long-term care expenditure in the EU-27 in 2019, 26 % went on cash benefits, 26 % on home care, and 48 % on -residential care, with marked variations from these averages across the Member States. Typically, the average cost of residential care per person is higher than in home care, but that is also influenced by the fact that the population in residential care has a greater degree of dependency.

Higher levels of public long-term care expenditure also translate into better social protection coverage for long-term care and access to long-term care services in general. Nevertheless,

<sup>&</sup>lt;sup>49</sup> European Commission and Economic Policy Committee, 2021, <u>The 2021 Ageing Report</u> – Economic and budgetary projections for the EU Member States (2019-2070), Publications Office of the European Union, Luxembourg.

public expenditure needs to be fiscally sustainable to ensure the ability of a government to sustain its current spending, tax and other policies in the long run. Moreover, also the wider macroeconomic policies, such as fiscal, monetary and trade policies, shape long-term care in the context of women's and men's opportunities in paid employment and the resources available for policies aimed at reducing gender inequalities.

# 3.1.3. Financing long-term care

Long-term care is either financed by public expenditure, which can be tax-based or social insurance-based social protection, or via private expenditure, which includes compulsory and voluntary private insurance schemes and out-of-pocket payments. However, in most cases, long-term care is financed through a mix of public and private sources. Data regarding the financing sources of long-term care is only partial, as many Member States report expenditure on the category long-term care (health) in the System of Health Accounts<sup>50</sup>, but no data for the category long-term care (social). As it can be seen in Figure 4, taxation rather than social insurance is the predominant form of public financing of long-term care in the EU (for 12 MS<sup>51</sup>), while a number of Member States mix social insurance schemes with tax-financing (10 MS<sup>52</sup>) and five Member States<sup>53</sup> use predominantly compulsory social contributions. The specific design usually is grounded in the historical and institutional context of the Member State.

Social insurance systems are financed from contributions, generally from employees and employers in the form of payroll taxes. A main advantage of social insurance-based systems is that funds are ear-marked for long-term care and the contributions give a person the entitlement to receive long-term care when they need it, thus likely increasing residents' willingness to finance long-term care. With their contributions, the public expects clear eligibility criteria and a right to a level of benefits that is not means tested.<sup>54</sup> 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 and are sensitive to changes in the labour market and the wage share of national income. 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. However, also social insurance systems incorporate either user charges or the benefit rates are not necessarily sufficient to fund the full care package a person requires.<sup>55</sup>

<sup>&</sup>lt;sup>50</sup> The System of Health Accounts (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.

 $<sup>^{51}</sup>$  AT, BG, CY, DK, ES, FI, HR, IE, IT, LV, RO, SE

<sup>&</sup>lt;sup>52</sup> CZ, EE, FR, HU, LT, MT, PL, PT, SK, SI

<sup>&</sup>lt;sup>53</sup> BE in the Flemish Federated entity, DE, EL, LU, NL

<sup>&</sup>lt;sup>54</sup> Karagiannidou, M. and Wittenberg, R., 2022, Social Insurance for Long-term Care, LSE Care Policy and Evaluation Centre, forthcoming.

<sup>&</sup>lt;sup>55</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities</u> in an ageing society, Volume I, Publications Office of the European Union, Luxembourg.

In tax-financed systems, the costs of long-term care are met out of the general revenues from taxes levied on a national, regional or local level. These taxes can include taxes on labour, consumption, capital, etc. and it is the discrete and flexible choice of governments how much funds to allocate to long-term care. 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 and mitigating fluctuations in the labour market. A well-diversified taxation system thus implies a lower cost on labour compared with insurance-based systems, supporting employment and growth.<sup>56</sup>

It can be distinguished between universal tax-funded systems and safety net tax-funded systems. Nordic countries (e.g. SE, DK, FI) are typical examples of universal tax-funded long-term care systems with generous coverage and low out-of-pocket payments. Nordic long-term care systems are usually decentralised and municipalities and local governments have some autonomy in determining the needs assessment and eligibility criteria and providing long-term care services. By contrast, safety net tax-funded systems provide long-term care services only based on assessment of care needs and an assessment of the person's (and sometimes their family's) income and assets. Thus, publicly funded long-term care is prioritised to those with the highest care needs and with less income and assets. The principle aim of the means-test is to protect those individuals who would otherwise be unable to pay for long-term care themselves and would have unmet needs for care. However, such systems may result in increasing unmet needs if the threshold is set to low that the lower middle class is not poor enough to be eligible but nevertheless struggle with care expenses.<sup>57</sup>

Private long-term care insurance can take the form of either compulsory or voluntary schemes. Compulsory private insurance exists mainly as a substitute for social health insurance in countries where some population groups can opt out of public insurance if they obtain private coverage instead (e.g. DE). Voluntary private insurance generally complements existing coverage from a publicly financed benefit package, but play only a limited role in a number of Member States (e.g. AT, DE, FR), except for Cyprus, where voluntary insurance schemes for long-term care account for 26.4 % of expenditure.

Practically all EU Member States apply some form of cost-sharing or fees. The very few countries with safety net schemes that do not rely on fees, have high means testing thresholds that limit the beneficiaries' access to the public long-term care system.

Compared to the risk sharing approach of the other financing sources, out-of-pocket payments do not feature any pre-payment and funds are not pooled across the population. Figure 4 shows that the share of reported out-of-pocket payments for health-related long-term care expenditure ranges from 77 % in Bulgaria to 0.2 % in Czechia. The unweighted average of absolute out-of-pocket health long-term care expenditure in the EU is equal to 0.1% of GDP. However, there are six EU countries where this value is equal to at least 0.3% of GDP (AT, DE, ET, FI, FR, MT). The OECD (section 3.2.3) analyses to what extent people in need of long-term care would

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<sup>&</sup>lt;sup>56</sup> Ibid.

<sup>&</sup>lt;sup>57</sup> Karagiannidou, M. and Wittenberg, R., 2022, Social Insurance for Long-term Care, LSE Care Policy and Evaluation Centre, forthcoming.

be able to pay the out-of-pocket costs of long-term care, as the costs of long-term care in many cases exceed a person's income.

The minor role voluntary private insurance schemes play in Europe may reflect the fact that the costs of voluntary private insurance are very high, while it usually provides only limited coverage. Technical problems, largely in terms of information for both providers and potential buyers, suggest that the actuarial mechanism is not well suited to addressing risks associated with developing long-term care needs.<sup>58</sup> These include problems of adverse selection, in particular when people buy premiums later in 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 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.<sup>59</sup> 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, there may be a role for voluntary private long-term care insurance in supplementing them. <sup>60</sup>

<sup>&</sup>lt;sup>58</sup> Barr, N., 2010, Long-term Care: A Suitable Case for Social Insurance, Social Policy & Administration 44 (4), pp. 359-374.

<sup>&</sup>lt;sup>59</sup> OECD, 2021, Public and Private Sector Relationships in Long-term Care and Healthcare Insurance.

<sup>&</sup>lt;sup>60</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities in an ageing society</u>, Volume I, Publications Office of the European Union, Luxembourg.

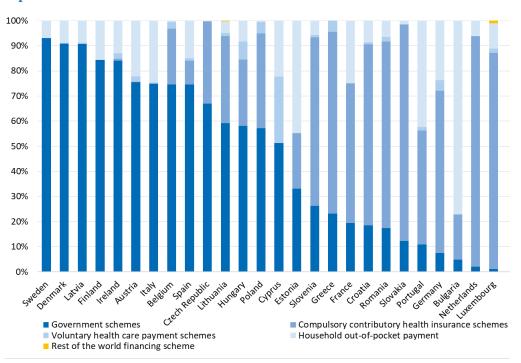


Figure 4: Share of expenditure by financing schemes for the health component of long-term care expenditure

Source: Eurostat, SHA<sup>61</sup> 2019, hlth\_sha11\_hchf, data for long-term care (health). No information available forMalta and EU-27; voluntary healthcare payment schemes for CZ, SK and SE; and rest of the world financing scheme for BE, BG, CY, CZ, ES, FI, FR, HR, IE, IT, LV, PT, RO, SE, SI, and SK (assumed as 0 in figure).

# 3.2. Social protection for long-term care

Social protection coverage is an important factor for determining the affordability of long-term care services and ultimately access to long-term care. Although all Member States offer some social protection coverage for long-term care, in many Member States, financial constraints are the most important reason why households do not use (more) home care services if needs are present (see Figure 8). The generosity of social protection can play a key role in addressing such financial risks. At the same time, long-term care is less developed in many countries than other social protection branches (e.g. pensions and healthcare). Social protection for long-term care needs is highly fragmented among different branches of social protection, which are not always integrated with one another. In addition, public expenditure is often too limited to provide the services people would need.

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<sup>&</sup>lt;sup>61</sup> 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.

#### 3.2.1. Eligibility for social protection for long-term care

**Individual needs assessments** form the basis for the provision of long-term care benefits and 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 %.<sup>62</sup> 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.<sup>63</sup> Estonia modified legislation in May 2022 that obliges local governments to identify/assess the need for support for a person with a care burden and liberates second degree relatives from the requirement to provide maintenance.

In relation to the way they define eligibility to long-term care social protection, EU countries differ as to whether they adopt a **universalist approach** (characterised by high social protection coverage for all residents, and universal publicly provided services and benefits) or a **selectivist** one (characterised by targeting or customising services and policies for particular groups, usually safety net tax-funded systems). A 'selectivist model is present in 10 Central-Eastern European and Southern European countries (BG, CY, EE, EL, HR, HU, PL, PT, RO, SI); in these countries, access to long-term care public provision, either cash benefits or in-kind services, is dependent not only on an assessment of care needs, but also on financial means testing (usually based on income, and in some cases property, often including close relatives' economic resources).<sup>64</sup>

# 3.2.2. Coverage of social protection for long-term care

Member States provide long-term care services either **in-kind or via cash benefits** that enable the recipient to cover (part of) the costs of long-term care, or via a combination of both. In-kind services usually include home care or a place in residential care, but in some countries it may also cover other necessities such as adaptations of the home (e.g. lift) or technical devices (as part of home care). Cash benefits are funds that recipients can use to purchase services themselves, and are often used to compensate informal carers. Differences in the depth of social protection stem rather from the level of service coverage than from the different ways in which social protection is provided. In some (mostly Nordic) Member States, social protection is mostly delivered in the form of services (e.g. DK, FI, SE); in others, long-term care coverage

<sup>&</sup>lt;sup>62</sup> Medizinischer Dienst der Krankenversicherung, 2021, <u>Richtlinien des GKV-Spitzenverbandes zur Feststellung der Pflegebedürftigkeit.</u>

<sup>&</sup>lt;sup>63</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities in an ageing society</u>, Volume I, Publications Office of the European Union, Luxembourg.

is predominantly based on cash benefits (e.g. AT, CY, 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)<sup>65</sup>.

The large majority of EU countries also offer cash benefits for carers, either through specific ad hoc programmes (DK, EE, HU, IE, MT), or by allowing informal carers to receive the cash benefit allocated to individuals with long-term care needs. Figure 5 shows that the estimated number of potential dependants aged 65 or over receiving publicly provided or funded home care varies between 132 % (NL) and 3 % (PT). The EU-27 average stands at 31 %. Figure 5 shows that the estimated number of potential dependants aged 65 or over receiving publicly provided or funded residential care coverage is 19 %, and for cash benefits 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 adjustment of the services and coverage of the services and c

Some Member States that indicate a high coverage of the population with long-term care benefits may only provide benefits at a low level and they may not be targeted specifically to people with long-term care needs. In the case of Poland, for example, a cash allowance is paid to all people above the age of 75 independently of their disability status. Therefore, it is important to also **consider the generosity of the long-term care benefits** (see section 3.2.3).

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<sup>&</sup>lt;sup>65</sup> Spasova, S., Baeten, R., Coster, S., Ghahilani, D., Peña-Casas, R., Vanhercke, B., 2018, Challenges in long-term care in Europe. A study of national policies, European Social Policy Network (ESPN), Brussels: European Commission.

<sup>&</sup>lt;sup>66</sup> Pavolini, E., 2021, <u>Long-term care social protection models in the EU</u>, European Social Policy Network (ESPN), Luxembourg: Publications Office of the European Union.

<sup>&</sup>lt;sup>67</sup> The high coverage rates, exceeding 100 %, for home care (DK, NL, SE) and cash benefits (PL) can be explained by the fact that, on the one hand, cash and in-kind benefits can be cumulative, and on the other hand, 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).

<sup>&</sup>lt;sup>68</sup> 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.

<sup>&</sup>lt;sup>69</sup> European Commission and Economic Policy Committee, 2021, <u>The 2021 Ageing Report</u> – Economic and budgetary projections for the EU Member States (2019-2070), Publications Office of the European Union, Luxembourg.

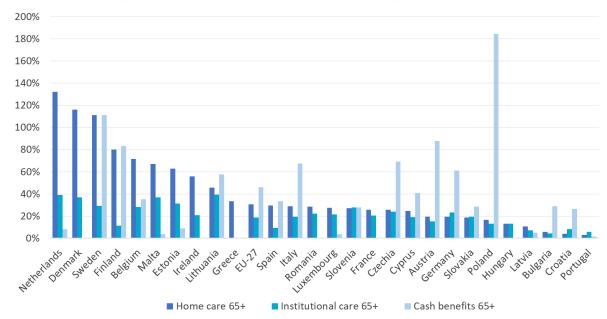


Figure 5: Share of potential dependants aged 65+ who receive public care or cash benefits

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+.

The European Social Policy Network (ESPN) analysed Member States' long-term care systems and proposed an **analytical framework with a typology of public long-term care models in the EU**<sup>70</sup>. Interestingly, each model includes countries adopting different sources of funding. The choice of how to finance public long-term care systems seems almost independent from the choice of how much to spend and on which type of provision. The six identified models are:

- 1. **A limited State intervention model**: one third of all EU Member States falls under this category, which is characterised by a very low level of public expenditure on long-term care (on average 0.4% of GDP). The countries belonging to the cluster are exclusively either Southern European (CY, EL, PT) or Central-Eastern European countries (BG, EE, HR, HU, LV, RO).
- 2. A mild State intervention through cash benefits model: around one fifth of EU Member States belong to this second model, where public expenditure on long-term care is higher than in the previous one (on average 0.8% of GDP), and almost half of this expenditure is channelled through cash benefits (46.0%); Spain and four Central-Eastern European countries (LT, PL, SI, SK) belong to this cluster.

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<sup>&</sup>lt;sup>70</sup> Pavolini, E., 2021, <u>Long-term care social protection models in the EU</u>, European Social Policy Network (ESPN), Luxembourg: Publications Office of the European Union.

- 3. A mild State intervention through services model: around one Member State out of ten belongs to this cluster, where countries invest more resources in long-term care than the previous models but still below the EU-27 average level; at the same time, funding goes essentially to home care and residential care services; (IE, LU, MT).
- 4. **A strong State intervention through cash benefits model**: Austria, Germany, Italy and Czechia share a model where financial support for long-term care needs is relatively consistent (1.7% of GDP), and often takes the form of cash transfers.
- 5. **A strong State intervention through services model**: Belgium, France, and Finland spend a relatively high share of their GDP on long-term care policies (2.0% of GDP), using mostly services as a tool of provision.
- 6. A very strong State intervention through services model: two Nordic countries (DK and SE), together with the Netherlands, are part of this last group investing a very high share of public resources in coverage of long-term care needs (3.5% of GDP), and mostly counting on in-kind provision in order to support individuals and households.

ESPN analysis indicated that the limited State intervention model has the weakest performance: it provides the lowest coverage rate of long-term care needs and has a very high share of older people with severe activity limitation who are at risk of poverty and social exclusion. The model based on mild State intervention through cash benefits offers a higher coverage of potential beneficiaries than the previous model, but at the same time, being an older person with severe activity limitation is still a strong predictor of poverty or social exclusion compared to not having activity limitation. The mild State intervention through services and the strong State intervention through services models provide a high coverage of potential beneficiaries through services. At the same time, they help to strongly reduce the impact of activity limitation on the risk of poverty and social exclusion. The model based on strong State intervention through cash benefits covers a large part of potential beneficiaries, more often through cash transfers rather than through services. At the same time, it produces relatively good results in terms of reducing the risk of those with strong activity limitation being poor or socially excluded. The very strong state intervention through services model covers practically all potential beneficiaries, and can intervene and provide services also to individuals with medium-low levels of long-term care needs. At the same time, it helps to strongly reduce the impact of activity limitation on the risk of poverty and social exclusion.

# 3.2.3. Adequacy of social protection for long-term care

To measure the **depth of social protection for long-term care in old age** and compare it across Member States, with the support of the European Commission, the **OECD**<sup>71</sup> developed a set of eight typical cases of long-term care needs. The cases vary according to the types and severity of their needs, the professional services required, and the level of income and assets of older people in need of care.

<sup>&</sup>lt;sup>71</sup> Cravo Oliveira Hashiguchi, T. and Llena-Nozal, A., 2021, <u>The Effectiveness of Social Protection for Long-term Care in Old Age: Is social protection reducing the risk of poverty associated with care needs?</u>, OECD Health Working Papers No 117, OECD Publishing, Paris.

The OECD analysis reveals that without social protection, the estimated total costs of long-term care often exceed the disposable income of people in need of long-term care and can push individuals into poverty. Furthermore, it suggests that even after social protection, the out-of-pocket costs for care can be very high especially for older people with severe long-term care needs receiving home care. It is assumed that all eligible people take up social protection for long-term care and that long-term care services are also available to them.<sup>72</sup>

Across countries and subnational areas, **out-of-pocket spending as share of income is lowest for low needs and highest for severe needs**. Figure 6 shows that the out-of-pocket costs of home care for low and moderate needs are lower than the median income among older people in 19 countries or subnational areas. Out-of-pocket spending on home care generally represents less than 50% of the median income among older people with low needs, and in a majority of countries and subnational areas out-of-pocket costs are lower than disposable incomes. In seven countries or subnational areas (HU, South Tyrol in IT, FR, SI, HR, LV and Tallinn in EE) the out-of-pocket costs of home care for severe needs are higher than the income for an older person earning a median income. In these cases, care recipients may have to turn to family members, friends and others for financial support or informal care as a way to receive long-term care, or they will have unmet care needs.

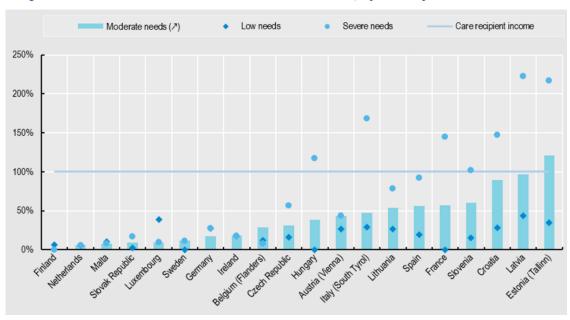


Figure 6: Out-of-pocket costs of home care as a share of income (after public support), for care recipients with a median income and with no net wealth, by severity level

Source: OECD analyses based on the OECD long-term care social protection questionnaire, the OECD Income Distribution Database and the OECD Wealth Distribution Database

<sup>72</sup> **I** 

<sup>&</sup>lt;sup>72</sup> In reality, determining current availability and uptake of public social protection for long-term care in old age in all Member States is challenging, given limited detailed data on the existence and geographical location of public social protection offices in Member States, and their capacity to handle requests for support (e.g. conduct needs assessments). Even then, assuming full availability of public social protection for long-term care, effective use also depends on availability of providers, whose availability and geographical distribution is also difficult to establish across all Member States. Finally, even if public social protection offices and providers are available, older people with long-term care needs may choose not to use the public sector, in which case they will not take up public formal long-term care services.

It is important to consider 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**. While people may be able to pay for care, it is often that **they cannot afford care without going below a certain level of income**. This remaining income is needed to cover all other normal expenses of life, like housing, food, clothing, transport, etc. In a next step of the project, the theoretical typical cases were matched with responses from the SHARE and TILDA surveys (waves 7 and 3 respectively), thus estimating the size of the group that would fall into the different typical cases across the 20 Member States, and also making it possible to determinate their socio-economic characteristics.

Whether social protection can prevent people from being at an increased risk of poverty due to developing long-term care needs, can be analysed by **comparing the observed risk of poverty among older people with a hypothetical measure of the risk of poverty if all older people estimated to have long-term care needs received public support.** This comparison gives an indication of the hypothetical impact on poverty risks if everyone who is estimated to have long-term care needs sought formal care and had access to public social protection. It should not be seen as reflecting the actual impact of long-term care provided through public social protection systems on poverty rates in countries today, as many older people with long-term care needs do not receive formal care.

Across the 20 jurisdictions assessed, in 15 jurisdictions a majority (50% or more) of older people with low needs would not be able to afford home care from their income alone without social protection (i.e. they would be at risk of poverty), in all 20 jurisdictions a majority with moderate or severe needs would be in this position for home care. If it were not for public social protection for long-term care in old age, the majority of older people in the EU jurisdictions analysed would thus not be able to pay the out-of-pocket costs of care from their incomes alone without being at risk of poverty. Even with social protection, the estimated share of people facing a **relative risk of poverty** in many EU jurisdictions is still **higher for those with long-term care needs** than in the older population in general. Figure 7 shows the poverty risk associated with long-term care for people with a median income and moderate needs. <sup>73</sup>

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<sup>&</sup>lt;sup>73</sup> Conclusions are drawn on the assumption that the rules applicable in the jurisdictions considered would apply to the entire Member States concerned.

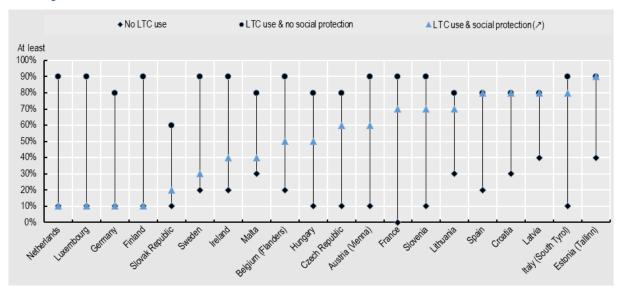


Figure 7: Share of the old age population that would be at risk of poverty after paying for the out-of-pocket costs of home care for moderate needs

Source: OECD analyses based on the OECD Long-Term Care social protection questionnaire, the OECD Income Distribution Database and the OECD Wealth Distribution Database

# 3.3. Availability and accessibility of long-term care

Long-term care services must not only be affordable, but also available and accessible for people in need of long-term care. However, the availability of formal long-term care services still differs greatly among Member States and the **variety of long-term care options is often insufficient**, despite formal long-term care becoming even more important in the future due to population ageing and changing family structures. More person-centred care options, such as home care and community-based care, have started to expand, though not evenly, across the EU. Furthermore, persons with disabilities, who represent a large proportion of those in need of long-term care, are also confronted with accessibility challenges.

#### 3.3.1. Availability of long-term care services

The availability of long-term care refers to the **relationship between volume and types of services and resources that are offered by the system and users' needs**. Already now the supply of formal care services is restricted due to both financial constraints and workforce shortages. Within the formal provision, there is a diversity of models for the delivery of care services, combining to different extents **home care, community-based care and residential care**.

Although home care services were used by on average 28.6 % of people aged 65 or over living in private households who needed long-term care (at least one severe difficulty in ADLs or IADLs), the share ranged from 4.7 % in Romania to 53.7 % in Belgium in 2019. Among the respective populations with long-term care needs, slightly more women than men used home care services (29.9 % vs 25.7 %)<sup>74</sup>. The use of home care services is also influenced by

<sup>&</sup>lt;sup>74</sup> EHIS, 2019, indicator hlth\_ehis\_am7ta.

household composition. Although 37.2 % of older people with long-term care needs living alone used home care, only 22.4 % of people living with others did so<sup>75</sup>. Furthermore, there was a **regional dimension** in the coverage by home care services. In cities, 29.7 % of older people in need used home care services, compared with 28.7 % in towns and suburbs, and only 26.4 % in rural areas<sup>76</sup>. Coverage by home care services fell slightly during 2014-2019, from 29.8 % to 28.6 %<sup>77</sup>.

Data on **residential care infrastructure suggest very heterogeneous availability** across the EU. The number of long-term care beds per 100 000 residents of all ages<sup>78</sup> ranged from 27.4 in Bulgaria to 1378.4 in the Netherlands in 2019, 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 deinstitutionalisation policies. But even when residential care infrastructure exists, it often operates at limited capacity due to staff shortages. In Austria, for example, thousands of long-term care beds in particular in more rural areas cannot be filled due to staff shortages and relatives report difficulties to organise residential care for people in need.<sup>79</sup>

Differences between countries in care provision and care use are also affected by institutional and cultural factors. The willingness to use care, particularly institutional is influenced by **cultural reasons and attitudes**. In southern and some eastern European countries, for example, family relationships are closer than in western or northern countries, social protection is not as well developed and an expectation towards being cared for by family is expressed.<sup>80</sup>

People in need of care mainly do not use professional long-term care services because they are unaffordable or unavailable. Figure 8 shows that for 35.7% of households with a person in need of long-term care, the **costs of the services where the main reason for not using** (more of) them although they would require (more) assistance; 9.7% mentioned shortages in supply and 2.1% cited quality concerns as main reasons across the EU-27. Besides, the lack of care services is more pronounced in towns and suburbs (12.3%) and rural areas (10.4%) compared to cities (7.4%). Also, in rural areas professional care is more often refused by the person needing them (5.9%) than in cities or in towns and suburbs (4.6%). If formal care services are not needed or refused by the person needing them, it is implying that the care tasks are taken over by informal carers or that people have an unmet need for care. In the 2019 data, **46.6% 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 (47.7%) than for older men (44.2%)<sup>81</sup>, and for the lowest income quintile (51.2%) compared with the highest (39.9%).<sup>82</sup>

<sup>&</sup>lt;sup>75</sup> EHIS, 2019, indicator hlth\_ehis\_am7th

<sup>&</sup>lt;sup>76</sup> EHIS, 2019, special extraction for degree of urbanisation

<sup>&</sup>lt;sup>77</sup> EHIS, 2019, indicator hlth\_ehis\_am7ta

<sup>&</sup>lt;sup>78</sup> Eurostat, 2019, Long-term care beds in nursing and residential care facilities, indicator hlth\_rs\_bdsns.

<sup>&</sup>lt;sup>79</sup> Thalhammer, A, 2021, <u>Tausende Pflegebetten wegen fehlenden Personals gesperrt</u>, DiePresse. (accessed on 7 June 2022)

<sup>&</sup>lt;sup>80</sup> Spasova, S., Baeten, R., Coster, S., Ghahilani, D., Peña-Casas, R., Vanhercke, B., 2018, Challenges in long-term care in Europe. A study of national policies, European Social Policy Network (ESPN), Brussels: European Commission.

<sup>81</sup> EHIS, 2019, Indicator hlth\_ehis\_tadlh. The self-reported lack of help does not distinguish between formal or informal care.

<sup>82</sup> EHIS, 2019, Indicator hlth\_ehis\_tadlhi.

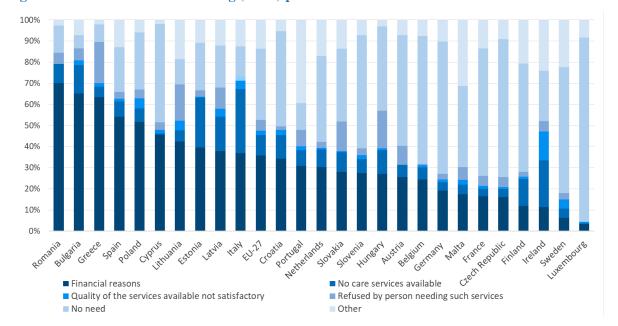


Figure 8: Main reasons for not using (more) professional home care services

Source: EU-SILC ad hoc module, 2016, ilc\_ats15.83

#### 3.3.2. Accessibility of long-term care services

Accessibility to long-term care refers to the **prevention and removal of barriers that people** with disabilities face to participate and access such services on equal basis with others. It concerns the design of products/devices, services, and infrastructure so that they can be used by people with disabilities, regardless their age, on an equal basis with others. Accessibility concerns the buildings where the services are provided, the transport from home to the delivery place and the information and communication about the services.

The lack or limited accessibility of long-term care services prevent people with disabilities from using long-term care services. Further, objective barriers and subjective motives can prevent people with disabilities from accessing long-term care. The geographical distance and travel costs in case the place of service provision is not the care user's home may be prohibitive. Waiting time for the initial long-term care needs assessment by the competent authorities or between the initial contact between service provider and user and the date of actual service is also an element that can limit accessibility. The overly complex application procedure for benefits may be disproportionate with the time and ability of people in need of care to cope with this. Besides, 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 also a role. While there is no EU-wide data on the accessibility of long-term care services in the EU, anecdotal evidence suggests that people with disabilities can face obstacles.

# 3.4. Quality of long-term care

Member States employ a mix of policies and practices to improve the quality of long-term care, but **long-term care quality standards and their assurance mechanisms are often weak**. A

<sup>83</sup> Data for Denmark are not available. Long-term care services are mostly free of charge in Denmark.

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 registration and accreditation processes. Among different approaches, the person-centred model, based on the needs and preferences of the person in need of care, seems to be gaining attention. Quality of care is also affected by factors that include workforce, organisation (e.g. integration of services to cater for complex needs), technology, and funding. The efforts to ensure quality are mixed and mainly focus on residential care, thus more attention is needed also on home and community-based care.

#### 3.4.1. Defining the quality of long-term care

For people receiving long-term care, its quality is critically important, and in some cases can be the difference between life and death. For society as a whole, the quality of long-term care services, determines its ability to uphold fundamental rights and dignity. Quality long-term care can improve as much as possible and/or prevent the deterioration of physical and mental condition of people in need of care, enable their independent living and personal well-being, safeguard their dignity and protect them from harm and abuse. Better quality care can help avoid unnecessary hospital or residential care admissions or can slow down the deterioration of physical condition, thus potentially alleviating the pressure on resources.

There is no common definition of long-term care quality at the EU level, but breaking down the concept of quality into a number of principles helps to build a more comprehensive picture and to better target policy tools. The principles of the voluntary European Quality Framework for Social Services agreed in 2010<sup>84</sup> apply to long-term care services, in particular the principles of prevention, respect, person-centredness, comprehensiveness, continuity and transparency (see section 5.3.2 for more on quality principles).

As quality is multifaceted, it is difficult to define indicators to measure and monitor it. One way to operationalise the concept is by looking at the structure, process and outcomes<sup>85</sup>. 'Structure' refers to inputs and resources, e.g. physical facilities, equipment, human resources, including training, working conditions and pay. 'Process' is the way care is delivered, e.g. diagnosis, treatment, preventive care, patient education, obtaining information from medical records, interviews with patients and doctors, or direct observations. 'Outcomes' are the effects of care on patients, e.g. changes to their health status or functionality.

There is an emerging consensus that there is a need to measure quality based not only on clinical indicators, but also by taking a person-centred perspective and including measurements of the users' quality of life<sup>86</sup>. This is in line with the shift to a more holistic view in which older people's well-being and quality of life and their preferences regarding care and support are

<sup>&</sup>lt;sup>84</sup> Social Protection Committee, 2010, A voluntary European quality framework for social services, SPC/2010/10/8 final. These principles were adapted to long-term care further in 2012 by the WeDO project: <u>Principles and guidelines for the wellbeing and dignity of older people in need of care and assistance</u>.

<sup>&</sup>lt;sup>85</sup> For an overview of indicators used to measure long-term care quality see chapter 3 of European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities in an ageing society</u>, Volume I, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>86</sup> Zigante, V. and King, D., 2019, <u>Quality Assurance Practices in Long-term Care in Europe</u>, Research note for the Social Situation Monitor.

central to the design of services in line with existing human rights standards. <sup>87</sup> The latter include the rights of people with care needs, including people with disabilities, to **live independently** and be included in the community, with choices equal to others, to have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and not to be obliged to live in a particular living arrangement. Independent living applies equally to private and residential homes. It requires a differentiated landscape of quality, accessible, person-centred and affordable, community- and family-based services to allow people in need of long-term care to have control over their daily lives, in particular those living in residential care homes. However, the situation is particularly difficult in remote and rural areas and the COVID-19 pandemic highlighted and intensified the challenges faced by people living in institutions <sup>8889</sup>.

# 3.4.2. Quality assurance in long-term care

Quality assurance practices vary between and within Member States due to various factors, including quality assurance mechanisms themselves, which may be different at national, regional and local levels, the nature of quality standards and how they apply to different types of care providers, whether public, private for-profit or non-profit. Quality assurance in long-term care is a point of debate in a number of countries, including due to a string of cases of poor care and mistreatment. This has caused substantial debate over how quality can be better assured and monitored in both public and private care settings. A EUROFOUND report highlighted few challenges linked to expansion of private provision increases, indicating that costs to users are likely to become a more significant issue unless there is an increase in public benefits to subsidise funding. There are also differences in the location of different types of care homes, with private care homes more likely to be found in affluent urban areas. The types of residents prevalent in each type of care home are influenced by the profitability of the services they require – residents who require less profitable care services are more likely to be in public care homes. In most countries where information about staff-to-resident ratios was available, there were more staff per resident in public care homes.

The main elements of long-term care quality assurance systems, namely the setting and monitoring of quality standards, improving current practice and involving relevant stakeholders, are briefly discussed below<sup>93</sup>.

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<sup>87</sup> Birtha, M., Rodrigues, R., Zólyomi, E., Sandu, V. & Schulmann, K., 2019, <u>From disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people.</u> Vienna: European Centre for Social Welfare Policy and Research.

<sup>88</sup> N. Crowther (ANED synthesis report), 2019, <u>The right to live independently and to be included in the community in European States</u>. The right to live independently and to be included in the community in European States.

<sup>89</sup> European Commission, 2021, Union of Equality: Strategy for the Rights of Persons with Disabilities 2021-2030.

<sup>90</sup> For more information on quality assurance practices of long-term care provided by private providers, see Zigante, V. and King, D., 2019, Quality Assurance Practices in Long-term Care in Europe, Research note for the Social Situation Monitor.

91 Ibid

 $<sup>^{92}</sup>$  Eurofound (2017), Care homes for older Europeans: Public, for-profit and non-profit providers, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>93</sup> Based on Barslund, M., Pacolet, J., Leichsenring, K., De Wispelaere, F., Waeyaert, W., Harald Hauben, H, De Smedt, L., Schepers, W., 2022, Analytical support under VC/2020/066.

Although countries have different approaches to quality assurance in long-term care, the most common approach is establishing mandatory **quality standards** as well as monitoring procedures and enforcement or remedy measures to ensure that providers comply with them. Quality standards usually address the structural features and can refer to input / physical environment (e.g. fire and safety concerns, room size, common space available, number, training and education of staff caring for recipients), process of care (e.g. documenting the frequency with which staff apply creams and/or turn bed-bound resident to prevent pressure ulcers), and outcomes to which providers should aspire, most often clinical (e.g. occurrence of skin pressure ulcers or uncontrolled pain)<sup>94</sup>. Regulation of residential care is more common than regulation of home and community-based care. At the same time, key criticism of residential care quality standards is that they are too 'medical', rigid, not evidence-based and do not measure what is important, which is now increasingly understood as the quality of life of the person receiving care.

The next step in the regulatory process is the **authorisation and accreditation** of provider organisations. Authorisation usually confers the right to operate a facility or service, while accreditation also entitles providers to receive public funding. Both procedures are usually linked, and quality is assessed before a service is delivered. For instance, in DE, where only accredited providers can offer their services on the market, this procedure has been delegated to the regional branches of the long-term care insurers. In other Member States such agreements are linked to distinct accreditation or licensing procedures and may be administered at one of different levels: national (MT), regional (e.g. AT, IT) or municipal (e.g. DK, SE). Regional instead of national authorisation may lead to regional variations of quality, both in the definition of standards and regarding the implementation of quality assurance procedures. There are also variations in terms of requirements and standards applied to different care settings, with such standards being more developed for residential rather than for home-based care settings.

Following the initial assessment of compliance with quality standards, the next step is to aim to monitor and constantly improve results. This could be done through follow-up to proposals for improvement resulting from systematic **self-assessment** of long-term care providers and/or **inspections** and/or reviews by third party that has been employed to certify the organisation's quality management system. The design of enforcement systems needs to be carefully considered. While shortcomings and errors must be identified to be overcome and addressed, enforcement measures and **penalties** could also reduce the resources of already 'low performing' organisations, thus leading to even lower performance and further harming care recipients. Still, while enforcement of measures is necessary to sanction abuses and they therefore exist in most countries (e.g. AT, BE, BG, DE, FI, MT, PT, RO, SE), **economic incentives** for quality improvement and collaborative approach (inspectors working with providers to solve problems) should be further fostered, to increase ownership towards continuous improvement of quality.

In addition to a strict regulatory approach to quality assurance, there are different mechanisms that allow relevant stakeholders, first of all people receiving care and their family members, to

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<sup>&</sup>lt;sup>94</sup> V. Mor, T. Leone, A. Maresso (ed), 2014, Regulating Long-Term Care Quality: an international comparison, for the European Observatory on Health Systems and Policies.

have a say on quality of care. **Complaint mechanisms** for users and their families are widely established instruments at organisational level, though more developed in residential care settings. At national level, mechanisms are put in place at the level of the ombudsperson and now also of OPCAT commissions<sup>95</sup>, albeit, and again, focusing on residential care. The OPCAT commissions are now in place in all Member States to combat the worst cases of noncompliance, namely abuse and neglect of residents in care homes. **Mutual agreements** among stakeholders, though not widespread, provide the opportunity to reflect upon mutual expectations and the involvement of the various stakeholders in existing care arrangements and individual care planning. At an organisational level, users can be involved via **satisfaction surveys**. However, these tools have their limits in long-term care, particularly when it comes to involving people with cognitive difficulties or simply because users might fear to say what think really think. A way out, though also limited, could be to have quality assessed by proxies (friends, family), but this also has its caveats as interests may sometimes diverge.

#### 3.4.3. Drivers of quality

Quality is affected by a number of factors, including funding, workforce and technology. Adequate funding is key to ensure long-term care quality, but even with limited public expenditure (see section 3.1.2), it is still possible to find ways to achieve better outcomes with resources at hand. Better targeting care to individual needs and involving all relevant stakeholders (including informal carers) and services (including healthcare) that cater for these needs in a coordinated way via **integrated care provision** and the expansion of case and care management could improve the efficiency of resources. Also, when long-term care services are commissioned or procured, including quality indicators and performance standards focusing on positive outcomes for people receiving care in **public procurement** contracts could help to move from fee-for service to outcome based financing<sup>96</sup>. The availability and expertise of **care** workers has a major impact on the quality of care and the quality of life of those being cared for. This calls for policy measures to ensure adequate human resources for long-term care, including ensuring adequate staff ratio, providing quality management training for care managers and workers and involving care staff in the assessment, monitoring and improvement of care quality. **Technology** could help to improve care quality, including by making services more personalised and increasing users' independence. However, beyond cost considerations and the acknowledgement that technology cannot replace human contact, there are challenges regarding insufficient availability, accessibility, reliability, and acceptance of new technologies as well as concerns about the protection of personal data.

# 3.5. Long-term care workforce and informal carers

Carers are the backbone of long-term care systems. Meeting the rising demand for long-term care can support job growth, but Member States struggle to attract and retain care workers. Difficult working conditions and relatively low wages are drivers for labour shortages in the

<sup>&</sup>lt;sup>95</sup> The Optional Protocol to the Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment. The OPCAT was signed by all EU Member States, only Ireland and Belgium are still in the process of ratification.

<sup>&</sup>lt;sup>96</sup> European Social Network, 2021, Putting Quality First: contracting for long-term care.

sector. Skills requirements in long-term care are becoming increasingly complex. Informal carers, mostly women, carry out the bulk of caregiving in many Member States. Informal caregiving often comes with significant consequences for the carers, including difficulties to reconcile work and caring responsibilities as well as consequences on health and wellbeing.

# 3.5.1. The long-term care workforce

The long-term care workforce consists of a range of professions, most importantly personal care workers<sup>97</sup> and nurses<sup>98</sup>. In 2019, an overwhelming majority of 88% of long-term care workers were women in the EU<sup>99</sup>. In 2019, the share of foreign-born long-term care workers (from within and outside the EU) was close to 20% <sup>100</sup>.

Most long-term care workers have a medium education level<sup>101</sup> <sup>102</sup>. **Skills requirements in long-term care are becoming increasingly complex**, including the need for case management, soft and digital skills as well as geriatric and special knowledge (e.g. Alzheimer, chronic diseases). Despite the relatively high rate of training (58% of long-term care workers received training paid for or provided by their employer, compared to 38% overall), 24% of long-term care workers felt that they 'need further training to cope well with duties' (15% overall)<sup>103</sup>.

Live-in carers are a particularly vulnerable subgroup of long-term care workers prevalent in a number of EU Member States (e.g. AT, CY, DE, EL, ES, IT, MT)<sup>104</sup>. In most cases, they are mobile (intra-EU mobile workers) or migrant workers. Undeclared work among live-in carers can be a common issue in some Member States<sup>105</sup>. Live-in carers may face extremely low wages, sometimes not even receiving the applicable minimum wage in the country<sup>106</sup>. Given that live-in carers usually live with the care recipient (who is sometimes but not always their employer) under the same roof, working time arrangements, including adequate rest periods, may be blurry<sup>107</sup> and sometimes not compliant with labour law, while enforcement of rights of live-in carers may be limited due to limitations on inspecting private households in certain Member States<sup>108</sup>.

While data on this is still sparse, domestic work, including the provision of long-term care, is increasingly provided via **online platforms**, bringing along risks for the workers such as lack of security, guaranteed hours or minimum pay rates, constraints on collective bargaining and ratings

<sup>&</sup>lt;sup>97</sup> In this analysis defined per ISCO-08, falling under codes 5321 and 5322.

<sup>&</sup>lt;sup>98</sup> In this analysis defined per ISCO-08, falling under codes 2221 and 3221.

<sup>&</sup>lt;sup>99</sup> EU Labour Force Survey.

<sup>100</sup> Ibid

<sup>&</sup>lt;sup>101</sup> Upper secondary educational qualification or equivalent.

<sup>102</sup> OECD, 2020, Who Cares? Attracting and Retaining Care Workers for the Elderly, OECD Publishing, Paris.

<sup>&</sup>lt;sup>103</sup> Eurofound, 2020, <u>Long-term care workforce: Employment and working conditions</u>, Publications Office of the European Union, Luxembourg.

<sup>104</sup> Ibid.

<sup>105</sup> Ibid

<sup>&</sup>lt;sup>106</sup> Rogalewski, A. and Florek, K., 2020, <u>The future of live-in care work in Europe</u>. European Economic and Social Committee.

<sup>107</sup> Ibid.

<sup>&</sup>lt;sup>108</sup> International Labour Office, 2015, <u>Labour Inspection and Other Compliance Mechanisms in the Domestic Work Sector:</u> Introductory guide, ILO, Geneva.

and reviews to discipline workers<sup>109</sup>. **Undeclared work** is a challenge in particular in care services that are part of the personal and household services sector. 2.1 million people are estimated to work undeclared in the personal and household services care sector (including both childcare and long-term care), which account for 34% of the overall workforce working in this sector<sup>110</sup>.

# 3.5.2. Untapped job creation potential and labour shortages in the sector

The long-term care sector already accounts for a substantial number of jobs in many Member States. In 2019, there were **6.3 million long-term care workers in the EU** (3.2% of overall workforce)<sup>111</sup>. As shown in Figure 9, the number of full-time equivalent long-term care workers per 100 people aged 65+ was 2.4 on average in the EU-27 in 2019. However, there were large differences across Member States from fewer than 0.2 long-term care workers per 100 people in Greece to 12.5 in Sweden<sup>112</sup>.

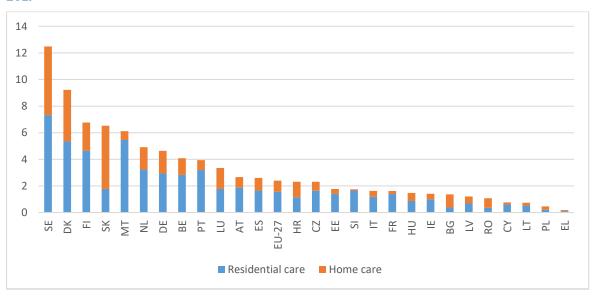


Figure 9: Number of (full-time equivalent) long-term care workers per 100 people aged 65+, 2019

Source: EU Labour Force Survey, 2019, in: Barslund, M., et al., 2021.

The long-term care sector has an **untapped job creation potential**, driven in particular by population ageing. In order to keep the current level of long-term care provision, many countries will have to significantly expand the long-term care workforce in the coming decades. More than 1.6 million long-term care workers would have to be added by 2050 to keep long-term care coverage at the same level. Most Member States would have to increase the number of long-term care workers by more than 15% by 2030, and for eight countries the figure is 30% or

<sup>&</sup>lt;sup>109</sup> Sedacca, N., 2022, <u>Domestic Work and the Gig Economy</u>. Forthcoming in "A Research Agenda for the Gig-Economy and Society".

<sup>&</sup>lt;sup>110</sup> European Labour Authority, 2021, Tackling undeclared work in the personal and household services sector.

<sup>&</sup>lt;sup>111</sup> Eurofound, 2020, <u>Long-term care workforce: Employment and working conditions</u>, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>112</sup> Barslund, M., Pacolet, J., Leichsenring, K., De Wispelaere, F., Waeyaert, W., Harald Hauben, H, De Smedt, L., Schepers, W., 2022, Analytical support under VC/2020/066.

more<sup>113</sup>/<sup>114</sup>. In a scenario, where Member States converge upwards in their number of long-term care workers per 100 people aged 65+ (reaching 5.6 workers by 2050), 150 000 long-term care workers would have to be added yearly for the next 30 years to the current long-term care workforce to keep service provision at 2019 level within the EU. This would amount to around 4.5 million additional long-term care workers by 2050.

However, many countries struggle to attract a sufficient number of workers into the long-term care sector. A large majority of Member States have reported significant numbers of unfilled vacancies, or have estimated expected **staff shortages** in the long-term care sector<sup>115</sup>. More than one in six of the 24.3 million online job advertisements analysed by Skills OVATE in 2021 <sup>116</sup> concerns the long-term care occupations <sup>117</sup>. Personal care workers were the most requested (39%), followed by nursing and midwifery associate professionals (33%) and nursing and midwifery professionals (28%). In 2020, nursing professionals, nursing associate professionals and home-based personal care workers were among the 19 occupations for which 'high magnitude shortages' were identified in a number of EU Member States <sup>119</sup>. As a result of the difficult working conditions during the pandemic, labour shortages in the sector became even more severe (for more information see section 3.6).

**Low wages** are a main reason for labour shortages in the sector. Analysis from Eurofound shows that on average in 2018, wages for social services workers (close to 70% of which worked in the long-term care sector) were 21% lower than the average national hourly earnings. The high prevalence of part-time work (42%) in the long-term care sector implies even lower monthly earnings for many. The wage difference was smallest in the Netherlands (96% of average earnings), Austria and Luxembourg (both 92%)<sup>120</sup>; three countries where almost 100% of long-term care workers are covered by social partner agreements<sup>121</sup>.

Across the EU, **social dialogue** plays a mixed role in the long-term care sector. Only in some Member States, close to 100 % of long-term care workers are covered by collective agreements (AT, BE, DK, ES, FR, LU, NL, SI), while in others social dialogue in the sector is almost absent (CZ, EL, PL)<sup>122</sup>.

<sup>113</sup> CY, DK, FI, IE, LU, MT, NL, SK

<sup>&</sup>lt;sup>114</sup> Barslund, M., Pacolet, J., Leichsenring, K., De Wispelaere, F., Waeyaert, W., Harald Hauben, H, De Smedt, L., Schepers, W., 2022, Analytical support under VC/2020/066.

<sup>&</sup>lt;sup>115</sup> Eurofound, 2020, <u>Long-term care workforce: Employment and working conditions</u>, Publications Office of the European Union, Luxembourg.

<sup>116</sup> Analysis from Cedefop

<sup>&</sup>lt;sup>117</sup> Reliable data is not available at the ISCO 4-digit level, therefore this analysis focuses on 3 occupations that are connected to provision of long-term care: These will be referred to as "long-care occupations" in this note: Nursing and midwifery professionals (ISCO 222); Nursing and midwifery associate professionals (ISCO 322); Personal care workers in health services (ISCO 532).

<sup>&</sup>lt;sup>118</sup> lack of employees amounting to more than 3% of the current employment in that occupation

<sup>119</sup> McGrath, J., 2021, Report on Labour Shortages and Surpluses November 2021, European Labour Authority.

<sup>&</sup>lt;sup>120</sup> Eurofound, <u>Living conditions and quality of life: Wages in long-term care and other social services 21% below average</u>. (accessed on 25 March 2022)

<sup>&</sup>lt;sup>121</sup> Eurofound, 2020, <u>Long-term care workforce: Employment and working conditions</u>, Publications Office of the European Union, Luxembourg.

<sup>122</sup> Ibid.

**Difficult working conditions** further contribute to the low attractiveness of the sector. Evening, night or weekend shifts are common in the long-term care sector, affecting working time quality. The large share of part-time work among the long-term care workforce (42%) is not always voluntary, as 30% of part-time long-term care workers in home care and 20% in residential care work part-time because they could not find a full-time job<sup>123</sup>. A significant share of long-term care workers (33%) have been exposed to adverse social behaviour, including verbal abuse, unwanted sexual attention, threats, physical violence, humiliating behaviour, bullying, and sexual harassment (compared to 16% in the overall workforce)<sup>124</sup>. Challenging working conditions take their toll on the health of long-term care workers. In 2015, 37% of long-term care workers reported that their job had a negative effect on their health, compared with 25% among the overall workforce. 38% of long-term care workers believed they would not be able to continue doing their job until they were 60 years old (compared to 27% overall)<sup>125</sup>. Occupational health and safety risks for long-term care workers include in particular lifting and moving people and handling materials that can be infectious, but also psychosocial risks<sup>126</sup>. Furthermore, lower staff ratios can cause a precarious burden of work, which puts employees under constant time pressure. A recent study analysing the occupational precariousness of nursing staff in nursing homes in Catalonia in Spain<sup>127</sup> found also that staff in privately owned facilities suffer greater precariousness with the main reasons for the precariousness being low wages and temporality of contracts.

# 3.5.3. Informal carers

Despite increased social and political acceptance of the need for the state to guarantee access to formal care services, **informal carers continue to provide the largest bulk of care in the EU.** In 2018, about a third of the EU adult population (around 100 million people) had caring responsibilities. The majority of them took care of children below 15 (84 %), for incapacitated relatives (12 %) or for both at the same time (4 %)<sup>128</sup>. On average around 52 million Europeans (14.4% of the population aged 18 to 74) provide informal long-term care to family members or friends on a weekly basis. When using full-time equivalents, informal carers account for close to 80% of care providers at EU level<sup>129</sup>.

<sup>&</sup>lt;sup>123</sup> Ibid.

<sup>&</sup>lt;sup>124</sup> Ibid.

<sup>&</sup>lt;sup>125</sup> Ibid.

<sup>126</sup> Ibid.

<sup>&</sup>lt;sup>127</sup>Occupational Precariousness of Nursing Staff in Catalonia's Public and Private Nursing Homes - PubMed (nih.gov). As limitations of the study, the authors mentioned that the small sample size and its contextualization do not allow inferences to be made at the national or international level.

<sup>&</sup>lt;sup>128</sup> Eurostat, Statistics Explained: Reconciliation of work and family life. (accessed on 11 April 2022)

<sup>&</sup>lt;sup>129</sup> Van der Ende, M. et al., 2021, Study on exploring the incidence and costs of informal long-term care in the EU.

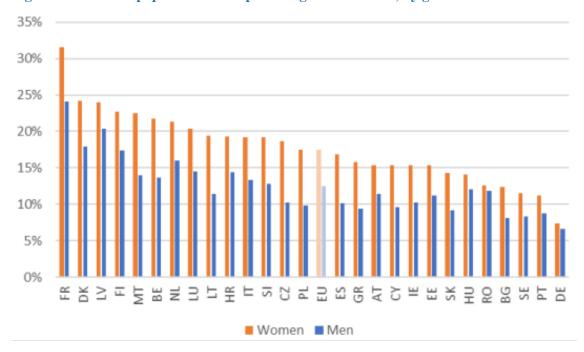


Figure 10: Share of population 18-74 providing informal care, by gender

Source: Van der Ende, M. et al., 2021.

Informal care has strong implications for gender equality, as a **majority of informal carers** (59%) are women. Women also provide more hours of care (17 hours per week for women, compared to 14 hours for men). The majority of informal carers (54%) provide less than 10 hours of care per week, while 25% provide between 10 and 20 hours, 11% provide 20-40 hours and 10% provide more than 40 hours per week. 5.3 million people in the EU are intense informal carers, providing more than 40 hours per week, of which 3.8 million are women<sup>130</sup>. A large share of people providing informal long-term care are also engaged in childcare for children under 18, thus facing a double care burden (71% of women and 79% of men providing informal long-term care)<sup>131</sup>. Fewer women (36%) than men (51%) who provide informal care use support from formal care services<sup>132</sup>.

**Informal care has a large economic and societal value.** Informal carers provide 33 to 39 billion hours of informal care per year. These hours can be associated with a certain value, applying different methods. When applying the proxy good method<sup>133</sup>, the most likely value of these hours is 2.7% of EU GDP. When applying the opportunity cost method<sup>134</sup>, their most likely value is 2.4% of EU GDP<sup>135</sup>. Both methods reach a value that is much higher than current public expenditure on long-term care (1.7% of GDP in the EU<sup>136</sup>).

<sup>&</sup>lt;sup>130</sup> Ibid.

<sup>&</sup>lt;sup>131</sup> EIGE, 2022, Gender inequalities in long-term care – draft statistical brief, forthcoming.

<sup>132</sup> Ibid.

<sup>133</sup> The proxy good method values the hours with the gross wages of care professionals providing similar activities.

<sup>&</sup>lt;sup>134</sup> The opportunity cost method values hours with the gross wage rate of what informal carers could have earned in their "real" professions, and with the value of leisure for people past the age of 65.

<sup>&</sup>lt;sup>135</sup> Van der Ende, M. et al., 2021, Study on exploring the incidence and costs of informal long-term care in the EU.

<sup>&</sup>lt;sup>136</sup> European Commission and Economic Policy Committee, 2021, <u>The 2021 Ageing Report</u> – Economic and budgetary projections for the EU Member States (2019-2070), Publications Office of the European Union, Luxembourg.

The majority of informal carers are employed, but **labour market participation decreases** with intensity of care provided. 64% of informal carers are employed, compared to 67% of the overall population aged 18-64. While 71% of informal carers providing less than 10 hours per week of care are employed, the employment rate of informal carers providing more than 40 hours per week is only 35%. Women, in particular in the age group 45-64, are more likely to drop out of the labour market as a result of caring responsibilities (their employment rate is 54% compared to 59% overall in this age group). Women with caring responsibilities in this age group who drop out of the labour market face on average an annual wage loss of EUR 18 000 net 137/138. This is also later on translated into lower pensions, and more difficulties in affording the costs of long-term care, once the informal carers become themselves dependent on receiving care.

Informal care is also associated with **costs for society as a whole**. Such costs include losses of tax and social security revenues due to informal carers' lower labour market participation, and expenditure on allowances for carers. Care responsibilities are still predominantly borne by women, keeping **7.7 million women out of the labour market** (compared to only 450,000 men)<sup>139</sup> and contributing to the gender employment gap. Estimates conclude that public costs associated with informal care could amount to around 1 % of GDP<sup>140</sup>, more than half of current public expenditure on long-term care (1.7% of GDP).

# 3.6. Impact of COVID-19 on long-term care systems

Long-term care systems have been strongly affected by the **COVID-19 crisis** in view of their users' high vulnerability to the virus and the impact on the carers. The pandemic has **reinforced the already existing structural challenges** regarding the availability, accessibility and quality of care as well as the situation of formal and informal carers.

In general, the **pandemic has disproportionately hit older people** who are at a higher risk of developing severe disease and more likely to die due to COVID-19 because of being frail and having underlying medical conditions<sup>141</sup>. Available cumulative data<sup>142</sup> up to spring 2021 has shown that COVID-19 deaths of people aged 60+ (IE, LT, ES, IT, DE, FR, CZ, NL, PT, SE, DK) or 65+ (AT, BE, SI) represent at least 90% of total registered COVID-19 deaths<sup>143</sup>.

Around half of Member States<sup>144</sup> (BE, DK, EE, FI, DE, EL, HU, LT, LV, NL, PT, ES, SE) had in place **emergency guidelines on infection control** in long-term care before the outburst of

<sup>&</sup>lt;sup>137</sup> Corrected for purchasing power.

<sup>&</sup>lt;sup>138</sup> Van der Ende, M. et al., 2021, Study on exploring the incidence and costs of informal long-term care in the EU.

<sup>&</sup>lt;sup>139</sup> EIGE elaboration of ISSP 2012 data.

<sup>&</sup>lt;sup>140</sup> Van der Ende, M. et al., 2021, Study on exploring the incidence and costs of informal long-term care in the EU.

<sup>&</sup>lt;sup>141</sup> OECD, 2021, Rising from the COVID 19 crisis: Policy responses in the long-term care sector.

Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, <u>COVID-19 in long-term care: Impact, policy responses and challenges.</u>
 OECD Health Working Papers, No. 131, OECD Publishing, Paris.

<sup>&</sup>lt;sup>143</sup> While reported COVID-19 deaths are an important measure, accuracy and comparability of this indicator is limited across countries due to differences in registration, coding practices, level of testing as well as the share of older people in the population, the share of the risk-factor conditions such as obesity and diabetes, or intensity of tourism. Yet, the above figures give a sense of the enormous magnitude of the impact that the pandemic has had on older people.

<sup>&</sup>lt;sup>144</sup> Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, <u>COVID-19 in long-term care: Impact, policy responses and challenges.</u>
OECD Health Working Papers, No. 131, OECD Publishing, Paris.

the COVID-19 crisis. Some EU countries (AT, FR, IE, IT, SI) had developed emergency preparedness systems for the healthcare sector in general, but not for the long-term care sector in particular. The ones with emergency preparedness, though, were not necessarily less affected by the COVID-19 crisis. The lack of **collaboration and coordination between the health and social sectors** was shed light on during the pandemic<sup>145</sup>. Most of the nursing homes were not medically prepared to meet the challenges of the pandemic. Before the outbreak, only several Member States (CZ, DK, FI, FR, DE, FI, LU, PT, SI) had reported having guidelines or legislation on the integration of long-term care and primary care.

The availability and accessibility of care have been impacted in different ways as a result the COVID-19 pandemic. More than half of the **Member States limited access to long-term care** services during the crisis<sup>146</sup>. In order to reduce the risk of spreading COVID-19, day care centres were temporarily closed or made subject to limited access in a number of EU countries (CZ, DE, HR, HU, LU, NL, PL, RO, SI, SK), at least during the first wave of the pandemic. Similarly, access to home care was reduced in several Member States (FR, LU, NL, SI), while in others home care services were limited to strictly necessary visits (e.g. BE, CY, FR, NL). In Austria problems in home care arose especially regarding live-in care at home, who come mostly from central and Eastern Europe. Travel bans prevented carers from travelling between their place of work and their home in a usually biweekly cycle. Conversely, long-term care facilities continued to provide care in most Member States 147. However, in most EU countries residential care providers appeared to be 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 <sup>148</sup>. In cases of COVID-19 outbreaks, the most common response of long-term care facilities was to minimise contact from outside as much as possible and reduce in-person interactions inside<sup>149</sup>. In several Member States (BG, EE, HR, LU, PL), the placement of new residents in residential care was temporarily restricted.

As an attempt to offset the reduced availability and accessibility of care services during the pandemic<sup>150</sup>, **caregiving via telecommunication was strengthened**. A number of countries have enhanced digital care provision (CY, ES, FR, NL, PL, RO). Nevertheless, 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 to receive care in order to minimise their risk of contracting

<sup>&</sup>lt;sup>145</sup> Ibid.

<sup>&</sup>lt;sup>146</sup> Unless specified differently, this paragraph is based on: European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities in an ageing society</u>, Volume I, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>147</sup> Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, <u>COVID-19 in long-term care: Impact, policy responses and challenges</u>. OECD Health Working Papers, No. 131, OECD Publishing, Paris.

<sup>&</sup>lt;sup>148</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities in an ageing society</u>, Volume I, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>149</sup> Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, <u>COVID-19 in long-term care: Impact, policy responses and challenges</u>. OECD Health Working Papers, No. 131, OECD Publishing, Paris.

<sup>&</sup>lt;sup>150</sup> This paragraph is based on: European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends</u>, challenges and opportunities in an ageing society, Volume I, Publications Office of the European Union, Luxembourg.

COVID-19. During the first months of the crisis, unmet long-term care needs may have increased.

Reduction in the availability of formal care services due to the pandemic and social distancing have possibly enhanced the dependence on informal carers, implying an additional psychological and financial strain on them. A survey of Eurocarers shows that the pandemic led to more and new informal carers, as more than 10% of respondents started to provide care as a result of the pandemic. COVID-19 negatively impacted several aspects of many carers' lives, including social network/participation (78.7%); quality of life (76.8%); mental health/psychological state of mind (66.5%); access to health/social services for the care recipient (59.8%); and care recipient's health status (54%)<sup>151</sup>. Informal care appeared to be taking a heavier toll on women, in comparison to men, in terms of increased intensity of the informal long-term care provided, decreased reliance on formal care services, or difficulties in reconciling work and care duties, to name just a few<sup>152</sup>. In addition, evidence suggests that the share of people aged 50 or over who became unemployed, were laid off, or had to close their business because of COVID-19 by August 2020 was higher for informal carers than for non-informal carers in almost all EU countries<sup>153</sup>.

Furthermore, the COVID-19 pandemic had a **negative impact on the quality of care and the quality of life of people receiving care**. In order **to prevent the COVID-19 virus from 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<sup>154</sup>. Only later, it was possible to alleviate some of the isolation and protection measures with an increase in testing and later in vaccination capacity across the EU. 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-19-related symptoms (DK, HR). Creative solutions were also deployed to help residents cope with isolation, such as 'corridor-games', music broadcasting, and entertainment events (FR, LU).

The COVID-19 pandemic has also worsened the working conditions of long-term care workers lost long-term care workers have been more exposed to the virus and related potential health risks, compared to other professions. Evidence from some Member States has shown that long-term care workers have taken more days of sick leave during the pandemic than during comparable periods before (DE, LU, SI). Not only the physical, but also the mental health of long-term care workers was of concern during the pandemic. As a result of the difficult working conditions during the pandemic, labour shortages in the sector increased. Between 2020 and

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<sup>&</sup>lt;sup>151</sup> Eurocarers, 2021, <u>Impact of the Covid-19 outbreak on informal carers across Europe</u>.

<sup>&</sup>lt;sup>152</sup> EIGE, 2022, Gender inequalities in long-term care – draft statistical brief, forthcoming.

<sup>153</sup> Eurocarers, 2021, How informal caregivers' life and care situations changed during the corona-pandemic in Germany,

<sup>&</sup>lt;sup>154</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities in an ageing society</u>, Volume I, Publications Office of the European Union, Luxembourg.

<sup>155</sup> Sources for this section include: European Commission and Social Protection Committee, 2021, Long-term care report: trends, challenges and opportunities in an ageing society, Volume I, Publications Office of the European Union, Luxembourg. And Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, COVID-19 in long-term care: Impact, policy responses and challenges. OECD Health Working Papers, No. 131, OECD Publishing, Paris.

2021, highly likely due to the pandemic, the published online job advertisements for long-term care occupations grew by 39%. According to a recent survey of the Federation of Social Employers among employers' organisations and social service providers from 20 EU countries, a large majority of respondents faced staff shortages, which for most worsened over the course of 2021, as a result of the pandemic. The sub-sector most concerned was services for older people<sup>156</sup>.

To address the issue of staff shortages urgently during the COVID-19 crisis, a number of countries implemented some temporary changes in rules, regulations or laws. These included: relaxation of education requirements<sup>157</sup> (CZ, DE, LT, NL, HU); short-term contracts<sup>158</sup> with foreign workers (LU); bonus payments<sup>159</sup> for long-term care workers (CZ, DE, PL, RO, SK) or live-in carers (AT); bans on firing<sup>160</sup> for long-term care workers (ES); accelerated accreditation of foreign diplomas<sup>161</sup> (DE, EL, LU, PT); mobilisation of workers from other sectors<sup>162</sup>, including the healthcare sector (BE, DE, FR, HR, PL); and mobilising volunteers, medical students, and retirees (CZ, DE, IE, LU, PL, RO).

Beyond the immediate effects of the COVID-19 crisis on long-term care systems, it is also important to consider the potential impact on the preferences for a specific long-term care setting after the pandemic<sup>163</sup>. Some first evidence comes from Canada, which was hit by the pandemic in a similar fashion as EU Member States. The study has established that as a result of the pandemic **residential care has become a less attractive long-term care option**, as there has been a shift towards stronger preference for home care. This is likely to influence people's saving behaviour as well as the type of policies they would support (e.g. citizens more likely to support home care subsidies financed by taxation). Moreover, a study<sup>164</sup> commissioned by the European Parliament points out that research consistently reveals a preference for home-based care among older people, in addition to evidence that home-based care is less costly and has the potential to offer better quality care, compared to traditional institutionalised care.

<sup>&</sup>lt;sup>156</sup> Federation of European Social Employers, 2022, <u>Survey results illustrate extent of current staff shortages in social services</u>.

 <sup>&</sup>lt;sup>157</sup> Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, <u>COVID-19 in long-term care: Impact, policy responses and challenges.</u>
 OECD Health Working Papers, No. 131, OECD Publishing, Paris.
 <sup>158</sup> Ibid

<sup>&</sup>lt;sup>159</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities in an ageing society</u>, Volume I, Publications Office of the European Union, Luxembourg. <sup>160</sup> Ibid.

Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, <u>COVID-19 in long-term care: Impact, policy responses and challenges.</u>
 OECD Health Working Papers, No. 131, OECD Publishing, Paris.
 Ibid.

Achou, B., De Donder, P., Glenzer, F., Lee, M. and Leroux, M.-L., 2021, Nursing Home Aversion Post-Pandemic:
 Implications for Savings and Long-Term Care Policy, Munich Society for the Promotion of Economic Research – CESifo.
 Barry, U. and Jennings, C., 2021, Gender equality: Economic value of care from the perspective of the applicable EU funds. Study for the FEMM committee of the European Parliament.

# 4. CURRENT UNION SUPPORT AND THE CASE FOR REINFORCED ACTION AT EU LEVEL

While the design and organisation of long-term care is primarily a **competence of the Member States** (**Article 153 TFEU**), long-term care touches on several policy areas with relevance for the European Union legal acquis and initiatives (e.g. social inclusion, social protection, social security coordination, free movement of workers, working conditions, skills, healthcare, gender equality, fiscal sustainability, etc.).

The **European Pillar of Social Rights** proclaimed in 2017 set out in its Principle 18 that 'everyone has the right to affordable long-term care services of good quality, in particular home care and community-based services'. <sup>165</sup> The Pillar principles also cover the carers' perspective by highlighting a number of principles related to working conditions as well as the right to leave. As part of the European Pillar of Social Rights action plan that followed in 2021, the European Commission proposed to turn principle 18 on long-term care into concrete action via an initiative.

The European Commission has been supporting the activities of the Member States at various levels by policy guidance, such as the Social Investment Package<sup>166</sup>. Further, it has undertaken analytical work in this area, monitored long-term care-related developments and supported mutual learning and exchange of best practices in close cooperation with the Member States, civil society, and other stakeholders. This is achieved mainly through the Social Open Method of Coordination and the European Semester. Existing acquis are also touching upon different dimensions of long-term care policies. Funding for policy reforms and investments, social innovations and research are equally part of the EU support mobilised for long-term care.<sup>167</sup>

# 4.1. EU initiatives relevant to long-term care

To date, several EU legislative acts or initiatives touch upon different aspects of long-term care, but these initiatives or legislative actions have a horizontal dimension, and therefore do not have a specific focus on the long-term care sector.

The European Commission's **proposal from 2016 for the revision of Regulation 883/2004 on social security coordination** aims to bring legal clarity and transparency regarding access to long-term care benefits when residing in another Member State. In the context of demographic ageing and the promotion of greater independence and mobility for disabled people, more and more mobile citizens need long-term care benefits. The proposal introduces specific coordination rules for long-term care organised on the same logic as the current sickness benefits rules.

<sup>&</sup>lt;sup>165</sup> Commission staff working document (SWD/2017/0201 final), Establishing a European Pillar of Social Rights.

<sup>&</sup>lt;sup>166</sup> Commission staff working document (SWD/2013/41 final), <u>Social Investment Package, Long-term care in ageing societies</u> - Challenges and policy options.

<sup>&</sup>lt;sup>167</sup> Leichsenring, K. and ICF, 2019, Mutual Learning Workshop on Taking Stock of EU action in the area of long-term care, Thematic Paper and Output Report, European Commission.

In December 2021<sup>168</sup>, a second provisional agreement was reached between the co-legislators<sup>169</sup> to **integrate long-term care benefits** into the chapter on sickness benefits and on the definition of long-term care benefits<sup>170</sup>. If final agreement is reached, the revised regulation will clarify what long-term care benefits are and where mobile citizens can claim them, (e.g. under which conditions mobile citizens are entitled to export long-term care benefits when they move abroad). This means that people's rights are better protected in cross border situations.

The importance of an accessible and balanced mix of long-term care services for people with disabilities is highlighted by the Strategy for the Rights of Persons with Disabilities 2021-2030<sup>171</sup>. It contains an ambitious set of actions and flagship initiatives in various domains to empower people with disabilities so they can enjoy their rights and participate fully in society and economy. These issues include amongst others accessibility (being able to move and reside freely but also to participate in the democratic process), having a decent quality of life and to live independently (as it focuses notably on the deinstitutionalisation process) and equal participation (e.g. equal access to all long-term care services) for people with disabilities. In particular, the strategy announced guidance on independent living and inclusion in the community, as well as a specific framework for Social Services of Excellence for people with disabilities.

Furthermore, the European accessibility act<sup>172</sup> aims to improve the functioning of the single market for accessible products and services. It covers products and services that have been identified as being most important for persons with disabilities while being most likely to have diverging accessibility requirements across EU countries. Furthermore, the Web Accessibility Directive<sup>173</sup> already requires websites and mobile applications of the public sector bodies to be accessible, including information, online contact and applications forms, to users, in particular to persons with disabilities. This proposal calls on Member States to ensure that long-term care information, services and facilities are accessible to persons with disabilities.

Most of the EU initiatives address the situation of **long-term care workers**, in terms of their skills, working conditions, including pay and occupational health and safety, and social protection. Regarding the **skills needs of the formal long-term care workforce**, the **European skills agenda** will also contribute to upskilling and reskilling in the long-term care sector. The Communication on a European skills agenda for sustainable competitiveness, social fairness

<sup>&</sup>lt;sup>168</sup> The second provisional agreement was not endorsed by the COREPER, thus negotiations remain open on a limited number of issues not related to long-term care (which is considered a close chapter).

<sup>&</sup>lt;sup>169</sup> Provisional agreement among Council of Ministers, European Parliament and European Commission, Document 7698/19 ADD1 REV1 of 25 March 2019.

<sup>&</sup>lt;sup>170</sup> A benefit in-kind or in cash the purpose of which is to address the care need of a person who, on account of impairment, requires considerable assistance from another person or people to carry out essential activities of daily living for an extended period of time in order to support his/her personal autonomy; this includes benefits granted for the same purpose to the person providing such assistance.

<sup>&</sup>lt;sup>171</sup> Commission Communication (COM/2021/101 final), <u>Union of Equality: Strategy for the Rights of Persons with</u> Disabilities 2021-2030.

<sup>&</sup>lt;sup>172</sup> Directive (EU) 2019/882 of the European Parliament and of the Council of 17 April 2019 on the <u>accessibility</u> requirements for products and services.

<sup>&</sup>lt;sup>173</sup> Directive (EU) 2016/2102 of the European Parliament and of the Council of 26 October 2016 on the <u>accessibility of the</u> websites and mobile applications of public sector bodies.

and resilience of July 2020<sup>174</sup> highlights that 'Demographic change will require Europe to draw on all of its talents and diversity. At the same time, it will also generate new job opportunities in the silver and care economies. These transitions show the need for an unparalleled shift in skill sets to reap their full potential.' The objective of the Pact for Skills (action 1) is to mobilise all relevant actors to assist people in developing the right skill set<sup>175</sup>, which can contribute to the upskilling and reskilling in the long-term care sector. In addition, a proposal for a Council Recommendation on a European approach to micro-credentials for lifelong learning and employability<sup>176</sup> can support upskilling and reskilling opportunities also in the context of care work. Micro-credentials are the outcome (e.g. certificate or award) of a short training course and can be awarded following targeted training that is developed in response to the fast-changing needs of the care sector.

Recent legislative measures at EU level relate to working conditions and minimum wage, and as such are also relevant for formal carers across the EU. The Directive on Transparent and Predictable Working Conditions<sup>177</sup> was agreed in 2019 and aims to improve working conditions by promoting more transparent and predictable employment. This includes amongst others the information workers must receive at the start of their employment relationship, the length of their probationary period, the right to additional employment, planning of the work schedule, anti-abuse legislation for on-demand work and cost-free mandatory training. The Directive applies to every worker in the European Union who has an employment contract or employment relationship as defined by the law, collective agreements or practice in force in each Member State, with consideration to the case-law of the Court of Justice of the European Union. 178 According to Recital 8, domestic workers and voucher-based workers, which also form a substantive part of the care workforce could also fall within the scope of the Directive if they fulfil the criteria mentioned above. In addition, this Directive can also help improve the transparency of working conditions for long-term care workers providing services abroad, which again are quite well represented in the care sector. Indeed, Member States are required to ensure that a **posted worker** (covered by Directive 96/71/EC) <sup>179</sup> is notified of the remuneration to which the worker is entitled in accordance with the applicable law of the host Member State and where applicable, any allowances specific to posting and any arrangements for reimbursing expenditure on travel, board and lodging. <sup>180</sup> Not only long-term care workers,

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<sup>&</sup>lt;sup>174</sup> Commission Communication (COM/2020/274 final), <u>European Skills Agenda for sustainable competitiveness, social fairness and resilience</u>.

<sup>&</sup>lt;sup>175</sup> The Pact for Skills is accompanied by a <u>Charter</u> outlining a shared vision from industry, social partners, vocational education and training (VET) providers, national, regional and local authorities as regards quality training.

<sup>&</sup>lt;sup>176</sup> Commission (COM/2021/770 final), <u>Proposal for a Council Recommendation on a European approach to microcredentials for lifelong learning and employability</u>.

<sup>&</sup>lt;sup>177</sup> Directive (EU) 2019/1152 of the European Parliament and of the Council of 20 June 2019 on <u>transparent and predictable</u> <u>working conditions in the European Union</u>.

<sup>&</sup>lt;sup>178</sup> E.g. Judgment of the Court of Justice of 3 July 1986, <u>Deborah Lawrie-Blum v Land Baden-Württemberg</u>, C-66/85, ECLI:EU:C:1986:284.

<sup>&</sup>lt;sup>179</sup> Directive 96/71/EC of the European Parliament and of the Council of 16 December 1996 concerning the <u>posting of</u> workers in the framework of the provision of services.

<sup>&</sup>lt;sup>180</sup> See Article 7 of the Directive. However, self-employed carers providing services in another Member State are not subject to the Posting of Workers Directive.

but also informal carers can benefit from this directive, as it allows better planning of the caring obligations for people in employment and thus when support from formal home care is needed.

The **Working Time Directive**<sup>181</sup> requires EU Member States to guarantee a limit to weekly working hours (48h), which may be calculated over a reference period, a rest break, a minimum daily rest period of 11 consecutive hours and a minimum weekly rest period of 24 uninterrupted hours and paid annual leave. In addition, it lays down extra protection in case of night work. However, the Directive allows for a possible derogation of these rights in order to ensure the continuity of services within a list of specific sectors and activities, notably for 'services relating to the reception, treatment and/or care provided by hospitals or similar establishments, including the activities of doctors in training, residential institutions and prisons' (Articles 17(3)(c)(i) and 22(1)). <sup>182</sup> Importantly, as other EU labour law Directives, the Working Time Directive is only applicable to workers, excluding the (genuinely) self-employed from its scope.

The proposal of the European Commission for a Minimum Wage Directive <sup>183</sup> in 2020 and the proposal for a directive on pay transparency <sup>184</sup> in 2021 touch on the issue of workers' pay. The proposal for a Minimum Wage Directive aims to establish a framework at EU level to ensure both that minimum wages are set at an adequate level and that workers have effective access to minimum wage protection, in the form of a statutory minimum wage or of minimum wages set by collective agreements. The approval of this directive could therefore provide an important step forward in ensuring adequate wages in the formal long-term care sector and increasing therefore also attractiveness of jobs in the sector. Finally, in low-wage economies better working conditions, including higher minimum wages may reduce outward labour mobility of long-term care workers (i.e. brain drain). The proposal on pay transparency should ensure that women and men in the EU get equal pay for equal work. The initiative aims to tackle the persisting inadequate enforcement of the fundamental right to equal pay and ensure that this right is upheld across the EU, by establishing standards for pay transparency to empower workers to claim their right to equal pay.

In 2021, the Commission adopted the **EU strategic framework on health and safety at work** (**OSH**) **2021-2027** <sup>185,186</sup>. This sets out three key objectives needed to improve workers' health and safety over the coming years: 1) anticipating and managing change in the new world of

<sup>&</sup>lt;sup>181</sup> Directive 2003/88/EC of the European Parliament and of the Council of 4 November 2003 concerning <u>certain aspects of</u> the organisation of working time.

<sup>&</sup>lt;sup>182</sup> Furthermore, reference can be made to judgments of the CJEU in cases C-175/16 *Hälvä* and C-147/17 *Sindicatul Familia Constanca*, which addressed respectively the situation of carers in a residential setting and of foster parents, as well as by analogy C-428/09 *Isère* which concerned staff at a residential recreational centre for children.

<sup>&</sup>lt;sup>183</sup> Commission (COM/2020/682 final), Proposal for a Directive of the European Parliament and of the Council on <u>adequate</u> minimum wages in the European Union.

<sup>&</sup>lt;sup>184</sup> Commission (COM/2021/93 final), Proposal for a Directive of the European Parliament and of the Council to <u>strengthen</u> the application of the principle of equal pay for equal work or work of equal value between men and women through pay transparency and enforcement mechanisms.

<sup>&</sup>lt;sup>185</sup> Commission Communication (COM/2021/323 final), <u>EU strategic framework on health and safety at work 2021-2027:</u> <u>Occupational safety and health in a changing world of work.</u>

<sup>&</sup>lt;sup>186</sup> The EU OSH legislative framework consists of a framework directive and 24 specific directives developed over time. The "Framework Directive" 89/391/EEC on the <u>introduction of measures to encourage improvements in the safety and health of workers at work is the basis for common principles and minimum requirements across the EU.</u>

work; 2) improving prevention of work-related diseases and accidents and 3) increasing preparedness for possible future health threats.<sup>187</sup> One of the follow-up actions to the strategy will be an occupational safety and health (OSH) overview focusing on the health and care sector, in cooperation with the European Agency for Safety and Health at Work (EU-OSHA) by the beginning of 2024. Moreover, the Commission calls on Member States to actively address hazards in the healthcare sector and to develop guidance for the healthcare on worker protection. These initiatives may contribute to better working conditions for workers employed in the long-term care sector.

With the Council Recommendation on access to social protection in 2019, Member States committed to extend the coverage of social protection systems to non-standard forms of employment, including long-term care workers who often work part-time or in non-standard forms of employment. The Recommendation applies to the following branches of social protection, insofar as they are provided in the Member States: unemployment benefits; sickness and healthcare benefits; maternity and equivalent paternity benefits; invalidity benefits; old-age benefits and survivors' benefits; benefits in respect of accidents at work and occupational diseases. Moreover, there can be a risk that the emergence of digital platforms enforces precarious working conditions. To address these, the European Commission published in December 2021 a proposal for a directive on improving working conditions in platform work<sup>188</sup>. The proposal includes new rules to correctly determine the employment status of people working through digital labour platforms and new rights for both workers and self-employed people regarding algorithmic management.

Recent EU initiatives introduced more flexibility but also more predictability of the work schedule to support people in combining care responsibilities and employment. The **Directive on work-life balance**, entered into force in August 2019, aims 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. According to the Directive, workers providing personal care or support to a relative should be entitled to five days of leave per year. Besides, it extends the right to request flexible working arrangements to carers and working parents of children up to eight years old. The rise in care needs should be considered by Member States when they develop their care policies, including with regard to carers' leave (recital 27). Member States are encouraged to make the right to carers' leave available to additional relatives, such as grandparents and siblings (recital 27). Member States have three years to adopt the laws, regulations and administrative provisions necessary to comply with the Directive.

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<sup>&</sup>lt;sup>187</sup> Expert panel on effective ways of investing in health. Furthermore, for workers in the health or care sectors, the "RESPOND" project aims to address adverse mental health effects due to the COVID-19 pandemic.

<sup>&</sup>lt;sup>188</sup> Commission (COM/2021/762 final), Proposal for a Directive of the European Parliament and of the Council on <u>improving</u> working conditions in platform work.

<sup>&</sup>lt;sup>189</sup> Defined by Article 6 of the Directive.

<sup>&</sup>lt;sup>190</sup> See also the Directive for the definition of some relevant concepts: Art. 3 (c): 'carers' leave' means leave from work for workers in order to provide personal care or support to a relative, or to a person who lives in the same household as the worker, and who is in need of significant care or support for a serious medical reason, as defined by each Member State; Art. 3 (d): 'carer' means a worker providing personal care or support to a relative, or to a person who lives in the same

# 4.2. EU analytical work

In addition to the above initiatives that contribute to framework conditions for long-term care, the European Commission has aimed to **strengthen the evidence base** over the last years. This effort includes not only studies, but also increasing the quality and availability of statistical data for long-term care that is collected by Eurostat.

A recent study explored the **incidence and costs of informal long-term care in the EU**<sup>191</sup> and resulted in first time estimates for the number of people providing informal long-term care, and an in depth analysis of their characteristics. It also estimated the costs associated with the provision of informal long-term care for the individual and the society as a whole. **Eurofound**<sup>192</sup> conducted a **study on the employment and working conditions in the long-term care sector**, looking also at the nature of employment and role of collective bargaining in the sector. It also discusses policies to make the sector more attractive, combat undeclared work and improve the situation of a particularly vulnerable group of long-term care workers: live-in carers.

A study on the **long-term care supply and market in EU Member States** <sup>193</sup> provides a mapping of the supply structure for long-term services and examines a sample of 16 Member States with a focus on provider structures. Furthermore, the **European Social Protection Network** conducted research on the **quality of long-term care** <sup>194</sup>, the **role of new technologies** in modernising long-term care systems <sup>195</sup> and long-term care and **social protection** models <sup>196</sup>.

The Commission has also worked with the **OECD on measuring the effectiveness of social protection for long-term care in old age**<sup>197</sup>. Using a set of 'typical cases' of long-term care need to ensure comparability this work shows cross-country and regional variations in the total costs of long-term care services, the degree of public coverage, the out-of-pocket costs that care recipients face, and the associated poverty risks. The cooperation entered a new phase in 2022, not only producing population level estimates of the typical cases, but also analysing the effectiveness of social protection more broadly.

This rich analytical work has been instrumental for building up a strong evidence base for the recent publication of the **2021 Joint Report on Long-Term Care** by the Social Protection

household as the worker, and who is in need of significant care or support for a serious medical reason, as defined by each Member State.

<sup>&</sup>lt;sup>191</sup> Van der Ende, M. et al., 2021, Study on exploring the incidence and costs of informal long-term care in the EU.

<sup>&</sup>lt;sup>192</sup> Eurofound, 2020, <u>Long-term care workforce: Employment and working conditions</u>, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>193</sup> KPMG, 2021, Study on the long-term care supply and market in EU Member States.

<sup>&</sup>lt;sup>194</sup> Zigante, V. and King, D., 2019, <u>Quality Assurance Practices in Long-term Care in Europe</u>, Research Note for the Social Situation Monitor.

<sup>&</sup>lt;sup>195</sup> Zigante, V., 2021, <u>The role of new technologies in modernising long-term care systems: a scoping review.</u> Research Note for the Social Situation Monitor.

<sup>&</sup>lt;sup>196</sup> Pavolini, E., 2021, <u>Long-term care social protection models in the EU</u>, European Social Policy Network (ESPN), Luxembourg: Publications Office of the European Union.

<sup>&</sup>lt;sup>197</sup> Cravo Oliveira Hashiguchi, T. and Llena-Nozal, A., 2021, <u>The Effectiveness of Social Protection for Long-term Care in Old Age: Is social protection reducing the risk of poverty associated with care needs?</u>, OECD Health Working Papers No 117, OECD Publishing, Paris.

Committee (SPC) and the Commission (DG EMPL)<sup>198</sup>. It has put a spotlight on the common challenges related to the provision of long-term care and set out key messages<sup>199</sup> on the way forward, endorsed by the Employment, Social Policy, Health, and Consumer Affairs Council (EPSCO) on 14 June 2021. The 2021 long-term care report follows the **first joint long-term care Report in 2014** <sup>200</sup>, which looked in more detail at strategies of prevention, rehabilitation/re-enablement, and age-friendly environments in the Member States.

Moreover, the Economic Policy Committee and the Commission (DG ECFIN) jointly published the **2021 Ageing Report**<sup>201</sup>, which amongst others collects and analyses data on public long-term care expenditure and cash and in-kind long-term care benefits. It states that 'the clear need for a broadening of formalised coverage of the European population with long-term care services will have to be balanced with the need to ensure the sustainability of public finances' (p 162).

# **4.3.** The social Open Method of Coordination

The **social open method of coordination (OMC)** is an important channel of dialogue and cooperation of the European Commission with the Member States in the area of long-term care. This coordination is implemented via the **Social Protection Committee (SPC)**, an advisory policy committee to the Ministers in the Employment and Social Affairs Council (EPSCO), established in accordance with Article 160 of the TFEU and acting as a forum for multilateral social policy coordination, dialogue and cooperation at EU level.

Member States agreed **common objectives for long-term care in terms of access, quality, and sustainability**<sup>202</sup> which form the background of collaboration on long-term care in the SPC. As part of its tasks to monitor the social situation in the EU and the development of social protection policies the SPC produces **annual reports**<sup>203</sup>. In its 2021 Report, the SPC highlighted that investment in the social, long-term care and health sectors and in human capital will need to be maintained or expanded where necessary and that Member States need to significantly step up their efforts to address the structural challenges in relation to long-term care.<sup>204</sup> As part of its annual **Social Protection Performance Monitor (SPPM)**<sup>205</sup>, the SPC highlighted the exposure of older people to the health risks of the COVID-19 virus, but also the

<sup>&</sup>lt;sup>198</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities in an ageing society</u>, Volume I, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>199</sup> Council (9144/21), Endorsement – Key conclusions on 2021 long-term care report of the Social Protection Committee and the European Commission.

<sup>&</sup>lt;sup>200</sup> European Commission and Social Protection Committee, 2014, <u>Adequate social protection for long-term care needs in an ageing society</u>, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>201</sup> European Commission and Economic Policy Committee, 2021, <u>The 2021 Ageing Report</u> – Economic and budgetary projections for the EU Member States (2019-2070), Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>202</sup> Commission Communication (COM/2008/418 final), <u>A renewed commitment to social Europe: Reinforcing the Open Method of Coordination for Social Protection and Social Inclusion</u>.

<sup>&</sup>lt;sup>203</sup> SPC, 2021, Annual Report.

<sup>&</sup>lt;sup>204</sup> In particular, this entails ensuring the availability of high-quality, affordable and accessible long-term care services to all those in need; addressing the workforce challenges and supporting long-term carers; and enhancing the cost-effectiveness of long-term care in times of rising demand and a shrinking workforce, including through tapping into the potential of digitalisation and focusing on prevention.

<sup>&</sup>lt;sup>205</sup> SPC, 2021, Social Protection Performance Monitor (SPPM).

burden that was placed on women as formal and informal carers and the need to reinforce cooperation between social services and healthcare systems.

A monitoring framework in the field of long-term care has been under development since 2018, through the joint efforts of the Indicators subgroup of the SPC and the European Commission. The group thereby supports the collection of comparative data as part of the open method of coordination long-term care work stream regarding access, quality and sustainability and works closely with Eurostat to develop and harmonise European data collections.

Thematic reviews and mutual learning activities on long-term care are regularly organised in SPC with the support of the European Commission<sup>207</sup>. Topics addressed included quality of long-term care, financing of long-term care, the work-life balance of informal carers, addressing workforce shortages in the long-term care sector, or deinstitutionalisation.

# **4.4.** The European Semester

At the core of the EU's socio-economic governance structure is the European Semester of policy coordination, through which the Commission and the Council set priorities, review national performance and reform programmes, and issue Country-Specific Recommendations (CSRs) to Member States.

The Joint Employment Report<sup>208</sup> provides an annual overview of the key developments, and the Union's and Member States' performances regarding the implementation of the Employment Guidelines, including the principles of the Pillar of Social Rights. The Social Scoreboard monitors Member States' performance in relation to the European Pillar of Social Rights. As part of the European Pillar of Social Rights action plan<sup>209</sup>, the European Commission proposed a revision of the Social Scoreboard that also includes secondary indicators relating to long-term care<sup>210</sup>.

In the area of long-term care, most CSRs have focused on access of the people in need of care, but it was also sometimes highlighted from a complementary perspective, that of carers and their labour market participation. Some CSRs were multifaceted balancing social and fiscal considerations, and several were sustainability-driven. In 2019, there were 8 long-term care-related CSRs focusing on sustainability (AT, BE), on access and female labour participation (IT, PL, SK), and on access, affordability, quality and cost-effectiveness (EE, FI, SI). In response to the COVID-19 pandemic, in 2020 the CSRs were streamlined and emphasised long-term care systems' resilience, with relevant aspects for long-term care regarding fiscal sustainability and female labour market participation were reflected in the recitals. Three Member States (FI, PT, SI) had a long-term care-related CSR. In 2021, the Commission did not propose non-fiscal Country Specific Recommendations, while in 2022 five Member States (AT, BE, EE, PL, SI) received a Country Specific Recommendation related to long-term care. These

<sup>208</sup> Commission (COM(2021) 743 final), Joint Employment Report 2022. Adopted by EPSCO on 14 March 2022.

<sup>&</sup>lt;sup>206</sup> Monitoring and benchmarking frameworks.

<sup>&</sup>lt;sup>207</sup> Peer reviews.

<sup>&</sup>lt;sup>209</sup> Commission (COM/2021/102 final), <u>The European Pillar of Social Rights Action Plan</u>.

<sup>&</sup>lt;sup>210</sup> Agreement on the secondary indicators is however still pending with the ISG and SPC.

touched upon issues such as improving the affordability and quality of long-term care, ensuring the adequacy and fiscal sustainability of long-term care systems, or improving access to long-term care as a way to enhance women's labour market participation.

Exceptional measures were adopted to support the recovery process during the COVID-19 pandemic and enhance the social and economic resilience through the Recovery and Resilience Facility (RRF). This led to a need to temporarily adapt the Semester to ensure synergies with RRF cycle. The Member States were invited to reflect their national agendas for reforms and investments in their recovery and resilience plans (RRPs) consistently with the challenges and priorities identified in the context of the European Semester. The Commission accompanied the proposals for the Council implementing acts with analytical documents assessing the substance of the recovery and resilience plans, which replaced the European Semester country reports in 2021. Given the comprehensive and forward-looking policy nature of the recovery and resilience plans, the Commission did not propose non-fiscal country-specific recommendations in 2021.

Reform implementation is monitored by the Social Protection Committee and Employment Committee through multilateral implementation reviews, respectively multilateral surveillance of reforms, focused on the previous years' country-specific recommendations in their areas of competence. The SPC 2022 thematic discussion on long-term care confirmed that social protection coverage for long-term care needs varies considerably across the Member States and even when available, it is in some cases insufficient to ensure that people in need of care are not pushed into poverty. As concerns workforce challenges, some Member States are taking measures to reinforce formal care services and provide support to informal carers. The role of person-centred care and integrated delivery of services focused on personal needs in ensuring continuity of care and supporting independent living in all care settings was stressed. The discussion showed that there is a need to draw up and/or expand quality standards to respond to structural weaknesses revealed by the COVID-19 pandemic, while reflecting the increasing diversity of care services and care settings and care users' preferences.

### 4.5. Funding opportunities at EU level

The EU-level funding opportunities to **support investments in long-term care** include the structural funding programmes such as European Regional Development Fund (ERDF), the European Social Fund plus (ESF+), the Employment and Social Innovation strand (EaSI), the European Agricultural Fund for Rural Development (EAFRD) and the Just Transition Fund (JTF). The Recovery and Resilience Facility (RRF) finances reforms and investments aimed at supporting recovery from the COVID-19 pandemic. Technical support is available from the Technical Support Instrument (TSI) for reform design and implementation. Finally, research projects can be financed via the Horizon Europe or Digital Europe programmes, while Erasmus+ programme can support sectoral skills cooperation and development for training curricula and programmes for carers.

#### 4.5.1. Structural funds

In the programming period 2014-2020, the ESF has supported several actions related to long-term care ranging from the reskilling and upskilling of the workforce, expanding access and

coverage, supporting integrated care services and independent living, to active and healthy ageing.

Expenditure related to type 4 - access to services which include long-term care stands at 19 % of expenditure declared by beneficiaries to Managing Authorities for TO9 operations:

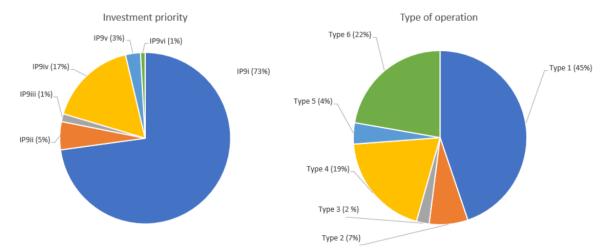


Figure 11: ESF Investment priorities and operations (2014-2020)

Source: SFC2014, based on AIR2018 (data extracted on December 10, 2018) and OP2018 (data extracted on July 1, 2019). Recorded expenditures include both EU and national amounts. ICF mapping exercise of OPs with planned TO9 operations. The sum exceeds the total number of OPs as an OP may cover multiple types of operations. For more information, please see Annex 2; Note: The IPs include: IP9i) Active inclusion, IP9ii) Socio-economic integration of marginalised communities, IP9iii) Non-discrimination and equal opportunities, IP9iv) Access to services, IP9v) Social entrepreneurship and IP9vi) Community-led local development strategy. The types of operation include: Type 1 – Employment focussed action, Type 2 - Enhance basic skills Type 3 - Basic school education, Type 4 – Access to services, Type 5 – Social entrepreneurship, Type 6 - Actions influencing attitudes and systems. The methodology for estimating expenditures by type of operation is presented in Annex 4.

Programming for the period 2021-2027 Member States is ongoing, and access to the European Regional Development Fund (ERDF) and the European Social Fund plus (ESF+) is conditional upon national or regional strategic policy framework for health and long-term care. ESF+, with a total budget of EUR 99.3 billion, supports the following specific objectives in the area of long-term care with regards to people with support needs:

- promoting a gender-balanced labour market participation, equal working conditions, and a better work-life balance including through access to affordable childcare, and care for dependent persons;
- promoting the adaptation of workers, enterprises and entrepreneurs to change, active and healthy ageing and a healthy and well adapted working environment that addresses health risks.
- enhancing equal and timely access to quality, sustainable and affordable services, including services that promote the access to housing and person-centred care including healthcare; modernising social protection systems, including promoting access to social protection, with a particular focus on children and disadvantaged groups; improving accessibility including for persons with disabilities, effectiveness and resilience of healthcare systems and long-term care services;

The ESF+ also promotes the transition from residential and institutional care to family and community-based care, in particular for those who face multiple discrimination and should not support any action that contributes to segregation or to social exclusion.

#### 4.5.2. The European Agricultural Fund for Rural Development

The European Agricultural Fund for Rural Development (EAFRD) supports European policy on rural development with a total budget of EUR 95.5 billion for the period 2021-2027. Also based on the relevant evidences and facts described in the Long-term Vision for Rural Areas1 the Regulation (EU) 2021/2115 on the Common Agricultural Policy Strategic Plans gives the possibility for Member States to support rural childcare and long-term care under the Specific Objective 8 (in coordination with and complementing to other EU funds). Rural areas and rural population all around the EU can face challenges related to access to care services which has a negative impact on the economic and living conditions. Also, depopulation and ageing are negative phenomena in many rural areas of the EU and often influenced by the lack of affordable and accessible basic services, which is why EU rural development policy is addressing to improve the current situation.

#### 4.5.3. The Just Transition Fund

The Just Transition Fund (JTF), equipped with EUR 17.5 billion (in 2018 prices; EUR 19.2 billion in current prices), is one of the key tools to support regions in the **transition towards climate neutrality** by 2050. It aims to alleviate the socio-economic costs triggered by climate transition, by supporting the economic diversification and reconversion of the territories concerned. This entails supporting productive investments in small and medium-sized enterprises, the creation of new firms, research and innovation, environmental rehabilitation, clean energy, up- and reskilling of workers, job-search assistance and active inclusion of jobseekers programmes, as well as the transformation of existing carbon-intensive installations when these investments lead to substantial emission cuts and job protection. It is expected to mobilise close to EUR 30 billion in investments within the 2021-2027 budget cycle.

While the main aim of the programme is to support investments to mitigate the impact of the climate transition, where duly justified, territorial just transition plans may contain activities in the areas of education and social inclusion including, investments in infrastructure for the purposes of training centres, child- and long-term-care facilities as indicated in territorial just transition plans.

#### 4.5.4. EASI social innovation projects on long-term care

The Employment and Social Innovation (EaSI) programme promotes a high level of quality and sustainable employment, guaranteeing adequate and decent social protection, combating social exclusion and poverty and improving working conditions. It became strand of the European Social Fund Plus (ESF+) for the period 2021-2027.

A 2019 EASI call for social innovation projects in the area of long-term care funded seven projects (total budget: EUR 9 million), which aim to design and test innovative ways to address long-term care challenges. They include designing integrated care models, new ways to provide long-term care in rural sparsely populated areas, new funding models for long-term care, strengthening individual autonomy and introducing participatory decision-making in long-term care policy formation. Some projects have a regional focus while others have a pan-European dimension and cover a number of countries (France, Italy, Portugal, Greece, Germany, Poland,

Austria, Spain, North Macedonia, Belgium, Montenegro, Republic of Serbia, etc.). Their implementation is ongoing (running between 2020-2024), and if successful, the new models can later be up-scaled using EU structural funding.

#### 4.5.5. Technical Support Instrument

The Technical Support Instrument (TSI) provides technical support to EU Member States on reform design and implementation. The TSI follows an annual cycle with a total budget of EUR 864.4 million for the period 2021-2027 (in current prices), thus around EUR 120 million annually.

The programme already supports a number of projects aimed at improving the affordability, quality and availability of long-term care benefits and services.

Provision of integrated care services in Estonia

The overall aim of this project was to contribute to a more integrated and person-centred provision of social, medical and vocational support services to people with disabilities and elderly with high support needs in Estonia. To this extent, the project provided a strategy to the Estonian government, which should contribute to: (i) improvements in the interoperability of registries and administrative datasets; (ii) the development of measures and indicators through which to support quality improvement and assess performance; (iii) the introduction of performance-based financing and payment elements to incentivise integrated service provision; and (iv) a closer cooperation between services administered at central and at local level, as well as between local stakeholders.

The Communication on a European care strategy announces a **flagship 'Towards person-centred integrated care'**. Such support aims at facilitating reforms in line with the proposal for a Council Recommendation on access to affordable high-quality long-term care. The flagship will help Member States, upon demand, to design and implement reforms aimed at strengthening the coordination between health, social care and long-term care and the integration of the different levels of care provision, by putting the person at the centre of services to ensure better access and better quality of care at every stage of life.

# 4.5.6. The Recovery and Resilience Facility

The outbreak of COVID-19 has changed the economic outlook for the years to come in the European Union. Investments and reforms are needed more than ever to ensure convergence and a sustainable economic recovery. The Recovery and Resilience Facility, with EUR 732.8 billion in grants and loans<sup>211</sup>, provides Member States with significant opportunities to fund reforms and investments in social resilience, including in long-term care.

A large number of Member States<sup>212</sup> mobilised the RRF for the long-term care sector.

Examples of **reforms** under the RRPs include strengthening long-term care system and promoting a change in the model of support and long-term care, increasing human resources

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<sup>&</sup>lt;sup>211</sup> In current prices, see here.

<sup>&</sup>lt;sup>212</sup> 18 Member States: Austria, Belgium, Bulgaria, Croatia, Cyprus, Czechia, Estonia, France, Greece, Italy, Latvia, Lithuania, , Poland, Portugal, Romania, Slovakia, Slovenia, Spain and Sweden.

and infrastructure capacity for the provision of long-term care services, training, reskilling and upskilling of long-term care professionals. Additional reforms are also expected to improve long-term care provision by modernising or expanding social services, including community-based services, and by supporting long-term fiscal sustainability of long-term care systems. Many plans also include measures to support high-quality long-term care services through targeted investments in public utility housing and housing for vulnerable persons and related services as well as in community-based care and outpatient facilities and services. Quality and access of long-term care services will also be supported through energy-efficient renovation and modernisation of long-term care institutions, including the improvement of digital infrastructure.

#### Lithuania - Reform 'Provision of long-term care services'

The objective of the reform is to improve the accessibility of integrated social and healthcare services by developing and implementing a sustainable long-term care model. An action plan for training, reskilling and upskilling of long-term care professionals shall be developed and a plan for ensuring the necessary infrastructure for the provision of long-term care services at the level of each municipality and region shall ensure an optimal use of existing infrastructure for health and social protection and resources of municipal and nongovernmental organisations. For each region, the analysis of resources for institutional, community-based and home-based long-term care shall be made and a new model for the provision of long-term care shall become operational. This reform is accompanied by two sub-measures: (1) Adoption of the long-term care model (sub-measure 1); (2) Increase of human resources and infrastructure capacity for the provision of long-term care services (sub-measure 2).

Examples of **investments** under the RRPs cover equipping social services with the means to enable home care (e.g. setting up rapid response units), setting up community-based care and outpatient facilities, equipping long-term care facilities with digital infrastructure such as internet connections, computers and software as well as with equipment to better identify needs and improving quality, implementing energy efficient renovation and modernisation of long-term care structures such as elderly homes (nursing homes), day care and community care centres, and hospital infrastructure.

#### Austria - Investment in the implementation of community nurses

The objective of the establishment of **community nursing in Austria** is to make a significant contribution to local, low-threshold and needs-based care; community nurses are central contact people who coordinate various services (such as therapies and social services) and play a central role in the field of prevention. The investment consists in the establishment of a network of community nurses close to their patients. Community nurses are qualified nurses with at least two years of professional experience. Community nurses with a further relevant qualification (such as courses on community nursing, family health nursing, public health nursing) shall preferably be employed. In the course of the project, 150 community nurses shall be posted nationwide as part of the pilot project within the framework of fixed-

term employment contracts. The implementation of the investment shall be completed by 31 December 2024.

# 4.5.7. Horizon Europe

Horizon Europe is the EU's key funding programme for research and innovation with a budget of EUR 95.5 billion.<sup>213</sup> It facilitates collaboration and strengthens the impact of research and innovation in developing, supporting and implementing EU policies while tackling global challenges. It supports creating and better dispersing of excellent knowledge and technologies.

Several components of Horizon Europe can support long-term care, including the health component<sup>214</sup>. The Work Programme 2023-2024 contains a research project on 'Integrated care solutions for better quality, person-centred long-term care and territorial inequalities in their provision' with a budget of EUR 9 million.

# 4.5.8. Digital Europe

The Digital Europe Programme focuses on bringing digital technology to businesses, citizens and public administrations. It provides supports projects in five key capacity areas: in supercomputing, artificial intelligence, cybersecurity, advanced digital skills, and ensuring a wide use of digital technologies across the economy and society, including through Digital Innovation Hubs.

With a planned overall budget of EUR 7.5 billion (in current prices), it aims to accelerate the economic recovery and shape the digital transformation of Europe's society and economy, bringing benefits to everyone, but in particular to small and medium-sized enterprises.

As digital technologies play an important and growing role in the transformation of health and care delivery, health promotion, disease prevention, assisted living technologies and monitoring devices, various initiatives under Digital Europe Programme could promote Long-Term care. These include in particular the 'Artificial Intelligence Testing and Experimentation Facility in Health' and the 'Uptake of Digital solutions in Health and Care' Calls, but also other topics supporting the cybersecurity in health, as well as the exchange of health data and of Electronic Health Records, as one of the ambitions set in the Digital Decade Communication is to have 100% of citizens having access to medical records by 2030. In addition, the network of Digital Innovation Hubs<sup>215</sup> co-funded by DIGITAL will help innovators, also in the health domain, to scale-up their solutions across European regions.

#### 4.6. Why and how the EU should act now

Long-term care systems are designed nationally and long-term care services are delivered in local communities, but challenges are shared among the countries and the consequences of not acting to improve them spill over across borders. Long-term care is increasingly relevant for the single market, as care providers and recipients take advantage of the freedom to move and

<sup>&</sup>lt;sup>213</sup> European Commission, 2021, Horizon Europe, budget. Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>214</sup> Ibid

<sup>&</sup>lt;sup>215</sup> Digital Innovation Hubs.

to establish and provide and receive services, including digitally enabled ones. Access, affordability, quality challenges as well as workforce shortages and gender inequalities have a negative impact on social cohesion, labour market participation and economic growth. Effective long-term care systems are crucial for improving living conditions and ensuring proper social protection, as enshrined in Article 151 of the Treaty on the Functioning of the European Union (TFEU).

The scale of the problem demands a focused and comprehensive approach at EU level. Current Union efforts to support Member States in addressing long-term care challenges – notably exchanges of best practice, mutual learning, and joint analysis and reporting – have exhausted their potential to address a substantial and growing concern. Furthermore, the existing EU initiatives which are indirectly touching various aspects of long-term care provide a scattered picture of the EU policy framework on long-term care.

The European care strategy provides an EU-level response to and recognition of the societal and economic importance of long-term care. On one hand, it proposes concrete supportive actions at EU level, and, on the other, it provides Member States with comprehensive policy guidance on addressing the multifaceted challenges in this area. The measures outlined in the initiatives respect national competences and do not prevent EU countries from maintaining or introducing more ambitious measures that are compatible with the Treaties.

# 5. POLICY OPTIONS FOR ADDRESSING THE CHALLENGES OF LONG-TERM CARE

This chapter sets out different policy scenarios and practical examples of how to strengthen affordability, availability, and quality of long-term care and how to address the challenges faced by formal and informal carers. It concludes by underlining the importance of sound policy governance in long-term care and of adequate and sustainable funding for long-term care.

It builds on the rich array of policy practices currently in place at EU, national, regional and local levels. It factors in the input received during the targeted stakeholder consultation underpinning the initiative. It also runs some policy simulations to illustrate the potential costs and benefits associated with action to improve social protection, increase the availability of care and to invest in the long-term care workforce. The calculations are only indicative due to the scarcity and limited comparability of data.

## 5.1. Social protection for long-term care

The proposal for a Council Recommendation on long-term care invites **Member States to improve the adequacy of social protection for long-term care**, in particular by ensuring that long-term care is:

- timely, allowing people in need of long-term care to receive the necessary care as soon as, and for as long as, needed;
- comprehensive, covering all long-term care needs, arising from mental and/or physical decline in functional ability, assessed on the basis of clear and objective eligibility criteria:

• affordable, enabling people in need of long-term care to maintain a decent standard of living and protecting them from poverty due to long-term care needs.

#### 5.1.1. Providing adequate social protection for long-term care

The adequacy of social protection depends not only on the rules granting social protection, but also on providing it in a **timely manner**. Therefore it is important to ensure the existence and geographical proximity of the authorities responsible for care in Member States, and that they have the capacity to handle requests for support (e.g. to conduct needs assessments). Especially when social protection is provided via benefits in-kind, public care services should be available shortly after the request, in the area where the person in need lives.

Shock plan to reduce waiting times in Spain<sup>216</sup>

A shock plan approved in January 2021 brought in reforms designed to simplify administrative procedures, speed up the processing of applications, reduce waiting lists for dependents that are not receiving the services to which they are entitled and reduce differences in levels of care across the country. The immediate actions also included strengthening the quality of professional services, improving working conditions and increasing the coverage of different types of financial benefits.

The Spanish authorities identified that long waiting times are a multi-causal phenomenon, caused partly by the complexity of the administrative process, process fragmentation, interoperability and insufficient staffing. To address these challenges, the reforms integrate administrative and technical procedures and integrate computer systems, while also taking steps to improve data quality. The reforms also include boosting the workforce for both the management and the needs assessment. Lastly, Spain plans to invest more in technical and material resources, and to expand the effective availability of services and benefits.

Though it is still a work in progress, the reform has already brought down the average waiting time between the date a person submits an application and when they actually receive the benefit by 36 days in the first year, from a very high starting point of 457 days in 2020.

Adequate social protection to cover long-term care is based on a **comprehensive needs** assessment with clear and objective eligibility criteria. Member States can define long-term care needs in a narrower or broader sense and this has a significant impact on the level of social protection benefits, as the criteria are usually used by authorities to differentiate among levels of long-term care needs.

In general, health professionals (GPs, gerontologists, or nurses) and social workers make this assessment. The needs assessment and its regulation can be centralised or devolved to regional/local levels, depending on whether they have an integrated long-term care system and on the level of government in charge of organising long-term care public provision. In Nordic

<sup>&</sup>lt;sup>216</sup> IMSERSO, 2022, Long-term care reforms in Spain. Presentation at the Social Protection Committee.

countries, for example, the criteria and assessment are highly devolved to municipalities and their long-term care professional teams.

To encourage and help people in need of care to apply for social protection, it is also important that the criteria used to assess needs and the application procedures are clear and objective.

Capacity building for the assessment process of long-term care recipients in Slovenia<sup>217</sup>

The Slovenian authorities have developed a tool to assess long-term care needs via a prepilot project building on a German long-term care assessment tool. Through two subsequent pilot projects<sup>218</sup> financed by the European Union through the European Social Fund, the assessment tool suggested by the pre-pilot project was upgraded and tested by over 5 000 people.<sup>219</sup> The project then added a single entry point, new services for users (including ecare services) and monitoring functions.

The Long-Term Care Act, adopted in December 2021, specifies that this assessment scale is now the uniform tool used to assess an insured person's entitlement to long-term care rights, amongst other provisions. The assessment of long-term care eligibility takes into account the applicant's:

- 1. ability to move in the environment where the insured person lives;
- 2. cognitive and communication skills;
- 3. behaviour and mental health;
- 4. ability to be self-sufficient (in terms of self-care) in the environment where the insured person lives;
- 5. ability to cope with disease and illness, the treatment-related requirements and burdens;
- 6. daily routine and social contacts;
- 7. ability to perform activities outside the home environment; and
- 8. ability to perform household chores in the environment where the insured person lives.

The reform also established the Health Insurance Institute of Slovenia as the single entry point for long-term care. This Institute carries out professional and administrative tasks, including the needs assessment. Before the new long-term care Act, services that could be classified as long-term care were provided through multiple social protection systems (healthcare system, pension system, social care system, disability care system...) with different entry points and different assessment procedures.

The long-term care assessment will now be provided at the individual's home, after they submit the application for an assessment of long-term care eligibility. If the applicant is eligible for care, reaching the entry threshold, they will be put into one of five categories,

<sup>&</sup>lt;sup>217</sup> Slovenian Ministry of Health, Information provided by the Department of Long-term Care on 29 May 2022.

<sup>&</sup>lt;sup>218</sup> (1) <u>Implementation of pilot projects supporting the implementation of the long-term care systemic law</u> and (2) <u>Redesign of</u> existing networks and entry of new providers to provide community services and programs for the elderly.

<sup>&</sup>lt;sup>219</sup> The evaluation summary of the pilot project Implementation of pilot projects supporting the implementation of the long-term care systemic law, including the assessment scale, is available <a href="here">here</a>.

indicating the basis for benefits (long-term care at home, long-term care at an institution, benefits in cash, carer of a family member, or eligible for services to maintain and strengthen their independence and e-care). All long-term care beneficiaries will be regularly assessed after five years.

Over the last 20 years, Member States have implemented or mainstreamed policies that aim to both broaden long-term care service provision to more groups (e.g. people with dementia), and deepen the social protection given (e.g. raising the level of cash benefits).

# Long-term care coverage for dementia

In 2017, Germany<sup>220</sup> extended long-term care benefits to around 500 000 more people suffering from dementia (Second Long-Term Care Act Strengthening Act - PSG II). Dementia is regarded as one of the most expensive brain disorders that typically requires permanent monitoring and intensive caregiving. The government's response has been to redefine the care-level grades through the use of a new assessment tool. Compared to before, the tool no longer calculates the time needed for nursing care but assesses the degree of self-reliance restrictions. The assessment takes into account all kinds of self-reliance restrictions: disabilities both in physical as in mental health and in cognition. The three care levels (Pflegestufen) are replaced by five new care degrees (Pflegegrade).

This reform has been accompanied by a substantial increase in cash and in-kind benefits by more than EUR 2.5 billion. It was preceded in 2015 by the first Long-Term Care Strengthening Act (PSG I), which expanded benefits to all 2.7 million beneficiaries. Germany has increased long-term care benefits for people living at home by EUR 1.4 billion every year, and for people in residential care by EUR 1 billion for every year.

Providing adequate social protection for long-term care makes services affordable, in particular for the least well-off. As discussed in chapter 3, if long-term care is unaffordable, care needs go unmet, which may later on translate into greater and more costly care needs and more pressure on the health system. This can undermine other essential spending and puts an undue burden on informal caregivers.

Social protection<sup>221</sup> coverage for long-term care varies greatly. There are three main dimensions to these differences, which determine the affordability of long-term care for the overall population in need: who is covered (the people in need of long-term care who are covered by social protection for long-term care), what is covered (the range of needs and the types of services covered, usually based on the care needs assessment (breadth)), and how much is covered (depth of financial protection, reflecting cost-sharing arrangements, often referred to as adequacy).

Most countries that provide social protection for long-term care needs apply some form of costsharing arrangement. They either provide cash benefits that do not cover the full cost of care, or require the care recipients and their families to co-pay part of the costs of long-term care

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<sup>&</sup>lt;sup>220</sup> Germany's Long Term Care Strengthening Acts

<sup>&</sup>lt;sup>221</sup> Muñoz De Bustillo Llorente, R., Fernandez Macias, E. and Gonzalez Vazquez, I., 2020, Universality in social protection: an inquiry about its meaning and measurement, Publications Office of the European Union, Luxembourg, p. 21-22.

services provided as in-kind benefits. Without social protection, the estimated total costs of long-term care often exceed the disposable income of people in need of long-term care.

As illustrated in section 3.2, even when social protection is available, in some cases social protection for long-term care needs is still insufficient. On average nearly half of older people with long-term care needs would be below the poverty threshold after meeting the out-of-pocket costs of home care. Thus, it is important that social protection covers a sufficient share of the costs of care. In some cases, cost-sharing can be deferred, with the co-payments made on the death of the long-term care recipient when their assets are sold. Regular indexation of long-term care cash benefits can also help ensure that they remain adequate over time.

In January 2020, Austria brought in 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 July 2019, Czechia brought in a 4% increase in the personal care allowance for the most dependent groups of beneficiaries (apart from people in residential care facilities).

Given that historically, long-term care lies at the intersection between universal healthcare services and sometimes discretionary social care services, it has been long seen as a family responsibility<sup>222</sup>. However, in recent years, several Member States have increased the social protection available to cover long-term care by reducing the legal obligation on families to provide or cover the costs of care.

In Austria, in 2007, the federal provinces stopped recourse to the assets 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. 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. Since 2017, co-payments for people receiving residential care no longer depend on the level of care needed. Everyone in a nursing home who needs long-term care and has been assessed as needing higher levels of care pays the same care-related co-payment (though the amount differs between residential homes)<sup>223</sup>.

Member States are reforming their social protection systems to adjust them to the requirements of an ageing population. This includes establishing a sustainable financing base often in combination with an increase in financial protection and quality of long-term care. As research by Pavolini<sup>224</sup> shows, Member States with a high level of social protection for long-term care usually have a dedicated social protection branch for long-term care.

<sup>&</sup>lt;sup>222</sup> Leitner, S.,2003, Varieties of familialism: The caring function of the family in comparative. Perspective, European Societies 5(4): 353-375.

<sup>&</sup>lt;sup>223</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report, Vol. 2 Country profiles</u>, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>224</sup> Pavolini, E., 2021, <u>Long-term care social protection models in the EU</u>, European Social Policy Network (ESPN), Luxembourg: Publications Office of the European Union.

In order to improve the provision of care for older people and people with disabilities, France aims to set up a fifth social protection branch in its general social security system covering the risk of loss of autonomy. Current branches cover the risks of sickness, retirement, family, work-related accidents and occupational disease. The Social Security Financing Law of 2021 defines the first measures for organising the governance and financing of this new branch, with EUR Ibillion co-financed via the RRP. The main guidelines of a deep-seated reform were presented in the Libault report of 2019, which includes the recommendation to invest almost EUR 10 billion in long-term care by 2030.

Slovenia adopted a long-term care Act in December 2021 introducing compulsory long-term care insurance. The compulsory health insurance (HIIS) covers everyone aged 18 and over in Slovenia. Another act will set the other conditions for long-term care insurance, such as contribution rates and a contribution base. Until its adoption (estimated to be in June 2025), 3.8% of HIIS funds and 2.2% of funds collected by the Pension and Disability Insurance Institute will be used to finance long-term care, in addition to transfers from the state budget. The new act defines the rights and assessment mechanism for categories of care and it emphasises community care and brings in e-care and some other new services.

The COVID-19 pandemic is also an opportunity to further re-think the paradigm of social protection in long-term care and to adjust it to an evolving social contract regarding care. As people in need of care and their families are often unable to pay for the high cost of long-term care, nor to adequately provide informal care, public long-term care provision is crucial. It should build on a renewed social contract and sense of intergenerational solidarity.

#### 5.1.2. Illustrating the impact of improving social protection for long-term care

The European Commission has worked together with the OECD to simulate a number of policy scenarios that estimate the potential impact of expanding or deepening the social protection coverage for long-term care across the EU<sup>225</sup>. They illustrate how increasing social protection can reduce the share of people at risk of poverty after using formal long-term care services.

The **baseline scenario** estimates the impact of public social protection for long-term care in old age under current circumstances (based on latest available information and data as of March 2022), and under certain key assumptions. First, the **EU-27 average uptake of any formal long-term care services by people in need of care is estimated to be 27%<sup>226</sup>.** According to

<sup>&</sup>lt;sup>225</sup> No models of social protection for long-term care in old age are available for Bulgaria, Cyprus and Romania, the information lacking was imputed for those three Member States. The models for Denmark, Greece, Poland and Portugal have not yet been validated with Member State representatives. OECD, forthcoming, 2022, Measuring social protection for long-term care in old age, OECD Health Working Papers, OECD Publishing, Paris.

<sup>&</sup>lt;sup>226</sup> Calculated as an average between the European Health Interview Survey (EHIS), the Survey of Health, Ageing and Retirement in Europe (SHARE) and the Irish Longitudinal Study on Ageing (TILDA). Determining current availability and uptake of public social protection for long-term care in old age in all Member States is challenging, given limited detailed data on the existence and geographical location of public social protection offices in Member States, and their capacity to handle requests for support (e.g. conduct needs assessments). Even then, assuming full availability of public social protection for long-term care, effective use also depends on the availability of providers, whose availability and geographical distribution is also difficult to establish across all Member States. Lastly, even if public social protection offices and

these estimates, across the EU-27, around 7.2 % or 6.3 million people 65+ receive formal care, 1.7 million of whom have severe needs and receive residential care<sup>227</sup>. Second, in the baseline scenario, the breadth and depth of social protection are derived from the latest OECD-developed models of social protection for each Member State for people with long-term care needs. Under the baseline scenario, if all older people use formal long-term care to fully cover their long-term care needs, about 37% of them would be at risk of poverty (compared to 22.74% of older people with no long-term care needs).

However, not all older people take up social protection for long-term care. This may be due to their limited administrative capacity, limited capacity to cover out-of-pocket costs, the limited availability of services, or by choice not to use public formal long-term care services or benefits. The estimated level of uptake of formal care differs significantly across the EU, from 8% in Romania to 46% in France<sup>228</sup>.

In the two simulated policy scenarios, **two hypothetical levels of uptake of social protection for long-term care**<sup>229</sup> **are considered:** 40% **and** 60% **of people in need of long-term care**. In the 40% take-up scenario, the number of people over 65 years of age using social protection for long-term care would increase to 9.4 million and in the 60% take-up scenario, it would increase to 14 million<sup>230</sup>. In Belgium, Cyprus, Denmark, France, Germany and the Netherlands, the estimated uptake of public social protection at baseline is over 40%. No Member State has a take-up ratio at baseline higher than 60% (the highest is France at 46%). The assumption is that the probability of uptake of older people with long-term care needs is higher for people with more severe needs and lower income.

In **policy scenario 1**, the breadth (types of services covered) and depth of financial protection (cost-sharing arrangements) remain at current levels, with hypothetical levels of uptake of 40%, 60% (coverage). Figure 12 shows the average out-of-pocket costs of long-term care, as a share of disposable income, averaged across respondents receiving home care for low, moderate and severe needs and institutional care for severe needs. The EU-27 average out-of-pocket costs of long-term care, as a share of disposable income, are 59% at 40% uptake and 47% at 60% uptake. In these scenarios, the risk of poverty would decrease only slightly by 2 percentage points (pp) (40% uptake) and by 6.8pp (60% uptake) for people using formal long-term care compared to the baseline (uptake of social protection by 27% of people with long-term care needs). This shows that **simply increasing the take-up of public social protection for long-term care without addressing gaps in financial coverage** is not enough to reduce the at-risk-of-poverty rate significantly at EU-27 level.

providers are available, older people with long-term care needs may choose not to use the public sector, in which case they will not take up public formal long-term care services.

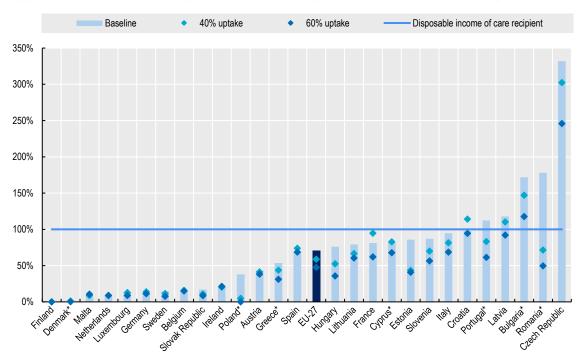
<sup>&</sup>lt;sup>227</sup> It is estimated that they use on average 7.6 hours of care a week.

<sup>&</sup>lt;sup>228</sup> The assumption is that people with higher needs take up long-term care first. As the uptake level increases, the distribution of needs among people receiving social protection will also change; there will be more people with less severe needs.

<sup>&</sup>lt;sup>229</sup> The underlying assumption is that these older people are able to do so, i.e. public social protection is available and accessible to them.

<sup>&</sup>lt;sup>230</sup> All people in need would receive on average social protection for 10.7 hours and 12.9 hours of care a week respectively.

Figure 12: Simulated out-of-pocket costs of care, as a share of disposable income after public support, averaged across respondents who take up formal care services under policy scenario 1



Note: EU-27 is the unweighted average. Estimates shown are averages of three approaches to estimating long-term care needs among older people. \* Member States for which no models of social protection for long-term care in old age were available and for which information on total costs and cost coverage is estimated (Bulgaria, Cyprus and Romania) and Member States for which models of social protection for long-term care in old age have not yet been validated by country representatives (Denmark, Greece, Poland and Portugal). Outliers are removed using the interquartile range method to calculate the mean OOP as a % of disposable income.

Source: OECD analysis based on the OECD long-term care social protection questionnaire, SHARE survey (Wave 7, 2017) and the TILDA survey for Ireland (Wave 3, 2015).

Policy scenario 2 estimates the impact of public social protection for long-term care in old age when all Member States converge upwards to reach the EU-27 average depth of financial protection and extend the financial coverage to fully eliminate the poverty risks associated with out-of-pocket expenditure for formal long-term care services (Figure 13). In this scenario, paying for long-term care does not change an older person's poverty risk. To illustrate, an older person that was in relative income poverty before receiving care would continue to be in relative income poverty, but under this scenario, people that were not previously income poor would be prevented from being at risk of poverty due to the intervention of public social protection. The average depth of financial protection is the unweighted average of public financial coverage as a share of the total costs of care. In this scenario, Member States with an above-average depth of financial coverage would maintain that level of coverage, and Member States with a below-average depth of coverage would increase it to reach the average depth of coverage<sup>231</sup>.

<sup>&</sup>lt;sup>231</sup> Bulgaria, Croatia, Cyprus, Czechia, Estonia, France, Greece, Hungary, Latvia, Portugal, Slovenia and Spain have lower than the EU-27 average financial coverage for home care for low, moderate and severe needs. These countries will converge upward to the EU-27 average of 67% of the total costs of home care being covered by public social protection systems. Belgium, Bulgaria, Croatia, Cyprus, Czechia, Estonia, France, Hungary, Portugal, Romania, the Slovak Republic and

In this scenario, the EU-27 average out-of-pocket costs of long-term care, as a share of disposable income, are 38% at 40% uptake and 31% at 60% uptake, leading to a bigger reduction in average out-of-pocket costs of long-term care compared to policy scenario 1. This would reduce the risk of poverty by 13.9pp at 40% uptake and by 22.4pp at 60% uptake among older people with long-term care needs, compared to the baseline scenario. This scenario eliminates the poverty risk associated with out-of-pocket costs of formal long-term care services for people with long-term care needs who receive social protection. It would also decrease the out-of-pocket costs of long-term care as a share of disposable income, across the EU-27.

Baseline 40% uptake 60% uptake Disposable income of care recipient 350% 300% 250% 200% 150% 100% 50% Cled Regulate Slovak Regulité Romania German Shegel

Figure 13: Simulated out-of-pocket costs of care, as a share of disposable income after public support, averaged across respondents who take up formal care services under policy scenario 2

Note: EU-27 is the unweighted average. Estimates shown are averages of three approaches to estimate long-term care needs among older people. \* Member States for which no models of social protection for long-term care in old age were available and for which information on total costs and cost coverage is imputed (Bulgaria, Cyprus and Romania) and Member States for which models of social protection for long-term care in old age have not yet been validated by country representatives (Denmark, Greece, Poland and Portugal). Outliers are removed using the interquartile range method to calculate the mean OOP as a % of disposable income.

Source: OECD analysis based on the OECD long-term care social protection questionnaire, SHARE survey (Wave 7, 2017) and TILDA survey for Ireland (Wave 3, 2015).

Table 1 provides an overview of the outcomes at baseline and under different policy scenarios, averaged across the EU-27. Though policy scenario 1 does lead to major reductions in the atrisk-of-poverty rate for all older people in some Member States (e.g. Romania and Poland), simply increasing the take-up of public social protection for long-term care without addressing

Slovenia have lower than the EU-27 average financial coverage for institutional care for severe needs and they would converge to the average of 70% of the total costs of institutional care being covered.

gaps in financial coverage is not enough to reduce at-risk-of-poverty rates significantly at EU-27 level.

Under policy scenario 2, the at-risk-of-poverty rate would fall the most, especially at higher levels of take-up of public social protection for long-term care. However, because of the assumption that older people estimated to have long-term care needs who do not take up public social protection pay all costs of care out-of-pocket, the at-risk-of-poverty rates are difficult to compare directly with the at-risk-of-poverty rates among older populations (using Eurostat figures).

As expected, a higher uptake of public social protection for long-term care also leads to higher total government spending on financial coverage for long-term care in old age, relative to total government spending in the baseline scenario. The differences across Member States can be significant, depending on current social protection arrangements. Total spending of all EU-27 countries for social protection for long-term care was estimated at EUR 229 billion in 2019 (unweighted average of 0.9% of GDP). Under scenario 1, total spending would increase by EUR 103 billion to 1.5% of GDP, while it would increase by 147 billion to 1.8% of GDP under scenario 2 by 2030 (with 60% uptake).

Table 1: Overview of EU-27 average outcomes, at baseline and under different policy scenarios

Policy scenarios and uptake levels among older people (65+) in need of LTC		Average hours of SP for care per older person (65+) in need	Share of older people (65+) receiving care	Average OOP costs as share of income	Median OOP costs as share of income	Percentage point changes AROPE among LTC users	Spending increase over baseline
Baseline		7.6	7.7%	70.9%	74.3%	-	-
Policy scenario 1	40%	10.7	12.5%	58.7%	55.2%	-2.0	35%
	60%	12.9	18.7%	47.5%	44.4%	-6.8	65%
Policy scenario 2	40%	10.7	12.5%	38.2%	33.9%	-13.9	71%
	60%	12.9	18.7%	30.7%	28.1%	-22.4	104%

Note: EU-27 is the unweighted average. OOP – out-of-pocket. AROP – at-risk-of-poverty. Estimates shown are averages of three approaches to estimate long-term care needs among older people. Outliers are removed using the interquartile range method to calculate the mean OOP as a % of disposable income.

Source: OECD analysis based on the OECD long-term care Social Protection questionnaire, SHARE survey (Wave 7, 2017) and TILDA survey for Ireland (Wave 3, 2015).

The different country examples and policy scenarios in this section show how Member States extend the timeliness and generosity of social protection for long-term care, both in terms of expanding coverage to broader groups and increasing the level of benefits. This illustrates the impact that extending coverage would have on reducing poverty risks associated with long-term care. The calculations are first estimates underpinned by a number of assumptions (using modelling where data were lacking for some countries). These cost estimates also do not take into account the potential costs associated with expanding the administrative system to manage the increased take-up of social protection. Well-designed policies to protect older people from the total costs of long-term care can have a major impact on out-of-pocket costs and the

<sup>&</sup>lt;sup>232</sup> Please note that estimated spending on social protection differs from the total public expenditure on long-term care in the 2021 Ageing Report, as it does not include spending categories such as administrative costs, infrastructure investments, spending on medical or rehabilitative care, and spending on community care, for example. In 2019, total public expenditure on long-term care was 1.7% of GDP (2021 Ageing Report).

associated poverty risks for older people. Policy making on long-term care would benefit from sound monitoring of the affordability of long-term care and the impact of social protection for long-term care in old age, looking at the adequacy of benefits and eligibility rules, as well as the take-up of benefits.

# 5.2. Availability of long-term care

The proposal for a Council Recommendation on long-term care encourages Member States to increase the offer of long-term care services, while providing a balanced mix of long-term care options and in all care settings to cater for different long-term care needs and supporting the freedom of choice of people in need of care. This can be achieved in particular by developing and/or improving home care and community-based care. In addition, attention should be paid to closing territorial gaps in availability of and access to long-term care, in particular in rural and depopulating areas, and to rolling-out accessible innovative technology and digital solutions. Member States should also ensure that long-term care services and facilities are accessible to persons with specific needs and disabilities, respecting equal rights.

## 5.2.1. Expanding long-term care services

A balanced mix of high-quality long-term care options in home, community-based and residential care, adjusted for the different levels of long-term care needs, is necessary to meet the rising demand for long-term care. At the same time, it is important that all care settings comply with high quality standards and care is delivered in the most cost-effective setting. For people with low and moderate care needs, the most cost-effective setting can be home and community-based care. Importantly, expanding home and community-based care reflects the preferences of people to continue to live at home for as long as possible and supports the freedom of choice of people in need of care in line with the principle of independent living.

The UN Convention on the Rights of Persons with Disabilities<sup>233</sup> and the common European Guidelines on the transition from institutional to community-based care<sup>234</sup> already support the deinstitutionalisation process across the EU. According to the guidelines, deinstitutionalisation requires a long-term strategy with sufficient investment to develop alternative home care and community-based services. Institutions are not necessarily residential, but defined as such when their residents are isolated from the broader community and no longer have sufficient control over their lives.

At the same time as residential care is transformed to support independent living, it is important to make available additional home and community-based care services. Measures to develop long-term care services in the community<sup>235</sup> should not only include home care, day care and respite care, but also technical aids and assistive technologies (e.g. wheelchairs, social alarms,

<sup>&</sup>lt;sup>233</sup> UN, 2006, Convention on the Rights of Persons with Disabilities.

<sup>&</sup>lt;sup>234</sup> Ad Hoc Expert Group, 2009, <u>Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care</u>, convened by the European Commission.

<sup>&</sup>lt;sup>235</sup> European Expert Group on the transition from institutional to community-based care, 2021, <u>EU Funds checklist to</u> promote independent living and deinstitutionalisation, p. 8.

hearing and visuals aids, communication aids etc.), supported living and housing adaptations and general accessibility of the environment, products/devices, services, and information.

France<sup>236</sup>, as part of its Ageing Reform, is rolling out a number of measures to both modernise residential care and expand home care.

One of the aims is to transform the care institutions into living and caring places, by:

- increasing the number of caregivers and the number of people working with residents: coordinating physicians, night nurses;
- providing more support for neurodegenerative diseases: psychologists, psychomotor therapists, occupational therapists and closer health and medical-social cooperation: mobile teams, palliative care, direct hospitalisation;
- redefining medical and care functions in institutions;
- renovating facilities and adapting the living and working environment, including rolling out digital technology.

In parallel, France is focusing on reforming home care services, adapting housing and expanding the supply of housing, in particular inclusive housing and independent living facilities. It will also expand respite care solutions for caregivers via day care, temporary accommodation, relaying at home etc.

Leveraging public and private investment, both at EU and national level, could improve the availability of long-term care, including in rural areas<sup>237</sup>. It can target private actors (both forprofit and non-profit), civil society organisations, the social economy, local authorities and private households.

Public and private investment to increase the availability of long-term care

Cultivating public-private partnerships (PPPs) might be one of the options to facilitate joint public and private investments in long-term care. One goal could be to involve private-sector partners in innovation for better and cost-effective service delivery. Another option is to provide subsidies for care recipients to purchase assistive care devices and make structural adjustments to their homes and environments (i.e. 'age-friendly housing' and 'age-friendly environments'). The innovative use of technology often fits in with ageing in place strategies. Assistive technology, telemedicine, and remote health and safety monitoring have a positive impact on the perceived health status and security, and the overall quality of life of older adults. These investments also boost the quality of long-term care (e.g. better infrastructure or digitalisation of services) and working conditions.

<sup>&</sup>lt;sup>236</sup> Puiseux, A., 2022, the Ageing Reform. Presentation for the Mutual Information System on Social Protection.

<sup>&</sup>lt;sup>237</sup> In A long-term Vision for the EU's Rural Areas – towards stronger, connected, resilient and prosperous rural areas by 2040, the Commission refers to the need for rural areas 'to become places equipped with accessible and affordable public and private services, providing tailored solutions (such as long-term care)'.

Often as an alternative to residential care<sup>238</sup>, new long-term care models are emerging, such as shared housing or intergenerational housing. In these models, people with different care needs live in a shared private home or residential development and share outside spaces, domestic support, care and nursing.

Local authorities in Ljubljana in **Slovenia** collaborated with private-sector partners to provide over 400 **sheltered apartments reserved for older people** who were still able to live independently and were not interested in living in nursing homes. This reduced the pressure on nursing homes and gave older people a higher quality of life, adapted to their care needs. <sup>239</sup>

Also in **Germany**, the model of **shared housing** ('ambulant betreute Wohngemeinschaften') has gained prominence since first emerging in 1995. A limited number of six to eight people in need of care rent private rooms in ordinary apartments, while sharing a common space, domestic support, and access to nursing care. The aim of this model is to provide a small-scale, home-like facility with ample leeway for individual activities and autonomy, alongside group-based activities, and is particularly well suited to the needs of people with dementia <sup>240</sup>. Typically, a case manager responsible for all residents is on the premises and organises ambulatory professional care services through long-term care insurance, while relatives, friends and community volunteers are involved in social aspects. The state supports shared housing by providing specific financial grants to create residential groups and barrier-free homes, and by paying an additional monthly supplement of around EUR 200 per resident.<sup>241</sup>

The availability of services should be strengthened in particular in rural and depopulating areas, also addressing territorial gaps in access to long-term care within countries. People in rural areas are not only older on average, but typically have more frequent long-term care needs. With people moving to find work, their children may live far away from their parents and thus are not able to care for them. One key aspect is also the need to attract a long-term care workforce to rural areas.

**RuralCare**<sup>242</sup> is a EU funded social innovation project (see section 4.5.4) in social services that aims to design, test and evaluate a new model of integrated long-term care services in the rural region of Castile and León in **Spain**. The new model involves adapting care services to the individual needs of a person living in their home in a rural area to make care more accessible, affordable, sustainable and of better quality.

<sup>&</sup>lt;sup>238</sup> Frisina Doetter, L., Barbabella, F., Guillen, M., Le Bihan, B., Marczak, J., Rodrigues, R., Rothgang, H., Santolino, M., Sopadzhiyan, A., Sowa-Kofta, A. and Wittenberg, R., 2019, <u>Improving outcomes for people with long-term care needs</u> through personalization, in: Enhancing the sustainability of long-term care. Eurohealth, WHO, pp. 6-9.

<sup>&</sup>lt;sup>239</sup> Konjar, M., Niksic, M., Grom, J.P., Mujkic, S., and Fikfak, A., 2018, Ensuring living condition for ageing population by public-private partnership (PPP), E3S Web of Conferences, p. 13.

<sup>&</sup>lt;sup>240</sup> Moise, P., Schwarzinger, M., Um, M.Y., 2004, Dementia Care in 9 OECD Countries: A Comparative Analysis; OECD Publishing: Paris.

<sup>&</sup>lt;sup>241</sup> Frisina, Doetter, L., 2021, <u>Rethinking home-based settings for long-term care: the novel approach of shared living arrangements in Germany</u>.

<sup>&</sup>lt;sup>242</sup> RuralCare.

The project carries out a proactive segmentation of households at risk, factoring in not only the individual situation but also their environment. Households at risk should be transformed into safe households, allowing people requiring long-term care to remain at home. The portfolio of services is customised and may include home adaptations, technological support, social community support and professional care. To achieve these, a multilevel partnership for care provision is put in place, including public and private actors and coordination of social and health services at local, regional and national levels, and involving the users.

Older people, including those living isolated or in rural areas, are also affected by loneliness. Targeted and effective measures to combat social isolation and loneliness among older adults in long-term care can improve their mental health and quality of life.

Addressing social isolation and loneliness<sup>243</sup>

The Sällbo Housing Programme is a multicultural and multigenerational living space in a small port city in southern Sweden. The goal of the project is to combat loneliness and promote social cohesion by giving residents incentives and space for social interaction. More than half of the residents are over 70, and the rest between 18 and 25 years old. All residents have to sign a contract promising to spend at least two hours a week socialising with neighbours.

Madrid's 2021-2023 action plan against loneliness is a strategy implemented at city level with the goal of tackling loneliness among the older population. The strategy has four pillars. First is data collection on loneliness and social isolation among older people at city level (Madrid más cerca de ti). Second is to prevent loneliness and identify individuals at risk of loneliness (Madrid contigo). The third pillar is based on the development of a mobile app (Madrid en red) to help connect lonely people to their families and a loneliness helpline (Madrid te escucha). The last pillar seeks to develop a broad set of collaborations across different actors with the shared goal of reducing loneliness among older adults (Madrid te acompaña).

Schlomann et al.  $(2020)^{244}$  also investigated the **potential of ICT applications on feelings of loneliness, anomie, and autonomy** among people in the oldest age category (aged between 80 and 103) in Westphalia, **Germany**. The quantitative data analysis found that individuals using web-connected ICT reported lower levels of loneliness and anomie, and higher levels of autonomy. These differences remained significant when checking for indicators of social inclusion and individual characteristics.

#### 5.2.2. Illustrating the impact of expanding the availability of home care

A simulated policy scenario based on the European Health Interview Survey (EHIS) data illustrates the impact of increasing the share of older people in need of long-term care who

<sup>&</sup>lt;sup>243</sup> Casabianca, E. and Kovacic, M., 2022, Loneliness among older adults - A European perspective, JRC Policy brief.

<sup>&</sup>lt;sup>244</sup> Schlomann, A., Seifert, A., Zank, S., Woopen, C., & Rietz, C., 2020, Use of information and communication technology (ICT) devices among the oldest-old: loneliness, anomie and autonomy, *Innovative Aging* 4(2).

use formal home care to 60% by 2030. Under the baseline for this scenario, 29.4% of older people are in need of long-term care<sup>245</sup>, and 13.9% of all older people 65 + use care services (9.1 million home care (of which 6.6 million are considered to be need of long-term care) and 3.4 million institutional care). Thus, 38% of older people in need of long-term care use care services in 2019, and they receive 12 hours of home care per week on average. In this scenario, home care is expanded until 60% of people in need of long-term care receive care by 2030, maintaining the average care intensity of 12 hours of home care a week constant. In 2030, 15 million older people with long-term care needs will receive home care under this scenario, increasing by 7 million relative to the baseline in 2030 (8 million), equivalent to an increase of 89%.

Projecting to 2030<sup>246</sup>, the long-term care workforce would increase from about 2.1 million full-time equivalent (FTE) workers to 3.2 million FTE workers. The additional staff cost would be around EUR 30 billion (at 2030 wage levels) or 0.19% of GDP (unweighted average) extra in 2030. The total cost of the long-term care workforce (at 2030 wage levels) would be around EUR 114 billion for home care and EUR 206 billion for institutional care<sup>247</sup> in 2030. At 2019 wage levels, the additional staff cost in 2030 for home care would be EUR 27 billion, with total costs for the workforce reaching EUR 101 billion for home care and EUR 182 billion for institutional care.

This simulated increase in the availability of long-term care can be combined with a scenario where long-term care workers' salaries are increased to the average salary level in the healthcare sector (see section 5.4). With labour cost convergence, the total cost of home care in this scenario would increase from EUR 114 billion (at 2030 wage levels) in 2030 to EUR 172 billion (at 2030 wage levels) in 2030.

#### 5.2.3. Increasing access to long-term care via digitalisation

More national and EU-level support is becoming available for technology development in care, often linked to healthcare but increasingly with long-term care<sup>248</sup>. The challenge is to progress from the piloting stage to large-scale production of assistive technologies and to encourage their widespread use.

The aim of the State Competence Centre Digital Care Baden-Württemberg <sup>249</sup> (PflegeDigital@BW) is to shape digitalization in long-term care and to be a contact point for all stakeholders. Initiated by and in cooperation with the Ministry of Social Affairs, Health and Integration Baden-Württemberg, the centre develops, analyses and communicates digitally supported solutions for long-term care together with partners from

<sup>&</sup>lt;sup>245</sup> Defined as having a severe difficulty with ADLs or IADLs, see chapter 2.

<sup>&</sup>lt;sup>246</sup> Wages have been projected by applying hourly labour productivity growth from the 2021 Ageing Report. GDP is projected by applying potential GDP growth rates from the 2021 Ageing Report.

<sup>&</sup>lt;sup>247</sup> Calculated using 'number of FTE workers X average labour costs in relevant sector', as per Eurostat.

<sup>&</sup>lt;sup>248</sup> The EU has provided substantial funding to stimulate research initiatives, development and marketing of innovative technologies for ageing well, including the Active and Assisted Living Programme (AAL JP) and the European Innovation Partnership on Active and Healthy Ageing (EIP AHA). These initiatives have funded projects on access to information for care providers and sensors for security in the home (Gehem & Sánchez Díaz, 2013).

<sup>&</sup>lt;sup>249</sup> Landeskompetenzzentrum Pflege & Digitalisierung BW.

the field, from academia, wider society, industry and government. The centre receives public funding of EUR 12 million.

It is based on four fields of action for digitalisation in long-term care:

- empowerment enhancing inclusion and independence of people that are in need of care and assistance
- new care providing digital support for care-related activities
- boosting care facilitating digital assistance for improved organisation and management in care
- smart consultation enhancing digital support for providing care and assistancerelated information and consultation services

Among its many projects, the centre offers for example a digital campus (Campus PflegeDigital) – a digitally fully equipped residential home that is used for teaching long-term care technologies to staff in a hands-on way. Besides, it offers a bus (Transfermobil) that is equipped with state-of the art technology used in long-term care, than can be booked by long-term care facilities to test the different technologies on-site and to receive consulting.

A literature review into the potential of digital technologies in long-term care highlighted three main functions of technology at different stages of long-term care: (i) to improve information for users and carers to understand what is available and to prepare initial interactions with care professionals; (ii) to facilitate easy access to services through various remote facilities such as telecare; and (iii) ongoing support mechanism enabling older people to remain in their home, i.e. ageing in place.

First, technology can offer cheap and effective ways of making information about the services available through online platforms, including information from other users and their families shared on social media. Second, at the stage when a person needs care, often when a patient is discharged from hospital or through a primary care referral, technology has been shown to be useful in integrating care measures. Third, technology has a great potential to enable access to services that facilitate 'ageing in place'. Telecare, smart home technologies and remote monitoring can help older people carry out everyday activities and improve physical safety and social communication. Older people reported that smart homes improved their sense of security, the quality of their daily life and activities and provided them with information about the care available.<sup>250</sup>

<sup>&</sup>lt;sup>250</sup> Zigante, V., 2021, <u>The role of new technologies in modernising long-term care systems: a scoping review.</u> Research Note for the Social Situation Monitor.

Table 2: The potential of digital technologies in improving access to long-term care

Theme	Examples of technologies	Expected benefits
Information and communication	Information platforms, online reviews, social media	Facilitating understanding of what is available and suitable. Better matching and targeting of services
Facilitate access to services	Telecare/telehealth Remote patient monitoring Hospital discharge/integration Community support	Reducing loneliness, fast access to services as part of hospital discharge or when a new need has arisen, or the person's health has deteriorated.
Ageing in place	'Smart' home technology, remote monitoring, telecare/telehealth	Enabling independence, reducing social isolation, preventing deterioration and hospitalisation

Source: Zigante, V., 2021.

Digital innovation in care cooperatives is driven by responding to community needs. CGM<sup>251</sup>, the main national consortium of social cooperatives in Italy, has promoted the digital revolution in the care sector, offering social services through the digital platform WelfareX. The platform provides services directly to public institutions: it works directly with 88 municipalities, receiving about 40 000 applications from single users, managing more than 152 000 vouchers and about EUR 6 million worth of services. A spinoff company CGM Welfare is specialised in providing assistance and training to local clusters that want to establish a local digital platform for welfare and care services. Through the local platforms, private citizens can purchase services, including care and residential services, directly from social cooperatives. The platforms grew rapidly during the COVID-19 pandemic.

Wang et al. (2019)<sup>252</sup> investigated the potential of **Technology-Enabled Long-Term Care Services and Supports (T-eLTCSS)** in home settings. They state '*T-eLTCSS refers to services provided for independent living via health information technology, telemedicine, assistive technology, online resources, apps and social media. T-eLTCSS in home settings consists of several major functional systems, including physiological monitoring, functional monitoring, safety monitoring and assistance, security monitoring and assistance, emergency detection and response, social interaction monitoring and assistance, cognitive assistance, and sensory assistance'.* In the care of older people, T-eLTCSS is being used in a variety of ways, ranging from using wearable devices (e.g. integrated in bracelets) to ambient devices, wireless devices and floor sensors. Moreover, smart detection devices e.g. smart water leak monitors, could alert older adults to potentially dangerous situations or detect potential hazards in their homes. Consequently, T-eLTCSS can help older adults with disabilities, chronic diseases or people needing long-term care to live in their homes with minimal assistance from their caregivers.

<sup>&</sup>lt;sup>251</sup> CECOP, 2022, <u>Cooperatives care!</u> Advantages of the cooperative model for meeting multiple care-related needs and challenges in the EU.

 $<sup>^{252}</sup>$  Wang, L., Gu, D. and Wu, B., 2019, Technology-enabled long-term care services and supports (T-eLTCSS) in Home Settings, Encyclopedia of Gerontology and Population Aging.

Digitalisation can help improve functional independence and long-term care efficiency, for example, by helping older people 'age in place'. This could reduce more expensive residential stays (in hospitals or residential care homes). Different types of technologies could facilitate this 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 digital solutions could also help reduce feelings of loneliness and isolation, which may benefit users' mental health.<sup>253</sup> Robotics can contribute and extend the period of living at home for older people. Robots have become increasingly able to interact with people in their environment, reducing feelings of loneliness and isolation, providing help with simple tasks, giving instructions, supporting medication compliance, or calling emergency services when needed.

The aim of the MOBISERV<sup>254</sup> project is to design and evaluate a system and service to support independent living of seniors by means of a proactive personal companion robot integrated with smart textiles, innovative sensors, and a smart home environment. The system monitors physical activity and health indicators by means of wearable fabrics. It monitors nutrition habits by smart home sensors and offers an extensive secure portal for informal and professional carers to use, set up, and fine-tune the support system. MOBISERV provides older adults with: (i) nutrition assistance and dehydration prevention by eating and drinking reminders and encouragements; (ii) a personal health coach encouraging physical activity and specific exercises, and supporting telemedicine services; (iii) well-being services for cognitive stimulation and social inclusion, responding to the user's emotions; (iv) games for entertainment; (v) a mobile remote control for the home environment; (vi) fall detection with direct communication to a care centre; and (vii) video communication to friends and family.

The literature<sup>255</sup> shows two aspects of quality where technology may have a positive impact. Firstly, digital tools can help improve the quality of services provided, for example by reducing errors, ensuring timely visits, freeing up carers' time to spend more time socialising with the users, making services more personalised and increasing users' independence. Secondly, technology can also support quality assurance efforts through monitoring of service provision. Tasks such as timing and duration of visits and logging medication can all be done electronically and monitored for quality assurance purposes.

The table below lists some examples of technologies and their potential benefits in the quality and quality assurance of long-term care.

<sup>&</sup>lt;sup>253</sup> Zigante, V., 2021, <u>The role of new technologies in modernising long-term care systems: a scoping review.</u> Research Note for the Social Situation Monitor.

<sup>254</sup> An Integrated Intelligent Home Environment For The Provision Of Health, Nutrition And Mobility Services To The Elderly | MOBISERV Project | Fact Sheet | FP7 | CORDIS | European Commission (europa.eu)

<sup>&</sup>lt;sup>255</sup> Zigante, V., 2021, <u>The role of new technologies in modernising long-term care systems: a scoping review.</u> Research Note for the Social Situation Monitor.

Table 3: The potential of digital technologies in improving the quality of long-term care

Theme	Examples of technologies	Expected benefits
Structural and process quality	Remote monitoring, telecare/telehealth	More efficient and safer provision of care. Also more personalised through improved space (i.e. structure) and work processes that allow individualised plans.
Users' outcomes (outcome quality)	Information platforms, social media	Connectedness, reduced loneliness and mental health issues.
	Telecare/telehealth, Remote patient monitoring, Hospital discharge/integration	Safety, hospital admissions, disease management, prevention
	'Smart' home technology	Independence and person-centred care
	ICT, social media	Social connectedness
Quality assurance and safeguarding	Electronic monitoring	Safer care, prevention

Source: Zigante, V., 2021.

**Digital technologies and innovations** have also proven useful in facilitating the integration between long-term care and healthcare. For example, CareWell<sup>257</sup> worked on delivering integrated healthcare to frail, older patients in a pilot setting through comprehensive multidisciplinary integrated care programmes where the role of ICTs can foster coordination and patient-centred delivery care. Carewell focused on complex, multi-morbid elderly patients who are most in need of health and social care resources and of more complex interventions due to their frailty and comorbidities. These interventions included health and social care coordination, monitoring, self-management of the patient and informal caregiver.

More recently, during the pandemic, a digital platform was developed in **Portugal** to help residential facilities monitor the health of residents by monitoring symptoms associated with COVID-19. In **Italy**, lung ultrasonography was used in nursing homes to measure the presence of lung damage in people with a history of COVID-19 symptoms<sup>258</sup>. In **Germany**, Lower-Saxony launched an initiative to develop digital health and social services by supplying tablets and the platform used for medical consultations as well as giving the necessary medical software free of charge to the general practitioners involved.

# 5.2.4. Strengthening the accessibility of long-term care

In order to support the accessibility of home care and help people remain independent for as long as possible while receiving care, age-friendly environments have to be created. This age-

<sup>&</sup>lt;sup>256</sup> This paragraph is based on: Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, COVID-19 in long-term care: Impact, policy responses and challenges. OECD Health Working Papers, No. 131, OECD Publishing, Paris.

<sup>&</sup>lt;sup>257</sup> Home (carewell-project.eu)

<sup>&</sup>lt;sup>258</sup> Dini, F.L.,Bergamini, C., Allegrini, A., Scopelliti, M., Secco, G., Miccoli, M., Boni, S., Brigada, R., and Perlini, S., 2020, Bedside Wireless Lung Ultrasound for the Evaluation of COVID-19 Lung Injury in Senior Nursing Home Residents. Monaldi Archives for Chest Disease 90 (3).

friendly environment already starts at home, so that it is suitable for the changing needs of older people.

Several Member States have brought in specific programmes/grants for modifying homes (i.e. housing adaptation)<sup>259</sup> in order to adapt unsuitable homes so that older people can continue to live independently and receive home care as long as possible. According to the WHO, important measures for achieving this are 'publicly subsidised provision and easy access to home maintenance and modification services to make homes more accessible and support ageing in dignity and autonomy'. Such locally implemented measures were evaluated positively by the older people who greatly valued such services.<sup>260</sup> Several Member States also have a system of personal assistance in place to allow people with disabilities to live independently and be included in society.

Sweden has set up a comprehensive support system to allow people with disabilities to live independently. Based on the Health and Medical Services Act (1982), assistive devices for daily living, for care and treatment, and also personal assistive devices for school and education are provided by the regions and municipalities. Based on the Law on Grants for Housing Adaptation (1992), municipalities also approve grants to adapt housing to enable people with functional impairments to continue to live in their own homes. Sweden also has a quite generous system of personal assistance (the Act concerning Support and Service for Persons with Certain Functional Impairments, 1993) to help people with activities in daily life (cooking, shopping, participating in leisure activities or work, parenting, etc.).<sup>261</sup>

# 5.3. Quality of long-term care

The proposal for a Council Recommendation invites Member States to ensure that high-quality criteria and standards are established for all long-term care settings, tailored to their characteristics, and strictly applied to all long-term care providers irrespective of their legal status. To this effect, Member States are recommended to ensure a quality framework for long-term care which is guided by the quality principles set out in the Annex of the proposal for a Council Recommendation and includes an appropriate quality assurance mechanism.

# 5.3.1. Long-term care quality framework

A quality framework helps ensure that service providers take a consistent and integrated approach to the quality of services. It also helps encourage and support all stakeholders involved in addressing gaps and in identifying systemic issues, best practices and opportunities for continuous improvement. It sets out a common understanding of: (i) the quality of long-term care; (ii) the quality standards that services should meet; (iii) methodological guidelines and

<sup>&</sup>lt;sup>259</sup> This can be defined as those 'alterations of permanent physical features in the home and the immediate outdoor environment that aim at reducing the demands of the physical environment in the home and its close surroundings' (Chiatti, C. and Iwarsson, S., 2014, Evaluation of housing adaptation interventions: integrating the economic perspective into occupational therapy practice, Scandinavian Journal of Occupational Therapy, 21(5), pp. 323-333).

<sup>&</sup>lt;sup>260</sup> WHO, 2017, <u>Age-friendly environments in Europe: A handbook of domains for policy action</u>, WHO Publications, Copenhagen, p. 160.

<sup>&</sup>lt;sup>261</sup> DOTCOM: The Disability Online Tool of the Commission

indicators to monitor and evaluate the quality of services; and (iv) regulatory enforcement mechanisms.

At EU level, the voluntary European Quality Framework for Social Services <sup>262</sup> provides guidance on how to define, provide, assess and improve social services, including long-term care. Most EU Member States do not have a comprehensive quality framework specific to long-term care<sup>263</sup>. A few (e.g. DE, LU, PT) have dedicated legal rules on the quality of long-term care, which apply to all types of facilities and providers. Usually, these frameworks follow the traditional approach, which looks more at the structural aspects of care provision, and they often have a heavy administrative burden. However, there are innovative attempts to base a quality framework on the quality of life of the person in need of care and to move from a bureaucratic to a partnership-based model. The COVID-19 pandemic also created a need for more guidance, as illustrated by the fact that at least half<sup>264</sup> of the EU countries that did not have specific long-term care measures in place before the pandemic issued public guidelines on infection control in long-term care facilities (AT, FR, IE, IT, LU, PL, SI).

#### Examples of national quality frameworks for long-term care

In Portugal, long-term care services are covered by the national network for continued and integrated care (RNCCI). The long-term care quality framework, legally formalised, is mandatory for all long-term care services - convalescent care, post-acute rehabilitation services, medium- and long-term care, home care and palliative care. There is no distinction between sectors (health or social care), care settings (residential or community care) or the type of service provider (public, for-profit or private). Quality is mainly ensured by: (i) setting minimum standards; (ii) using indicators to monitor processes and outcomes; (iii) listening to patient complaints; (iv) carrying out surveys of users, family members, informal carers and professionals; and (v) conducting internal audits and inspections.

# A novel quality framework for residential care<sup>265</sup>

The National Quality Council of the **Netherlands** has developed an innovative quality of care framework (see Figure 14), which focuses on the quality of life of the person and on learning and improving, rather than on accreditation, regulation and inspection. It aims to reduce the administrative burden with a smaller set of centrally-defined indicators (quality, safety and related aspects to enable person-centred care and support) and flexible reporting formats. Professionals are empowered to use this supportive environment to create trust rather than bureaucracy in quality assurance.

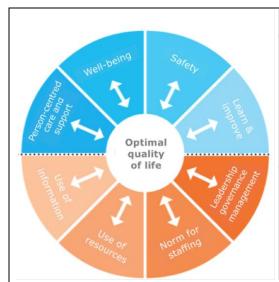
<sup>&</sup>lt;sup>262</sup> Social Protection Committee, A voluntary European quality framework for social services, 2010, SPC/2010/10/8 final.

<sup>&</sup>lt;sup>263</sup> Cès, S. and Coster, S., 2019, <u>Mapping long-term care quality assurance practices in the EU</u>, European Social Policy Network.

<sup>&</sup>lt;sup>264</sup> Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, <u>COVID-19 in long-term care: Impact, policy responses and challenges.</u>
OECD Health Working Papers, No. 131, OECD Publishing, Paris.

<sup>&</sup>lt;sup>265</sup> Nies, H., 2018, <u>Quality in long-term care and large-scale implementation – The introduction of new policy instruments in the Netherlands</u>.

Figure 14: Dimensions of quality of life (The Netherlands)



#### **Quality & Safety**

- 1. Person-centred care & support
- 2. Live & well-being
- 3. Safety
- 4. Learn & improve

#### Conditions

- 5. Leadership & governance
- 6. Norm for staffing
- 7. Use of resources
- 8. Use of information

Source: Nies, H., 2018.

In the absence of a comprehensive quality framework dedicated to long-term care, it is difficult to ensure a consistent approach to long-term care quality across different regions and care settings. This is especially challenging where quality assurance is mainly regulated at local, regional or municipal level (e.g. AT, BE, DK, SE) or when both care provision and quality assurance are decentralised (e.g. EE, SE, DK). Beyond the geographical challenges to consistent quality assurance, the lack of an integrated approach often leads to quality being considered from two different angles – social and healthcare – even in the same facilities. In a number of Member States (BE, CZ, EE, FR, HU, LT, PL, SI, SE and SK)<sup>266</sup> separate quality frameworks have developed for these two sectors, with separate regulations, including quality principles, guidelines, requirements and standards. Having parallel processes, however, creates room for inefficiencies and inconsistencies.

# 5.3.2. Long-term care quality principles

The basis for a quality framework is a common understanding of what quality is, which can be expressed as quality principles. Quality principles can guide the development of a quality framework for long-term care that applies to all long-term care providers irrespective of their legal status and are applicable in all care settings. Such principles are set out in the voluntary European Quality Framework for Social Services<sup>267</sup> and have been adapted to long-term care by the WedO project<sup>268</sup>. Some of the principles are discussed in other parts of this document, namely availability and accessibility in section 5.2, affordability in section 5.1, workforce in section 5.4 and facilities in section 5.2 and 5.4. The remaining principles are briefly presented in this section.

<sup>&</sup>lt;sup>266</sup> Cès, S. and Coster, S., 2019, <u>Mapping long-term care quality assurance practices in the EU</u>, European Social Policy Network.

<sup>&</sup>lt;sup>267</sup> Social Protection Committee, A voluntary European quality framework for social services, 2010, SPC/2010/10/8 final.

<sup>&</sup>lt;sup>268</sup> Principles and guidelines for the wellbeing and dignity of older people in need of care and assistance.

# Respect

According to this principle, long-term care providers respect the **human rights and dignity** of people in need of care, their families and carers, as outlined in the relevant national, European and international human rights instruments. This includes the equal right of all persons, in particular those with disabilities, to live independently in the community, with choices equal to others. It also includes compliance with general **safety standards** to ensure that long-term care services are provided in a safe environment that promotes the physical and mental well-being of the people receiving care and of their carers. This also includes the **prevention of abuse and neglect**. Prevention could be achieved by: (i) having in place clear rules for how long-term care providers operate, which are based on ethical guidelines that ensure the dignity and well-being of the people receiving care and their carers; (ii) by having a clear and simple procedure for complaints and for signalling potential cases of abuse or neglect by long-term care providers; (iii) by making sure that long-term care workers are informed, trained and prepared to raise awareness of, detect and fight abuse, harassment and neglect of people receiving care; and (iv) by having means for legal redress if breaches occur.

#### **Prevention**

According to this principle, long-term care aims to restore as far as possible or prevent deterioration in the physical and/or mental health of people in need of long-term care and strengthen their capacity to live independently. This builds on measures to promote healthy and active living and ensure age friendly environments and includes measures to prevent falls, **rehabilitation** and **strengthening autonomy**, for example, through home adaptation and use of assistive devices.

Health promotion and prevention should play an important role as part of healthcare already before people develop long-term care needs. 80% of the healthcare budgets are spent on non-communicable diseases, such as cancer, diabetes and cardiovascular diseases. More ambitious actions on health promotion and disease prevention are needed to ensure that people remain in good mental and physical health for as long as possible, a strong work force is ensured and the healthcare systems remain sustainable and resilient.

#### **Person-centredness**

According to this principle, long-term care services are provided without any discrimination and address the specific and changing needs of each individual in need of care. The services provided fully respect the personal integrity of people in need of care, taking into account their gender, as well as their different physical, intellectual, cultural, ethnic, religious, linguistic and social diversity, and, when appropriate, those of their families or their immediate social circle. The person in need of long-term care is the centre of attention and is the basis for service planning, care management, worker development and quality monitoring. This means that the person in need of care and/or their family or carers are involved in the assessment of their care needs and in planning their care provision. This assessment and planning focuses on the person's abilities, needs, preferences, and on the goals of care, including choosing the care setting and modalities consistent with their personal needs and lifestyle choices, which might change over time.

#### Personal participation in care planning

In **Finland**, care recipients participate in assessing their needs and drawing up their care plans. The person's participation is ensured, even in situations where they have lost the capacity to participate, by making a written statement in advance of their wishes as regards medical treatment if they become legally incapacitated. Traditionally, such decisions concern the end of life and define the conditions under which any treatments that keep the person alive on a short-term basis can be stopped. However, as the person may be dependent on long-term care for a number of years, they can state in advance the kind of things that are important to them in everyday life. This is especially valuable for patients with memory disorders.

# **Comprehensiveness and continuity (integration)**

According to this principle, long-term care is designed and delivered in an **integrated** manner with all other relevant services (e.g. healthcare) and with effective coordination between national, regional and local levels when required and for as long as needed. This means that the person in need of care can access an **uninterrupted** range of reliable and flexible services, from early intervention, care and support, to palliative care, depending on the complexity of their needs and how these evolve over time. This involves the timely and effective coordination of different stakeholders, including people in need of long-term care themselves and their families. This could be achieved by reducing the administrative procedures to access care, including via **case and care managers**, **multidisciplinary teams** or **partnerships** between care providers. These professionals can facilitate transitions between different care services and settings as the person's needs evolve (e.g. ensuring a proper transfer of information when a person is admitted to hospital or returns home).

# Strategy for the provision of integrated care services

The aim of this project was to contribute to more integrated and person-centred social, medical and vocational support services to people with disabilities and older people with extensive needs in **Estonia**. It provided a strategy to the Estonian government to contribute to: (i) improvements in the interoperability of registries and administrative datasets; (ii) the development of measures and indicators to support quality improvement and assess performance; (iii) the introduction of performance-based financing and payment elements to incentivise integrated service provision; and (iv) a closer cooperation between services administered at central and local level, as well as between local stakeholders.

After the outbreak of the COVID-19 pandemic, some countries<sup>269</sup> (EE, FI, LT, LU, PT, SI) introduced new measures to foster multidisciplinary teams, with the aim of integrating more primary care in long-term care facilities, while others (BE, EL, EE, FR, HU, NL) introduced new guidelines on the integration of long-term care and care in hospitals. Italy and Luxembourg obliged nursing homes to have a permanent medical presence to follow-up ill residents.

<sup>269</sup> Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, <u>COVID-19 in long-term care: Impact, policy responses and challenges</u>. OECD Health Working Papers, No. 131, OECD Publishing, Paris.

#### **Focus on outcomes**

According to this principle, long-term care services are focused primarily on the **benefits for the people receiving care**, while taking into account, wherever appropriate, the benefits for their families, informal carers and the community. The best possible services are delivered on the basis of **quality management** and the principles of **continuous improvement** involving all relevant stakeholders.

# **Transparency**

According to this principle, information and advice on long-term care is provided in **full** and in an **accessible** and **easy to understand** way to people in need of care, their families or carers. This should include information on: (i) social protection coverage for long-term care; (ii) the eligibility conditions and procedures to follow; (iii) the long-term care services available and who provides them; and (iv) quality standards and quality assurance arrangements. This information should be reliable, up-to-date and available upon request without a complicated administrative procedure. It should be available through communication tools such as helplines, leaflets, and websites that are accessible to everyone.

Long-term care providers are encouraged to provide clear and comprehensive information and advice to users and potential users about the services they offer, their cost to the user, how to access or cancel the service(s), and on the process for taking decisions on care. Information on the activities of providers should be made public, including reports of quality assessments (both internal and external), in accordance with the national legislation on the protection of personal data. People receiving long-term care are informed in good time about any change that will affect the service they receive and are provided with full, accessible and easy to understand information about alternative solutions, if they so require.

#### 5.3.3. Long-term care quality assurance

An integral part of a good quality framework is a clear and comprehensive mechanism for quality management and assurance, with appropriate funding and legally underpinned criteria and standards for the accreditation and control (i.e. auditing system) of all types of organisations providing long-term care services and facilities. Few Member States have in place **a dedicated agency** that is legally responsible for quality assurance in long-term care services and facilities. More often, responsibilities for quality assurance are shared by different organisations (see Annex 2). For example, in Denmark, the law on social services stipulates that all municipalities that are responsible for long-term care must annually adopt and publicise their quality standards on health and social services for adults. The municipalities are also required to monitor their provision of long-term care. Also, since 2018, the Danish Patient Safety Authority has monitored care for older people, both in nursing homes and at home. Unlike the municipalities, the Danish Patient Safety Authority is an independent body as it does not provide long-term care itself.<sup>270</sup>

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<sup>&</sup>lt;sup>270</sup> Barslund, M., Pacolet, J., Leichsenring, K., De Wispelaere, F., Waeyaert, W., Harald Hauben, H, De Smedt, L., Schepers, W., 2022, Analytical support under VC/2020/066.

Quality in long-term care has traditionally been ensured by making inspections to monitor compliance with minimum standards and, if necessary, via penalties to enforce compliance. However, there is a common trend to move away from mere bureaucratic inspection towards a collaborative approach that focuses on continuous improvement processes in combination with the involvement of relevant stakeholders, including the people receiving care, staff and informal carers (see box on DE).

Since 2019, Germany has applied a partnership approach to the external monitoring of the quality of residential care, whereby care providers have a bigger role in quality assurance and external monitoring focuses on identifying the support that providers need to improve their results. External quality monitoring takes place on a regular basis or following an incident or a complaint. Regular monitoring is announced one day in advance and focuses on nine residents, who participate voluntarily. Examiners are trained carers with additional training in quality assurance. Other professionals are invited to participate if there is a specific reason for this. External examiners first meet residents individually, then review information on the provider, discuss their evaluation and decide in which areas the provider could benefit from a consultation. Lastly, they talk to the provider about their strengths and the weaknesses to be addressed.

Continuous improvement of quality can also be organised via **third-party certification**, as is the case in some countries.

**Austria** has a dedicated agency (NQZ Austria) to manage the application process for the **national quality certificate** (NQZ) and the relevant audits, including the training of auditors. Eligible care homes (those that have already implemented one of the accredited quality management systems - E-Qalin, ISO, QAP or EFQM) may have been able to apply for the certificate voluntarily since 2012<sup>271</sup>. The NQZ focuses on process and outcome indicators and is granted after an assessment period of 8 months. The quality assessment includes 24 'quality and result areas' that are assessed from 5 perspectives:

- residents (e.g. self-determination, participation);
- staff (e.g. cooperation, participation and communication);
- management (e.g. leadership and personnel management);
- social context and external relations (e.g. families and suppliers);
- 'learning organisation' (e.g. continuous improvement).

The assessment is based on both the 'plan - do - check - act' quality cycle and results-oriented indicators proposed by each care home. The certification process consists of a pre-test (review of documentation), a certification visit to the premises by two trained auditors, who draft the certification report with recommendations and, eventually, the award of certification, which is valid for three years.

**PREZO**<sup>272</sup> is a quality management model developed in the Netherlands by the non-profit organisation Stichting Perspekt. It helps to assess and improve the performance of long-term

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<sup>&</sup>lt;sup>271</sup> NQZ-Austria

PREZO stands for 'PREstaties in de ZOrg', which could be translated as 'performance in care', <a href="https://perspekt.nu/prezo">https://perspekt.nu/prezo</a> and <a href="https://www.prezowoonzorg.be/">https://perspekt.nu/prezo</a>

care professionals and organisations by focusing on the quality of life of people with care needs and their perception of the care and support they receive. By avoiding protocols and guidelines, the model looks at the actual results of care: 'Do residents feel at home? Do they feel heard? Do they feel that they are enabled to make their own choices?' The tool assesses performance in a dialogue between staff and residents (clients) in six domains, including companionship, vitality, comfort and enjoyment; three pillars (continuity of care, care planning and communication/information); and eight enabling conditions on general organisation, continuous improvement and staffing issues (skills). PREZO provides software for the documentation and training of staff and management on continuous improvement, and for an external audit. The PREZO quality mark is valid for three years. If performance in some areas is not yet satisfactory, recommendations for improvement and an additional audit will be proposed. Apart from the Netherlands, this model has also been adapted for use in Flanders (Belgium) and is already being used by more than 140 facilities in Belgium.

# 5.3.4. Drivers of quality improvement

Member States differ considerably in their starting positions on quality assurance in long-term care and those with less-developed quality assurance systems would need more time to improve them. Table 4 lists some **drivers of quality improvement** that could be useful to consider when designing related policy interventions.

Table 4: Potential drivers of quality improvement

	Top-down	Intrinsic/organisational
Regulatory	Legal avenues  Public reporting vs. disclosed information (inspection only)  • Defined structural indicators  • Defined process indicators  • Defined outcome indicators  Choice of governance level: national, regional, local	Quality management (legally prescribed vs organisational requirement) Staff levels vs needs-adapted staff (skills & grade mix)
Economic	Financial incentives linked to implementation of quality management Linking price and quality indicators Linking public procurement and quality indicators	Quality management as marketing tool Balancing quality and price
Information/ knowledge based instruments	Registers regarding various quality indicators (clinical, e.g. pressure sores, dehydration) Good practice in assessing quality of life outcomes Support by research agencies	Quality management and continuous improvement process (outcome-and user-oriented)  Enabling management and staff  Steering by defined indicators  Continuous improvement by linking structures and processes to result-oriented indicators

Source: Barslund, M., et al., 2021.

# 5.3.5. Quality of informal care

Quality assurance in informal care is hampered by the fact that informal care takes place in private households, in family settings and thus in a situation of privacy. In some cases informal carers are not only providers of care, but also recipients of public support (via support services in-kind and in cash), which could be an entry point for selective supervision and assistance. However, it is challenging to systematically monitor and ensure the quality of informal care directly. Indirect measures such as the prescription of regular counselling by professionals (DE), selective visits to beneficiaries of cash allowances (AT), case management (NL, partly DE, AT, FR, PT) and training offered to informal carers (e.g. BE, ES, IT, AT, NL) are relatively frequent in many countries and may help to improve the situation in selected cases.

# 5.4. Long-term care workforce and informal carers

The proposal for a Council Recommendation outlines that Member States, in collaboration, where relevant, with social partners, long-term care providers and other stakeholders, should address **skills needs and worker shortages** in long-term care. The skills of the long-term care workforce can be strengthened by designing and improving initial and continuous education and training and by building career pathways in the care sector. More long-term care workers can be attracted for example by establishing pathways to a regular employment status and by exploring legal migration pathways. In order to attract enough workers into the sector, also **fair working conditions** in long-term care have to be ensured. This can be done by promoting national social dialogue and collective bargaining, including to support the development of attractive wages in the sector. For **informal care**, it is important to establish clear procedures to identify informal carers and support them in their caregiving activities.

# 5.4.1. Attracting a skilled long-term care workforce

Member States need to attract a sufficient number of adequately-skilled long-term care workers to meet the increasing demands for high-quality formal long-term care that results from the ageing of the population. However, many Member States face labour shortages in the long-term care sector. **A wide range of measures is needed** to make the long-term care sector more attractive to workers, including skills policies, better working conditions and higher wages.

In the Netherlands, the 'Labour market agenda 2023: working for older people' (Aan het werk voor ouderen), launched in 2017, and the general action programme 'Working in healthcare' (Werken in de zorg), launched in 2018, aim to support that there will be enough well-educated care professionals. These comprehensive strategies set out 11 action points on care for older people, which mainly focus on: (i) improving the attractiveness of the sector, e.g. by campaigns to improve its image; (ii) improving working conditions, e.g. quality of work, job security; (iii) better education, e.g. qualifications and (re)training; and (iv) working in a different way, e.g. (inter) sectoral cooperation, innovation, matching demand and supply. Regions and municipalities play a key role in carrying out these initiatives<sup>273</sup>.

<sup>&</sup>lt;sup>273</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report, Vol. 2 Country profiles</u>, Publications Office of the European Union, Luxembourg.

A **policy focus on skills** ensures that long-term care workers are equipped with the necessary skills and competence to provide high-quality long-term care. Measures to enhance the skills of current and future long-term care workers can include better initial and continuous education and training. Upskilling, reskilling, skills validation, the use of micro-credentials and individual learning accounts, and information and guidance services can support career pathways into an long-term care profession. Higher professional standards, and offering an attractive professional status and career prospects to care workers, can also help to make the long-term care profession more attractive.

Under a **policy scenario**<sup>274</sup> aimed at improving continuous training in the sector, it was estimated that the cost of 7 days of training a year for each long-term care worker (measured in full-time equivalents or FTE) would amount to EUR 482.5 million annually in the EU-27. In addition, there may be costs to replace the long-term care workers who cannot perform their tasks during these 7 days. These costs may be borne by long-term care providers or by the state. However, 7 days of training per year is standard in many sectors, and some providers may already be providing this. These training costs may therefore be an overestimation of the actual amount.

In Austria<sup>275</sup>, different measures have been taken over the last decade to increase the availability of carers at different levels of qualification. In 2016, the educational system for carers and nurses was reformed, with the goal of offering different levels of qualification to attract more new applicants. The federal provinces, partly in cooperation with the public employment service, offer different types of financial subsidies while people are in education for relevant professions. Another measure is the substantial expansion of advice services to validate or recognise qualifications acquired in other countries, which are also available for people in the caring professions.

Sweden provides an example of training for people already working in the sector. The largest private care provider (Ambea) provides skills development, training and coaching in social services and long-term care for older people and people with disabilities. One of these upskilling courses is the Dementia Academy, which offers a three-day training to teach appropriate skills to those working with older people suffering from dementia<sup>276</sup>.

Given that wages in the long-term care sector are comparatively low, **improvements in pay** that reflect the challenging tasks and working arrangements, as well as the value of long-term care to society, are likely to help attract and retain long-term care workers. Social dialogue and collective agreements for the long-term care sector play a significant role in this, so it is essential to improve the capacity of social partners at national level.

<sup>&</sup>lt;sup>274</sup> Barslund, M., Pacolet, J., Leichsenring, K., De Wispelaere, F., Waeyaert, W., Harald Hauben, H, De Smedt, L., Schepers, W., 2022, Analytical support under VC/2020/066.

<sup>&</sup>lt;sup>275</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report, Vol. 2 Country profiles</u>, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>276</sup> Eurofound, 2020, <u>Long-term care workforce: Employment and working conditions</u>, Publications Office of the European Union, Luxembourg.

Wages in the healthcare sector are higher than in the long-term care sector in many Member States, thus the long-term care sector is often less attractive for care workers. In a policy scenario where the long-term care workforce grows in line with the increase in the 65+ population and labour costs in the long-term care sector converge with those in the healthcare sector, the cost of wages in the long-term care sector would increase by 41% by 2030. Under the same scenario, total annual labour costs would increase from 1.65% of the EU-27's GDP in 2019 to 2.22% of GDP in 2030<sup>277</sup>. Improved wages in the long-term care sector promote fair working conditions, help to prevent unfairly low wage levels in Member States and help reduce wage inequality and in-work poverty. They may also help reduce outward labour mobility in low-wage economies, which exacerbates shortages in the sector.

Since 2014, the government in Czechia<sup>278</sup> has been increasing salaries in the social services sector to improve its attractiveness. In July 2017, the government increased the salaries of social workers and other workers in social services by 23%. There were further increases in salaries in the public sector, social services and long-term care including by 10% in November 2017 and by 10.8% in 2018. Latest data for 2019 indicate that the average wage of personal care workers represented 78% of the average wage in the residential care sector and 72% in home-based care. This is considered a partial improvement and to have contributed to stabilising the long-term care workforce at 100 000 people. However, difficulties in recruiting long-term care workers persist.

In Austria, collective agreements are regularly negotiated at company level between management and a work council, and annually at national level during negotiations between industry social partners (employers and trade unions). In 2019, the negotiation led to a 3.2% increase in wages for the whole workforce and also to paid leave agreements<sup>279</sup>. In spring 2020, the private-sector unions entered the annual collective bargaining round in the social economy sector with only one demand, to reduce working hours from 38 to 35 hours per week and waive a wage increase. A three-year agreement between the social partners was reached in April 2020. The social partners agreed to wage increases for 2020 and 2021, and to reduce working time to 37 hours from 1 January 2022. This agreement is considered a milestone by the unions<sup>280</sup>.

As a result of the **COVID-19 crisis**, some EU countries (CZ, FR, DE) increased wages<sup>281</sup> or gave long-term care workers additional days of annual leave <sup>282</sup> (LU). These have been introduced as permanent measures, set to remain even after the pandemic.

<sup>&</sup>lt;sup>277</sup> Barslund, M., Pacolet, J., Leichsenring, K., De Wispelaere, F., Waeyaert, W., Harald Hauben, H, De Smedt, L., Schepers, W., 2022, Analytical support under VC/2020/066.

<sup>&</sup>lt;sup>278</sup> European Commission and Social Protection Committee, 2021 <u>Long-term care report, Vol. 2 Country profiles</u>, Publications Office of the European Union, Luxembourg.
<sup>279</sup> Ibid.

<sup>&</sup>lt;sup>280</sup> Allinger, B. and Adam, G., 2022, <u>Impact of the Covid-19 pandemic on the social services sector and the role of social dialogue</u>, FORESEE project (VS/2021/0054).

<sup>&</sup>lt;sup>281</sup> Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, <u>COVID-19 in long-term care: Impact, policy responses and challenges.</u>
OECD Health Working Papers, No. 131, OECD Publishing, Paris.
<sup>282</sup> Ibid.

**Better staffing levels** help to improve the working conditions for long-term care workers, as they reduce stress levels, as well as the need to work at short notice. Better staff ratios are also essential to improve the quality of care as they allow carer workers to dedicate more time to each person receiving care.

**Finland**<sup>283</sup> passed a law on the nurse-client ratio in long-term care, which came into force in October 2020. The law sets the number of personnel in 24/7 services at around 4 400 by 2023, which would increase the ratio of nurses per client from 0.5, i.e. 5 nurses per 10 client, to at least 0.7.

The occupational health and safety of long-term care workers is a challenge, as the job often includes heavy lifting and handling infectious substances. Furthermore, atypical working times, shift work and exposure to harmful or challenging social behaviour and can lead to an increased risk of accidents at work, cardiovascular disease and depression. As outlined in section 3.6, long-term care workers have also been more exposed to the COVID-19 virus, compared to other workers<sup>284</sup>. Measures to improve the health and safety of long-term care workers, including training and information campaigns on how to avoid health risks at work, can improve their working conditions and help them to stay in their jobs until retirement age. Reducing psychological risks is also important, given that long-term care workers often face harmful social behaviour and are at risk of experiencing mental health issues, including burnouts. The problem of harmful social behaviour can be countered by appropriate supervision, discussion with colleagues and supervisors, and comprehensive aggression-management systems.

As a result of the pandemic, numerous Member States recognised the risk of infection of long-term care workers in the workplace and COVID-19 was defined by many as an occupational disease or, in a few cases, as an accident at work (AT, BE, CZ, DK, EE, FI, FR, DE, HU, IT, LT, LV, LU, PL, PT, SK, ES). Recognition involved a case-by-case investigation to establish a clear connection between the virus and workplace exposure. Once the medical and administrative requirements were met, workers could benefit from compensation to cover at least part of their lost salary. Compensation rules varied widely across the EU.

Because of the unprecedented nature of COVID-19 outbreaks in long-term care facilities, a number of countries offered support for **mental well-being** to long-term care workers, including access to a free phone line during the acute phases of the epidemic (BE, CZ, EE, FI, FR, DE, EL, HU, LT, LV, LU, NL, PT), or specialist consultations as part of psychological support systems (BE, CZ, EE, FI, DE, LT, NL, PT). Advocacy groups and stakeholders such as nurses' associations provided resources to support long-term care providers and workers.

**Effective regulation** (including ratification by all Member States of the ILO Convention 189 on domestic workers) and its proper enforcement can help to **professionalise the live-in care** model and give workers greater protection where needed. **Undeclared work**, which is

<sup>284</sup> Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, <u>COVID-19 in long-term care: Impact, policy responses and challenges</u>. OECD Health Working Papers, No. 131, OECD Publishing, Paris.

<sup>&</sup>lt;sup>283</sup> European Commission and Social Protection Committee, 2021 <u>Long-term care report, Vol. 2 Country profiles</u>, Publications Office of the European Union, Luxembourg.

particularly common among live-in carers, could be tackled by: (i) providing incentives to declare work (e.g. via voucher schemes or non-bureaucratic registration procedures); (ii) proper regulation and monitoring of employment situations, including via digital platforms; and (iii) improved labour inspections, including in private households.

To counter undeclared work, **Belgium** has introduced **a voucher system** for domestic services. The services included are cleaning, ironing, washing, mending, food preparation, transporting people with reduced mobility and food shopping. This does not include care services specifically, but the high take-up of vouchers by older people suggests that these services provide help with IADLs (and less so with ADLs). In 2020, one voucher cost EUR 9 per hour, reduced to EUR 7.20 after tax benefits. Workers paid with the vouchers are covered by social insurance. In 2016, 22% of Belgian households used the service voucher system and it is likely that the rate has increased since then. More than one quarter of voucher users stated that they used the services because they could not do the tasks themselves (i.e. older people and people with health problems) <sup>285</sup>.

While improving the working conditions and wages remains the most efficient way to attract enough workers into the long-term care sector, **proactive recruitment policies** to increase the pool of potential long-term care workers can also be explored. Such policies include the recruitment of non-EU nationals, pathways to legal employment for undeclared care workers, the retraining of workers in other sectors who are at risk of redundancy and the recognition and validation of skills and qualifications of informal carers.

Many people from non-EU countries are already working in the long-term care sector. However, they often work illegally, or under precarious conditions or their work is undeclared. The migration of workers in the global care chain also leads to a 'care drain' in their home countries, with a negative impact on the families that these carers, who are mostly women, leave behind.

Pathways to regularise the employment status of undeclared workers and non-EU nationals could provide opportunities for currently undeclared and migrant workers to officially work in the care sector, while helping to address gaps in the labour market. Such measures include integration programmes to encourage migrants already living in the EU to work in the care sector and official agreements with non-EU countries to recruit care professionals. **Proactive recruitment** may also include arrangements under which long-term care providers recruit workers at risk of redundancy in other sectors and retrain them to work in the care sector. This could become especially relevant in the context of greening European economies, as workers in carbon-intensive sectors, who are being made redundant in their original professions, could start a new career in the growing long-term care sector.

In 2019, **Germany** set up an agency for skilled labour in health and care occupations, DeFa (Deutsche Fachkräfteagentur für Gesundheits- und Pflegeberufe). This agency serves as a

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<sup>&</sup>lt;sup>285</sup> Eurofound, 2020, <u>Long-term care workforce: Employment and working conditions</u>, Publications Office of the European Union, Luxembourg.

contact point for health and care providers that want to recruit skilled staff from abroad, and helps with visa applications, the recognition of professional qualifications and work permits (for a cost of EUR 350 per case). It also organises the selection processes and offers language courses<sup>286</sup>. In Germany, 65% of all recognitions of qualifications obtained abroad concerned medical professions, in particular nursing occupations. The Federal Government has intensified its attempts to recruit long-term care professionals abroad, mainly from Central and Eastern European and Asian countries. In 2019, agreements on the recruitment of long-term care professionals have been reached<sup>287</sup> with Mexico, the Philippines and Kosovo<sup>288</sup>. In Kosovo, individual (nursing) schools design their curricula in such a way that they are equivalent to the degrees in Germany. In Mexico, a company-integrated adaptation course for the recognition of Mexican degrees is being developed, which has been coordinated with the recognition authorities. The German Society for International Cooperation (GIZ) is also setting up additional courses in nursing studies at universities in Mexico, leading to equivalence with German degrees.

In Sweden, training programmes for assistant nurses include vocational and language training designed so that immigrants and refugees can begin working in the care sector (for example, the YFI programme in Stockholm). A fast-track training course makes it easier to rapidly integrate migrants into the job market<sup>289</sup>.

In the Netherlands during the COVID-19 crisis, when the airline sector had to lay off workers, the airline KLM and the care organisation Actiz cooperated to enable airline personnel that were made redundant (mostly flight attendants) to switch to a career in long-term care rather than become unemployed. Airline personnel received a job guarantee, free professional nursing education and a similar salary to what they earned in their airline job<sup>290</sup>.

Many measures to attract workers into the long-term care sector have a cost and therefore more investment is needed. However, investment in the sector pays off in the long run, due to its significant employment potential (as outlined also in chapter 3).

In **Germany**<sup>291</sup>, following the law to increase care staff, (Pflegepersonal-Stärkungsgesetz) which came into effect on 1 January 2019, up to 13 000 additional posts were created in residential long-term care facilities, which will be financed by the Statutory Health Insurance

<sup>&</sup>lt;sup>286</sup> Eurofound, 2020, <u>Long-term care workforce: Employment and working conditions</u>, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>287</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report, Vol. 2 Country profiles</u>, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>288</sup> This designation is without prejudice to positions on status, and is in line with UNSCR 1244/1999 and the ICJ Opinion on the Kosovo declaration of independence.

<sup>&</sup>lt;sup>289</sup> Eurofound, 2020, <u>Long-term care workforce: Employment and working conditions</u>, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>290</sup> Ibid.

<sup>&</sup>lt;sup>291</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities in an ageing society</u>, Volume I, Publications Office of the European Union, Luxembourg.

fund. Moreover, healthcare funds have been obliged to fund health promotion for care workers at the workplace.

In **Sweden**, SEK 10 billion (EUR 0.92 billion) were allocated in 2016 to create job opportunities. Municipalities have a great deal of independence over how to spend this budget. In 2015-2018, the government allocated SEK 7 billion (EUR 0.64 billion) to increase staff in the long-term care sector, which is estimated to have created around 19 000 jobs. Municipalities received additional funding of SEK 2.5 billion (EUR 0.23 billion) in 2020, before the COVID-19 pandemic, to reduce the risk of lay-offs in the welfare sector<sup>292</sup>.

# 5.4.2. Tapping into the potential of digitalisation

Although robots and new technologies cannot replace long-term care workers, automation and digitalisation have the potential to enhance labour productivity in the sector, therefore requiring support for training in digital skills. Technology can take over certain tasks of long-term care workers and thus relieve them in their daily work, including helping with case management, lifting patients, managing electronic documentation, and remote monitoring of people receiving care at home<sup>293</sup>. Travel may be reduced through telecare and remote communication with users in their homes.

Table 5: The potential of digitalisation to support the workforce

Theme	Examples of technologies	<b>Expected benefits</b>
Training (I/F)	Learning technology	Retention, job satisfaction
Recruitment (F)	Algorithm, matching	Retention, job satisfaction
Work processes (I/F)	Formal carers: Robotics, patient monitoring, electronic records	Replacing/supporting care workers, job satisfaction
	Informal carers: Robotics, communication with care services, virtual consultation	Reduce caregiver burden
Workforce monitoring (F)	Video monitoring, electronic monitoring (including GPS)	Improving safety
Adoption and	Skills, attitudes, stakeholders/partnerships	Sustainable interventions
implementation (I/F)	Family decision making, knowledge and awareness	Reducing family and informal carer stress

Source: Zigante, V., 2021.

In 2012, an interdisciplinary international team of 14 institutions launched the Carer+ project, which is targeted towards care workers in Europe. The project aimed to identify and improve the digital and information technology skills of workers who care for older people at home, anticipating a new and vital role for care workers. The project set up a competence framework, a curriculum and training tools in theory and practice, training for trainers and

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<sup>&</sup>lt;sup>292</sup> Ibid.

<sup>&</sup>lt;sup>293</sup> Zigante, V., 2021, <u>The role of new technologies in modernising long-term care systems: a scoping review</u>. Research Note for the Social Situation Monitor.

policy exchange visits, as well as an open online learning space and community for care workers<sup>294</sup>.

# 5.4.3. Measures to support informal carers

While improving the provision of formal care remains the main answer to reducing pressure on informal carers, measures are needed to support those who decide to care for family members or friends, thus mitigating the negative consequences of care responsibilities. As many countries lack information about their informal carers, research on the characteristics of informal carers and their situation can help to target measures to their needs. Clear procedures to identify informal carers and clear regulation of the rights associated with informal care can help to understand the scale and impact of informal care and to define and guarantee the rights of informal carers.

With the support of the technical support instrument of the EU, **Croatia** undertook thorough research and reflection on the provision of informal long-term care in the country. The research encompassed the demographic, health, social, economic and other characteristics of older people and the people who care for them. The results fed into policy recommendations to introduce new in-kind/cash social benefits for informal long-term care). Based on the analysis, a proposal for the revision of the status of informal carers was developed. It is expected that the Croatian ministry will use the study for more strategic reflections on long-term care policy in Croatia.

Portugal implemented a comprehensive law on informal care in 2019, which established a formal status and a number of rights for informal carers, including the right to: (i) have their fundamental role acknowledged; (ii) receive training and follow-up; (iii) receive information from health and social security professionals; (iv) be provided with information on counselling for informal carers; (v) receive psychological support from the health services; (vi) benefit from respite periods; (vii) receive an allowance; (viii) reconcile caring with professional life; and (ix) be consulted about public policies aimed at informal carers<sup>295</sup>.

In Belgium, a law adopted in 2011 and amended in 2019 grants official recognition to informal carers. This recognition allows all informal carers to identify themselves to their health insurance organisation, which contributes to awareness-raising, helps prevent problems and provides an overview of the extent of informal care in the country. In addition, since 1 September 2020, under certain conditions on the level and duration of care provided, informal carers have been granted a right to a respite period of one month (full-time, or parttime over a longer period), which can be taken six times over the duration of the period of care, and which is compensated by up to EUR 1 400 for one month if taken full-time <sup>296</sup>.

Many informal carers have to reduce or stop paid employment completely due to their care responsibilities. Care allowances can partly compensate for this loss of income and serve as a

<sup>&</sup>lt;sup>294</sup> European Commission, 2014, Presentation of the Carer+ project: "From Carer to CarerPlus: developing digital competences in the care worker sector" | Shaping Europe's digital future (europa.eu) (09 July 2014)

<sup>&</sup>lt;sup>296</sup> Aidant-proches, Foire aux questions Foire aux questions - <u>Aidants Proches Wallonie.</u> (accessed on 11 April 2022)

form of recognition for informal carers. Pension credits can recognise the periods of informal caregiving to provide an income in old age. These financial compensations can therefore help reduce current and old-age poverty among informal carers, and reduce gender gaps in wages and pensions. Flexible working conditions and care leaves can allow informal carers to remain in the labour market for as long as possible.

Several EU Member States introduced specific measures to support informal carers during the pandemic. These included: (i) special care leave<sup>297</sup> (AT, BE, LU); (ii) a caregiver's allowance<sup>298</sup> to replace lost wages for an extended period of up to 20 working days (instead of 10 days), given to a person who provided or organised care in situations caused by the pandemic (DE); (iii) psychological support<sup>299</sup> (AT, SI); (iv) hotlines to receive advice and support<sup>300</sup> (FR, CZ); and (v) financial compensation for family carers taking leave to care for an ill older person (FR).

In a policy scenario where informal carers between 35 and 64 years old, who provide care intensively (more than 41.25 hours per week), would receive a care allowance and a pension credit, 3.1 million carers in the EU-27 could benefit from such support. The care allowance in this scenario would be set at a level equal to the minimum wage in each Member State, and the pension credit would be set at 10% of the minimum wage. Overall, the total annual cost in the EU-27 of providing this financial compensation to informal intensive caregivers would amount to EUR 47.4 billion (or 0.35% of GDP in the EU-27). The impact of financial compensation would be highest in Greece (0.65% of GDP), Denmark (0.52%), Italy (0.46%), and Croatia (0.45%)<sup>301</sup>. Estimates<sup>302</sup> show that total expenditure on care allowances in 2019 in the EU amounted to 0.19% of GDP. Therefore, under the scenario discussed above, the total expenditure on care allowances, including a pension credit, for those aged between 35 and 64 years old who provide intensive care is estimated to be 0.16 percentage points of GDP higher than the current estimate.

In **Ireland,** a Carer's Allowance is available to full-time family carers who care more than 35 hours per week for someone who has been medically certified as in need of full-time care. The Carer's Allowance also secures automatic access to other financial support including: (i) a GP visit card, which gives free access to GP care; (ii) an annual Carer Support Grant of EUR 1 850 paid to the carer, in respect of each person they care for; (iii) free travel on all public transport; and (iv) a Household Benefits Package (if the carer lives with the person receiving care) which gives discounts on monthly utility bills and exempts the carer from having to pay for a TV Licence. The Carer's Allowance is means tested<sup>303</sup>.

<sup>&</sup>lt;sup>297</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report: trends, challenges and opportunities in an ageing society</u>, Volume I, Publications Office of the European Union, Luxembourg.

<sup>&</sup>lt;sup>298</sup> Ibid.

<sup>&</sup>lt;sup>299</sup> Ibid.

<sup>&</sup>lt;sup>300</sup> Rocard, E., P. Sillitti and A. Llena-Nozal, 2021, <u>COVID-19 in long-term care: Impact, policy responses and challenges.</u>
OECD Health Working Papers, No. 131, OECD Publishing, Paris.

<sup>&</sup>lt;sup>301</sup> Barslund, M., Pacolet, J., Leichsenring, K., De Wispelaere, F., Waeyaert, W., Harald Hauben, H, De Smedt, L., Schepers, W., 2022, Analytical support under VC/2020/066.

<sup>&</sup>lt;sup>302</sup> Van der Ende, M. et al., 2021, Study on exploring the incidence and costs of informal long-term care in the EU.

<sup>&</sup>lt;sup>303</sup> Eurocarers, 2022. Example submitted via the call for evidence.

Since 2019, a pilot project in the Burgenland, the smallest region of **Austria**, aims to offer informal carers the opportunity to put their caregiving on a formal footing. Informal carers can sign a service contract with a state-owned care service (Pflegeservice Burgenland GmbH). Provided they meet the criteria (including a family tie with the person they care for, an acceptable care environment at home etc.) they can earn a salary at the level of the minimum wage, on a pro-rata basis according to the number of hours of care the person needs, plus national insurance contributions and holiday entitlement. In return, they must attend a ten-week course (one and a half days a week) to acquire basic knowledge of first aid and care, and receive guidance and support on their caring activities. Many of the carers who participated remain in contact after the course, sharing advice and experiences<sup>304</sup>.

**Germany** grants pension credits to informal carers who provide at least 10 hours of care a week (on at least two days per week) to a person whose need for care is at least at need level 2. The carer must not work more than 30 hours in paid employment<sup>305</sup>.

In **France**, a caregiver's leave (congé de proche aidant) is designed for those caring for a relative who is coping with a loss of autonomy. Caregivers can ask their employer to temporarily interrupt their work, while keeping their position and rights in the company. This leave can last up to three months (except if there is a collective agreement) and can be renewed. An allowance of EUR 52 per day for a single person, and EUR 43 for people living in a couple<sup>306</sup> became payable from 30 September 2020. The benefit also opens up pension rights.

Informal carers need access to training and counselling to help them provide good quality care. So it is important for them to have opportunities to exchange information and provide integrated care with formal healthcare and long-term care workers. Psychological support can help to prevent and tackle mental health issues among informal carers. Meeting other informal carers offers possibilities to exchange and share experiences with other people in similar situations.

Informal carers should be able to take a break from their care responsibilities. Being able to take some time off and having access to respite care that temporarily replaces them, such as temporary residential care or day care centres, allows informal carers to have some time for themselves and to improve their well-being.

Among other support measures, the **Finnish** Informal Care Act gives informal carers the right to at least two days of statutory respite care services per month. However, only one third of those who are eligible use the leave available to them. Many informal carers think that the options available are not good enough or not suitable for the person receiving care. Reflections are ongoing on how to tackle the lack of take-up and measures have been brought in to improve the respite care options. For instance, some municipalities have introduced pools of substitute carers, who can step in during the care leave. Family foster care can be

<sup>&</sup>lt;sup>304</sup> Pflegeservice Burgenland, <u>Gute Betreuung in vier Schritten</u>. (accessed on 11 April 2022)

<sup>&</sup>lt;sup>305</sup> Pflege.de, Rente für die Pflege von Angehörigen. (accessed on 11 April 2022)

<sup>&</sup>lt;sup>306</sup> European Commission and Social Protection Committee, 2021, <u>Long-term care report, Vol. 2 Country profiles</u>, Publications Office of the European Union, Luxembourg.

provided in the home of the care recipient or of the family foster carer. This form of respite care is arranged, supported and supervised by the municipality. An agreement between the municipality and the family foster carers outlines rights and responsibilities. Family foster care offers personalised care and takes into account the needs of the care recipient<sup>307</sup>.

France is currently experimenting with 'baluchonnage', an innovative solution from Quebec, whereby a care professional replaces the informal carer for several consecutive days (24 hours a day) to allow the carer to enjoy a break. At the end of the period of care, the care professional makes a series of suggestions aimed at improving support to the carer in the longer term. There are several benefits to this innovative approach: (i) support for vulnerable people who need care; (ii) support and recognition of the carer; (iii) better quality of life of the carer and the person cared for; and (iv) improved home-based care. Some pension funds and mutuals support the individual costs of the intervention<sup>308</sup>.

# 5.5. Long-term care governance and funding

The proposal for a Council Recommendation on long-term care recommends that Member States ensure sound policy governance in long-term care, including through a coordination mechanism to design and deploy actions and investments and to mobilise and make cost-effective use of adequate and sustainable funding.

#### 5.5.1. Sound policy governance in long-term care

Effective **coordination** at national, regional and local levels, active **involvement** of all relevant stakeholders in preparing, implementing, monitoring and evaluating long-term care policies and stronger **coherence** between long-term care and other relevant policies (including healthcare, employment, education and training, broader social protection and social inclusion and gender equality, and disability) can help reduce fragmentation between systems and thus achieve better outcomes while reducing costs.

France<sup>309</sup> is carrying out a comprehensive reform to improve the governance of the long-term care system. A new home autonomy service will act as a single contact point for people with long-term care needs, bringing together the players in home assistance and home care and coordinating the provision of care. This will bring clarity for the people in need and their caregivers, who until now had to coordinate the different assistance and care providers. Territorial resource centres will ensure the link between professionals in the sector, and will develop an offer of reinforced support at home. Conditions for success of these centres are a common tool such as a 'shared file' to monitor the progress of individuals, interdisciplinary training and sufficient funding also for the training of staff. The pricing system will be reformed to better reflect care and dependency needs and to allow for a real integration of home assistance and home care by creating the right incentives.

<sup>&</sup>lt;sup>307</sup> Eurocarers, <u>Towards care-friendly societies</u>, Eurocarers country profiles. (accessed on 11 April 2022)

<sup>&</sup>lt;sup>308</sup> BalunchonFrance, Mise en place du Baluchonnage: répit de longue durée pour les aidants. (accessed on 11 April 2022)

<sup>&</sup>lt;sup>309</sup> Puiseux, A., 2022, The Ageing Reform. Presentation for the Mutual Information System on Social Protection.

**Prevention** can postpone or reduce the need for long-term care and thus relieve pressure on resources. Even before it arises, Member States can act to mitigate the need for long-term care through policies to extend healthy life years, and by creating social and environmental conditions that allow adults to maintain functional independence throughout their old age. The WHO defines healthy ageing as 'the process of developing and maintaining the functional ability that enables well-being in older age'. The United Nations has designated 2021–2030 the Decade of Healthy Ageing<sup>310</sup>. 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,<sup>311</sup> but they are also often better at managing functional decline when it occurs.<sup>312</sup> As part of a life-course approach, intervention should start before a need for long-term care arises. In particular, primary prevention should start at as young an age as possible, in early childhood education and care.

Sound policy governance is guided by **evidence**, underpinned by relevant and timely data (including feedback from people receiving care and other stakeholders), evaluation, the collection of evidence, and the **sharing of lessons learned and successful practices**.

Integrated care seeks to achieve person-centred, effective and safe care for all age groups across the whole spectrum of health and social care: from disease prevention, to treatment, to management of chronic conditions (including at home), to long-term care. Patients with multiple morbidities, complex care needs and mental health conditions require a care delivery system that connects and coordinates a wide range of care service providers and skills. Policymakers have to ensure a systematic approach that integrates health promotion, primary care, hospital care, mental health services, long-term care, and social care. Through three key projects funded by the third health programme, the Commission is assisting national and regional authorities to build the capacity and know-how to deploy integrated care. The Vigour<sup>313</sup> and Scirocco-Exchange<sup>314</sup> projects leverage the experience of integrated care 'pioneers' and transfer knowledge to the 'next adopters' of integrated care. A third project, the Jadecare joint action<sup>315</sup>, works on the transfer of good practices from 'pioneers' to 'next adopters', with pilot projects on integrated care carried out by more than 20 'new adopters' (care authorities).

Furthermore, **forecasting long-term care needs** can help plan the resources needed, effective **outreach** can help improve the take-up of available support and the use of long-term care services, while **contingency planning** can help prepare long-term care systems for unforeseen circumstances and emergencies.

<sup>310</sup> WHO, 2021, Ageing and health.

<sup>&</sup>lt;sup>311</sup> 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 Member States.

<sup>&</sup>lt;sup>312</sup> The EU-funded <u>'FrailSafe'</u> project aims to delay frailty by developing a set of measures and tools, together with recommendations to reduce its onset.

<sup>313</sup> VIGOUR

<sup>314</sup> SCIROCCO

<sup>315</sup> JADECARE

A shift towards services to better manage chronic conditions, including at home, to offer more social care and to respond to end of life needs requires a healthcare workforce with the right professionals and skills. Health workforce planning can help health and social systems keep up with changing health needs and take advantage of innovative solutions. It should support comprehensive strategies on working conditions, compensation, recruitment, retention and the attractiveness of health professions, especially those which tend to be undervalued. The Commission is supporting Member States in better health workforce planning through the joint action 'HEROES—Health workforce to meet health challenges' which is being set up in 2022 on the initiative of 18 Member States under the EU4Health programme. It will last 3 years and contribute to health workforce planning by supporting the capacities of Member States in developing and using specific tools to define the best combination of professions and the best skill-mix.

# 5.5.2. Investing in long-term care

The proposal for a Council Recommendation outlines reform pathways to improve social protection, availability, and quality of long-term care services, and address the challenges faced by formal and informal carers. To support these reforms, the proposal recommends that Member States **mobilise and make the most cost-effective use of adequate and sustainable funding** for long-term care, including by making use of Union funds and instruments.

Public support for the care sector is a social investment, which entails health promotion, prevention, support for healthy and active ageing, using modern technologies to improve productivity in care delivery, tapping into the job creation potential of the sector and improving gender equality. This brings multiple returns, for individuals, society and the economy. More people in need of long-term care would be able to use high-quality formal care and be less at risk of poverty due to paying for care services. Their right to independent living and a generally good quality of life would be strengthened. Secondly, the burden of intensive caring on informal carers/family members, mostly borne by women, would be reduced and they could benefit from greater participation in the labour market, earnings and pension credits. Furthermore, there would be a positive impact on their health, work-life balance and general well-being. Thirdly, the long-term care workforce would benefit from better working conditions, pay, training and job satisfaction. Fourthly, long-term care service provision is expected to expand, implying new opportunities for service providers and care workers.

The **growth potential of the silver care economy** arises from the growing demand for care services. Research suggests that investment in the labour-intensive care sector would create **positive employment effects**, as 1.6% of GDP net investment could generate a rise of 8.5 percentage points increase in women's employment rate across the EU-28. In comparison, an investment of 5.3% of GDP would be needed to achieve a similar employment effect in the construction sector<sup>317</sup>.

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<sup>&</sup>lt;sup>316</sup> HEROES –Health Workforce to meet health challenges

<sup>&</sup>lt;sup>317</sup> De Henau, J. and Himmelweit, S., 2021, A care-led recovery from covid-19: Investing in high-quality care to stimulate and rebalance the economy. Feminist Economics, 27(1-2), pp.453-469.

Similarly, the International Labour Organization estimates that an annual investment of 0.8% of GDP in early childhood education and care and an investment of 1.9% of GDP in long-term care would create an **additional 13.6 million jobs in the EU by 2030**<sup>318</sup>.

Given its job creation potential, the care sector can attract workers from sectors impacted by the **green transition**. Active and healthy ageing and the effective prevention of the need for long-term care also depend on the physical and social environment where people live. An age-friendly environment is a green environment, supporting better health and providing more opportunities for social interaction across the generations. In addition to contributing to gender equality, addressing care needs also leads to job creation, which strengthens local communities. Investing in care can contribute further to **social fairness** by providing jobs for workers affected by the digital and green transitions.

While investing in long-term care pays off, **implementing reforms will still require a careful balancing between the adequacy of long-term care and ensuring the overall sustainability of public finances**. One cannot be reached at the expense of the other. In particular, Member States that are starting from low levels of public expenditure on long-term care will need to invest in the sector to not only strengthen social protection for long-term care, but also to increase the availability of long-term care, improve its quality and sustain its workforce. However, this expenditure would not only benefit people in need of long-term care and their carers, but it can also harness the social dividends of investing in the care economy and thus provide a significant return on investment. A recent study from **Austria**<sup>319</sup> concluded that for every euro spent on long-term care services in Austria, the aggregated value added is EUR 1.70 and it generates more than EUR 0.70 in taxes and social security contributions (due to the high share of labour costs in care).

In order to sustain long-term care financing also in light of increasing demand for care, it is important to **increase the efficiency of long-term care expenditure and services**, which could be done by ensuring sound policy governance (see section 5.5.1) as well as increasing the availability and accessibility of long-term care services, which would allow long-term care to be provided in the **most cost-effective setting**. For example, due to a lack of long-term care services, people in need of care often stay much longer in hospitals than would be medically required, adding thus to the pressure on healthcare systems. Typically, the average cost of residential care per person is higher than home care; if funds are steered in a way that fosters home and community-based care, people with low and moderate care needs can continue to live at home for much longer and thus avoid being placed in a much more expensive care setting. **Digitalisation can also help to reduce the need for long-term care services** and, in particular, residential stays by improving functional independence and the efficiency of care, for example, by helping **older people 'age in place'**.

Member States finance public expenditure on long-term care via employees' contributions in social insurance systems, via general revenues from taxes or via a

<sup>&</sup>lt;sup>318</sup> International Labour Organization (ILO), 2022, ILO Care Policy Investment Simulator (Geneva, forthcoming).

<sup>&</sup>lt;sup>319</sup> Famira-Mühlberger, U., Firgo, M., Fritz, O., & Streicher, G., 2017, Österreich 2025: Pflegevorsorge – Künftiger Finanzierungsaufwand und regionalwirtschaftliche Verflechtungen. Wien: Österreichisches Institut für Wirtschaftsforschung (WIFO).

**combination of both**. In addition, there may be a role for voluntary private long-term care insurance in supplementing social protection for long-term care, but due to adverse selection and other obstacles resulting in high insurance premiums and usually limited coverage, voluntary private insurance could not ensure that people in need can afford long-term care services.

**Maximising the available fiscal space** to expand the resources available to fund care policies would at the same time reduce unpaid care work. Given the ageing population, in the absence of further investment in social protection for long-term care, the costs to public budgets of informal care would increase over time. Thus, policymakers should take unpaid care work into account in relevant macroeconomic analyses and decision-making to uncover the effects on women and men.<sup>320</sup>

# 6. CONCLUSION

The analysis and evidence presented in this staff working document underpin the need to urgently address the common challenges and structural weaknesses of long-term care systems in the EU. Firstly, social protection for long-term care is in some cases inadequate and long-term care services are unaffordable for many people in need. Secondly, long-term care services are sometimes not available and a large share of older people report unmet care needs in all Member States. Thirdly, there are persisting concerns with the quality of long-term care services. Lastly, many Member States struggle to ensure a sufficient and adequately skilled long-term care workforce, adding to the pressure on informal carers, most of whom are women. These common challenges are impacted by the different ways long-term care is funded, organised, delivered and monitored across the EU.

The COVID-19 pandemic has shed further light on these challenges, highlighting at the same time how society and the economy are heavily reliant on care and the essential role of carers. The pandemic created a strong momentum to accelerate reforms and investments in long-term care and strengthen the resilience of long-term care systems, by expanding the offer of high-quality and affordable long-term care services and improving the working conditions of care staff. To be successful, long-term care reforms and investments need to be underpinned by sound policy governance, joint commitments and strong cooperation between public authorities, social partners, care providers, carers and those in need of care.

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<sup>&</sup>lt;sup>320</sup> ILO, 2022, Analysis submitted via the call for evidence.

# ANNEX 1 KEY DEFINITIONS

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	Formal long-term care provided and organised at community level, for example, in the form of adult day services or respite care.
Domestic long-term care worker	Any person engaged in domestic work who provides long-term care within an employment relationship.
Formal long-term care	Long-term care provided by professional long-term care workers, which can take the form of home care, community-based or residential care.
Home care	Formal long-term care provided in the recipient's private home, by one or more professional long-term care worker or workers.
Independent living	Independent living' means that all people in need of long-term care can live in the community with choices equal to others, have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others, and are not obliged to live in a particular living arrangement;
Informal care	Long-term care provided by someone in the social environment of the person in need of care, including a partner, child, parent or other relative, who is not hired as a long-term care professional.
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

Instrumental activities of daily living	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.  Household activities such as preparing meals, managing money,
(IADLs)	shopping for groceries or personal items, performing light or heavy housework, and using a telephone.
Live-in carer	Domestic long-term care worker who lives in the care recipient's household and provides long-term care.
Long-term care	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, 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, such as preparing meals, managing money, shopping for groceries or personal items, performing light or heavy housework, and using a telephone);
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	Formal long-term care provided to people staying in a residential long-term care setting.
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.

# **Member States**

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

# ANNEX 2 QUALITY ASSURANCE BODIES AND RESPONSIBILITES

Country	Quality assurance bodies and responsibilities
Austria	Federal Ministry for Social Affairs, Health, Care and Consumer Protection (Voluntary National Quality Certificate, consumer protection)
	Regional Governments with individual regulations, standards and procedures (inspections)
Belgium	Brussels: IRISCARE (accreditation, inspection)
	Wallonia: AVIQ - Agence pour une vie de qualité
	Flanders: Agentschap Zorg en Gezondheid
Croatia	Inspection of the Independent Sector for Supervision and Petitions at the Ministry of Labour, Pensions, Family and Social Policy
Denmark	Ministry of Health and the Elderly (quality framework), Local authorities (implementation), Danish Patient Safety Authority (registration, monitoring)
Finland	Ministry of Social and Health Care Affairs (legislation, quality standards, guidance by information)
	Institute of Health and Welfare (quality standards, national data-management, evaluation of state-financed development-projects)
	VALVIRA - National Supervisory Authority of Welfare and Health (national supervision)
	Regional State Administrative Agencies (regional supervision)
	Municipalities (local supervision as procurer)
	Provider units (reporting and self-assessment)
France	Agence Régionale de Sante (control and inspection)
	Cour des comptes (financial audits and control)
	Inspection Générale des Affaires Sociales (inspection)
Germany	Medical Review Board of the Statutory Health Insurance Funds' Federation (Medizinischer Dienst des GKV-Spitzenverbandes) (national guidance and supervision) and Medical Review Boards of the Statutory Health Insurance Funds (Medizinische Dienste der Krankenversicherung) (regional inspections and enforcement)
	Regional authorities to inspect structural, hygiene and safety standards
Ireland	HIQA – Health Information and Quality Authority (definition, accreditation, inspection and monitoring)
Italy	National Agency for Regional Health Services (analysis, monitoring, evaluation of health services)
	Regional Agencies for Social and Health Services (accreditation and quality control at regional level)
Latvia	Methodological Management and Control Department of the Ministry of Welfare (inspection, monitoring)
Luxembourg	Ministry of Family Affairs, Integration and the Greater Region (defining minimum standards for accreditation)
Malta	SCSA – Social Care Standards Authority (licensing, standard setting, inspection)
	Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing (definition of minimum standards)
	National Audit Office (financial audits and control)
Netherlands	National Healthcare Institute (definition of care standards for nursing homes)
	Healthcare Inspectorate (standard setting, inspection, public reporting)

	Care Needs Assessment Centres (individual needs assessment)  Regional care offices (accreditation and accounting of care providers)
Romania	National Agency for Payments and Social Inspection (accreditation, monitoring, enforcement)
Slovenia	Ministry of Labour, Family and Social Affairs (oversight, inspection)
Spain (examples	Region of Madrid: Autonomous community (periodic inspection and monitoring of implementation of quality standards)
from selected autonomous regions)	Region of Catalonia: UCQEC – Quality Control Unit at municipal level (monitoring contracts); CatSalut – Catalan Health Service (regional quality assurance regarding indicators included in contracts); AQUAS – Agency of Health Quality and Assessment of Catalonia
regions)	(monitoring framework, evaluation)
	Region of Asturias: Inspection Services of the Regional Ministry of Social Rights and Welfare
Sweden	National Inspectorate (accreditation and inspection)

Source: Barslund, M., Pacolet, J., Leichsenring, K., De Wispelaere, F., Waeyaert, W., Harald Hauben, H, De Smedt, L., Schepers, W., 2022, Analytical support under VC/2020/066.