<a> Chapter 8. **Coordinated action and local empowerment to strengthen social infrastructure in long-term care in Europe for older people**

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<b> Introduction

As the population ageing process is picking up pace at a global level, a growing number of older people living with functional and cognitive decline will depend on social support and long-term care (LTC) systems in order to maintain their ability to live independently, with dignity and a high quality of life. As the need for care grows, so does the pressure on countries to respond to these needs by ensuring affordable and high-quality care services are available. The UN Decade for Healthy Ageing recognizes access to LTC for all those who need it as a crucial area of action in order to improve the lives of older people, their families and communities. Similarly, the EU Care Strategy launched in 2022 has also made the case for investing in LTC infrastructure[1]. Despite the common value of pursuing affordable, high quality care for all, European countries vary substantially in their operationalization of LTC and subsequently in the development of LTC infrastructure. While some countries have invested significantly into the availability of formal services, relieving families of the obligation to provide care, others have supported and upheld the family's responsibility to provide care. As a result, the type and extent of LTC infrastructure across European countries remains unequal and fragmented.

While LTC is recognized as a core part of social policy, considerable challenges to the sustainability of care in Europe are also becoming more apparent. Development of formal care services has not kept up with increasing demand for care while changing demographic and socio-economic patterns have reduced the availability of informal care amongst some groups (Rodrigues et al, 2023), which remains the largest care component across Europe. The Covid-19 pandemic has also revealed important systemic vulnerabilities and large gaps in care capacity, data, service organization and responsiveness. Over the next 30 years, the number of older people (65 and over) is projected to increase by 41%, while the number of the very old (80 and over) will almost double from 26.6 million in 2020 to 49.9 million in 2050 (European Commission, 2021), putting significant pressure on states to meet growing demand for LTC. At the same time, the investment gap in social infrastructure for LTC across European Union countries has been assessed at 50 billion Euros per annum in 2018, far outstripping the investment gap for other areas of social policy

[1] Communication on the European Care Strategy: https://eur-lex.europa.eu/legal-content/EN/ALL/?uri=COM:2022:440:FIN#footnote24

(Fransen, Del Bufalo and Reviglio, 2018). Without rapid and sustained investment in crucial social infrastructure and service development in community-based settings, the goals of equitable, affordable and high-quality care for all cannot be reached.

In this chapter, we provide an overview of infrastructure for LTC for the older population, highlighting the most acute gaps. We focus our attention primarily on community-based care, both formal and informal, and only briefly discuss the role that residential care plays. Our choice aligns with the strategic direction of LTC policy across Europe (European Commission, 2021) and globally (WHO, 2020a) and with the goals of deinstitutionalization and ageing in place. While residential care facilities continue to be— and will likely remain in the future— an important part of formal service delivery, we argue social investment should emphasize home- and community- based care provision because it reflects the preferences of care users (Ilinca and Simmons, 2022), it builds on the principles of a rights-based approach to care. LTC remains a challenge in most countries throughout the world, particularly in the Global South and in low- and middle-income countries where LTC policy is neglected (Feng, 2019; Österle and Rothgang, 2021). However, we limit the discussion to European countries given the adoption of the European Care Strategy in 2022, an ambitious vision and strong framework for promoting policy change, which is expected to transform LTC systems across Europe in the years to come. We focus the discussion on service flows as the result of limited pan-European data on physical LTC infrastructure, but highlight stocks where possible.

We first discuss the specificities of social infrastructure for LTC, highlighting its function for society and nuances compared to other social infrastructures. Highlighting the current level of investment and spending in LTC across Europe, we then move to present the core elements comprising LTC infrastructure across European countries where gaps are most acute: formal services, the care workforce, support for informal care and digital technology/data infrastructure. We posit these gaps must be addressed with urgency through the commitment of significant financing and investment at European, national and local level. We conclude by recommending a strategy to guide investment in social infrastructure through the empowerment of local communities and local governing bodies to design and implement programs for social infrastructure development in LTC.

<b> Social infrastructure in the realm of LTC: function and nuances

LTC refers to a broad range of personal, social and medical services and support that ensure people, with or at risk of a significant loss of intrinsic capacity (due to mental or physical illness and disability), can maintain a level of functional ability consistent with their basic rights and human dignity. LTC is provided

over extended periods of time, although not necessarily continuously or at constant frequency and intensity (WHO, 2022a). Prior to the 90s, the public responsibility for LTC had typically fallen either under health systems or as a residual responsibility by local authorities (Ranci & Pavolini, 2015), although most care needs fell under the responsibility of family. The early 90s witnessed a recognition of LTC as its own area of social policy, and with it, an expansion of care infrastructure across many European countries previously defined as residual systems, and refinement amongst universalist systems (Ranci & Pavolini, 2015). Today, while LTC is recognized as a new social risk (Morel, 2006), European societies vary considerably in terms of what they offer for services and benefits, as well as the division of responsibility between the state, market and family (Österle and Rothgang, 2021).

The acknowledgment of LTC as a fundamental and social right has underpinned LTC systems across Europe. The European Pillar of Social Right reflects these values recognizing that 'Everyone has the right to affordable LTC services of good quality, in particular homecare and community-based services' (Principle 18). Viewing LTC with a human-rights based approach (See text box 1) entails the development of LTC in a way that aims to uphold the rights of holder people, while ensuring autonomy, dignity, equality and self-fulfillment of older people. Consequently, the main function of social infrastructure for LTC has been to materialize these rights by enhancing the well-being of older people in need of care and their families, either through financial support, or the provision of formal services, with an increasing emphasis on community-based care— the preferred option of most older adults (Ilinca and Simmons, 2022).

<c> Text box 1: A human-rights based approach to investment in LTC infrastructure

According to the United Nations Research Institute for Social Development (2016), a human-rights based approach (HRBA) is a conceptual framework based on international human rights standards and principles aimed at promoting and protecting human rights. Applied to LTC, a human-rights based approach is the implementation of LTC policies, programs and action plans using principles outlined in international human rights treaties, to uphold the rights of older people with care needs. The rights of older people are protected in a number of international and regional conventions (see Schulmann, Ilinca and Rodrigues, 2018 for a review), which collectively address not only the LTC needs of older people, but also their economic, social and cultural rights. In this vein, taking a HRBA to LTC extends beyond LTC systems simply providing services to care users, to an approach that ensures the autonomy, dignity, equality and self-fulfillment of older people. A HRBA to investment in LTC entails investing in infrastructure that will ultimately achieve these values and uphold the rights of older people by better matching the complex needs of users. This would include prioritizing investment in

home and community care options rather than institutional care and empowering older people to participate in the planning of LTC.

LTC systems primarily take the form of infrastructure that enables the provision of social services and support to those with care needs. Social infrastructure for LTC can include **tangible assets** – such as care facilities (providing residential or community-based services), protected and supported accommodation and housing, adjacent infrastructure to support mobile and home-based care– and **intangible assets** – such as data infrastructure, ICT and digital technologies; human resources; support programs for families and informal caregivers, research and development programs. We provide a more extensive overview of types and examples of infrastructure in LTC in **Table 1.**

Table 1: Infrastructure within LTC systems

Tangible	
Facilities dedicated to provision of formal LTC services	Residential care homes, nursing facilities, assisted living homes, daycare centers, meals-on-wheels
Assistive devices	Renovations in one's home (ramps, handles, etc.), mobility aids (crutches, wheelchairs), visual, auditory and memory aids, etc.
Technology	Medical equipment, electronic medical records, digital technologies (i.e. sensors, medication dispensers, artificial intelligence, robotics, etc.), community technologies (i.e. skype)
Intangible	
Formal services	Care services provided in one's home, cash benefits provided to individuals with care needs, health services for chronic diseases and age-related health issues
Support for informal care	Support programs for informal carers, respite services, trainings, etc.
Workforce	Homecare workers, nurses, care managers, etc.
Data infrastructure	LTC data collection systems, interoperability between systems
Other	Research and development programs, intellectual property

LTC diverges from other areas of social infrastructure in a number of key ways. First, a majority of LTC for older people is provided informally by either family or friends. Subsequently, a lot of LTC infrastructure is intangible and rather encompasses institutional structures and processes that support families in providing care for older people. This ranges from cash benefits either to care users or their informal carers, to programs that provide support and respite to informal carers. Similarly, many forms of LTC services are provided in one's home, eliminating the need for public tangible infrastructure, and instead taking the form of the care user's accommodation. LTC is also unique in that it intersects substantially with other social policy areas, such as health policy. As LTC encompasses health-oriented support needs, such as management of chronic diseases, some LTC services are provided by healthcare professionals in healthcare settings. In practice, LTC is fragmented across both systems, while in a minority of countries, the two areas are horizontally integrated or substitutes for each other (Spasova et al. 2018). Despite its close position to health, LTC remains severely underinvested and underserviced compared to health systems. Additionally, some forms of LTC are provided in alternative housing settings, such as in assisted living, raising the intersectionality of LTC and housing policy.

<b> Increasing gaps in service capacity, data and social infrastructure: What's missing?

First and foremost, the LTC sector is characterized by a severe lack of investment across countries. An estimate from the 2015 Report of the High-Level Task Force on investing in Social Infrastructure in Europe suggests that annual public investment in the EU-28 countries in health and LTC infrastructure amounted to 75 billion euros, or 0.5% of GDP (Fransen, Del Bufalo and Reviglio, 2018). As spending on health tends to be significantly higher than on LTC (OECD, 2021), more of this 75 billion likely pertains to health infrastructure. Instead, we rely on data on LTC expenditure on consumption, i.e. expenditure on services and cash benefits, to provide an approximate means of comparing variations in LTC infrastructure. In doing so, we recognize that this misses out on variations in different types of infrastructure spending (i.e. investment spending, accounting for depreciation in stocks and extending infrastructure) and private spending (i.e. care users and private for-profit organisations). Instead, relying on public expenditure highlights the direction of policymakers in terms of the development of LTC systems, which we argue is most relevant given commitments at the EU-level to improve care systems moving forward.

The variation in public spending on LTC across European countries is substantially larger than that in health, with the highest spenders concentrated in the Nordic and Continental countries, and conversely the lowest spenders concentrated in Eastern European and Southern countries (European Commission, DG EMPL, 2021). Ranging from 3.9% of GDP per year in the Netherlands, to 0.01% in Bulgaria (Ibid), this

variation in public expenditure points to the lag in development of LTC in some countries, although the reliability of such indicators is severely limited by lack of harmonization in definitions and data collection standards. Countries characterized by a lower level of spending (i.e. those in Southern and Eastern Europe) associate with a general lower level of LTC infrastructure and consequently less availability of services (Eurofound 2020a; Spasova et al, 2018). Although public expenditure on LTC has increased over the last 20 years across nearly all EU countries, projections suggest that total EU expenditure will need to increase from 1.6% of GDP in 2015 to 2.7% in 2070 to accommodate increased demand for LTC services brought on by population ageing (Spasova et al, 2018), with vast necessary increases in spending particularly in countries that are lagging behind (European Commission, 2021).

Data limitations are also reflected in the severe lack of data on tangible LTC infrastructure and physical facilities, apart from residential care. No cross-national comparative data exist concerning the number and type of care facilities outside of institutional care. Data on type of ownership of care facilities and their quality are even harder to come by. Instead, most LTC data consists of beneficiaries of care services. Similarly, investment and expenditure on LTC infrastructure by the private sector is difficult to gauge due to limited data, despite the fact that private care homes comprise a considerable share of the residential care market in many countries and have outpaced the growth of public sector care homes as the result of increasing marketization in care (Eurofound, 2017; Knight Frank, 2020; Ranci and Pavolini, 2015; Szebehely and Meagher, 2017). This lack of data not only prevents an understanding of the impact of investment on policy outcomes, but it also hinders informative decisions on where and how to invest in LTC infrastructure in the future.

The consequences of underinvestment in LTC systems, and particularly community-based infrastructure, are evident in the alarmingly high percentage of older adults reporting unmet care needs: across European countries, around half of adults 65+ living at home with atleast 1 ADL or IADL had unmet LTC needs (OECD, 2022), with most individuals forgoing care reporting financial constraints as the main barrier (49%) (Eurofound, 2020a). Older adults in countries where responsibility for LTC is primarily placed upon the family and formal services are limited, such as in Southern and Eastern Europe— most frequently reported unmet need, especially for higher levels of care dependency, compared to countries that have (relatively) well-developed LTC systems (Laferrère an Van den Bosch, 2015). Geographical disparities within countries are not captured in these averages, risking an under-evaluation of the impact of the investment gap in LTC infrastructure in rural areas. With projected increases in demand, aggressive investment will be needed to maintain and even expand care infrastructure to meet this demand and reduce unmet needs.

<b> Transitions away from residential care

Residential care, referring to living facilities where individuals, often with higher care needs, are provided assistance and support services on a daily basis, comprises a large portion of tangible LTC infrastructure and LTC expenditure. While societal preferences for care tend to be towards community-based care for moderate levels of needs, residential care tends to be a preferred option amongst those with severe care needs (Lehnert et al. 2018). In recent decades, deinstitutionalization efforts have underpinned reforms in LTC, and instead, investment in LTC has focused on expanding community-based care options. As a result, the number of beds in residential care facilities has decreased across many European countries, although cross-country variation in its availability remains (Spasova et al. 2018; OECD, 2021). Luxembourg and the Netherlands stand out as countries with the highest number of LTC bed per 1000 people aged 65 and over (81.6 and 74.0 respectively), compared to Greece with only 4.1 bed per every 1000 people (OECD, 2021). While some national data is available on the number of residential care homes by type of ownership in some countries, limited harmonization in data hinders comparability across countries. Recent figures suggest that an estimated 62,471 institutional homes (i.e. nursing homes, residential care homes and LTC facilities) existed across EU countries in 2016/2017, accumulating to over 3.4 million beds (Suetens et al. 2017).

<b> Development of LTC infrastructure in community-based care

In addressing care needs of older adults, LTC systems can provide cash benefits, which in many European countries account for a considerable part of the LTC budget, as well as formal LTC services. In community-based settings, LTC services generally take one of the following forms:

- Care services provided in the user's home, to aid with:
    - Personal care – addressing primarily Limitations with Activities of Daily Living (ADLs); i.e. bathing or showering, dressing, eating, getting in and out of bed or chairs, using the toilet, and walking around the home
    - Home maintenance – addressing primarily Limitations with Instrumental Activities of Daily Living (IADLs); – i.e. shopping, preparing and serving meals, managing medication, house cleaning and maintenance, managing money and bills
- Day centre or day care services – covering a wide variety of services ranging from rehabilitation, to physical and psychological support and social participation support – e.g. befriending, peer-to-peer

193 psychological support, physio and occupational therapy, arts and creative groups, sports activities,
194 cultural events
195 • Telecare and assistive technology services – e.g. mobility and sensory aids, to wearable devices and
196 home adaptations
197 • Services to support informal carers – e.g. respite care, psychological counselling, trainings.

198 In the push for supporting ageing at home, new forms of LTC services have emerged, blurring the
199 boundaries between community and residential care and forming new housing models. A case in point
200 are supported-living and protected housing arrangements, where individuals own a residence that is
201 designed to accommodate their growing care needs through time and where care services can be
202 provided on a continuous basis (Rogelj et al. 2023). Other examples include cohousing, which can consist
203 of either inter- or intra-generational living with shared common spaces, or villages developed and
204 governed by older residents and providing a range of social services are provided, including LTC
205 (Mahmood et al. 2022). While the vast majority of LTC services are directed at individuals with long-term
206 support needs deriving from functional or cognitive impairment, another key function of the system is to
207 provide support for informal or family caregivers, who still account for the most substantial part of LTC
208 provision across EU countries.

209 As a considerable amount of LTC is provided in the form of home-based care, LTC infrastructure can also
210 take the form of renovations or buying equipment to improve the living conditions of the person's home
211 and to better accommodate their care needs based on their functional capacities (Rogelj et al. 2023). This
212 consists of removing barriers, such as through the construction of ramps or removal of steps within one's
213 home, the use of shower handles or chairs, and so on. As an extension of this, LTC infrastructure can
214 encompass measures aimed to improve the quality and adequacy of housing for older people, such as
215 through public subsidies for rent and energy, or available funding for housing improvement (Cartagena
216 Farias et al. 2023). This is important given that one's environment has a strong influence on their health,
217 their well-being, their functionality/mobility and social interactions (Rowles and Bernard, 2013; Farias et
218 al. 2023).

219 Despite the significant role that community-based services play in the provision of LTC, data on tangible
220 infrastructure for these types of care remain limited, even from a national perspective. Most available
221 data on the use of community-based services is limited to the number of beneficiaries of these services
222 and focuses on home-care services (personal care and housework type of activities) and again, reveals
223 substantial variation from a cross-country perspective. In Portugal only 0.6% of older people (65+) use

formal LTC services in their own homes, while in Germany the share rises to 15.6% (32% of 80+ population) (OECD, 2021).

The severe fragmentation in responsibility and delivery of LTC across the national, regional and local level within countries has led to disparities in the access and adequacy of benefits and services (Spasova et al. 2018). Solutions can be found by optimizing the scale on which the services are organized, as part of efforts to deal with the general challenges of regional development. Both clustering (grouping together administrative units) and centralization have been noted as possible solutions. For instance, Finland has approached the uneven availability and quality of health and care services in different areas by providing government support to municipalities willing to cooperate between themselves in setting up a shared mechanism for administering and providing certain services (Tynkkynen et al, 2018). As an alternative to higher centralization, some European countries are emphasizing local community empowerment in order to improve service quality and acceptability. In the Netherlands, there has been an increase in residents' initiatives and village cooperatives in the more rural communities. When formal care started to withdraw from the more rural areas, inhabitants started to organize their own care, by taking the initiative to take over or establish community and residential care facilities, to stay and live in their own and trusted environment that reflect their needs and preferences (de Weger et al, 2020).

They also point to the need to expand formal LTC provision in the community, with a focus on reducing inequalities and ensuring more flexibility and responsiveness to local needs and community preferences. To provide flexible, tailored care and to support both early identification of increasing LTC needs and prevention, it is important to facilitate access to LTC early on and to strengthen links between LTC provision, rehabilitation and primary care providers. Investment in care infrastructure should take a life-course approach and target both individuals with a high level of dependency and those who need minimal support to maintain independence. Moreover, promoting the development of early care assistance could help to improve preventive capacity, thereby reducing or postponing the need for more intensive, and therefore more expensive, care (Eurofound, 2020a).

<b> The backbone of LTC services: the care workforce

The care workforce, defined as workers that provide direct, personal and relational care activities for pay to care recipients, are an essential intangible infrastructure in providing LTC services. These workers primarily consist of personal care workers and nurses that provide care in the recipient's home or in LTC institutions (apart from hospitals). Personal care workers' responsibilities include 1) providing assistance

with activities of daily living, 2) providing assistance with instrumental activities of daily living, 3) communication with care recipients and their families and 4) monitoring health care (OECD, 2020). Nurses are responsible for health care provision, health care monitoring, coordinating care and communicating with families (Ibid).

Comprised largely of middle-aged women and foreign-born workers, the LTC workforce in Europe has witnessed a sizeable increase over the last decade, from 4.7 million in 2009 to 6.3 million care workers in 2019 (3.2% of the entire EU workforce)(Eurofound, 2020b). Extreme regional variations persist across Europe, with the highest proportion of LTC workers to individuals 65+ in the Northern European countries where LTC services are extensive, while conversely, the Southern Mediterranean and Eastern European countries, where LTC services are underdeveloped, report the lowest levels. Within countries, substantial shortages of LTC staff exist in geographical areas that are remote and/or difficult to access (OECD, 2020).

Despite the importance of the LTC workforce in carrying out services for older people, the future sustainability of the workforce remains a challenge, as population ageing has exceeded the growth of the workforce supply. The ratio of LTC workers per 100 individuals aged 65 and over either stagnated or decreased in around two-thirds of OECD countries from 2011 to 2019 (OECD, 2021). Trends towards ageing populations and increasing longevity will continue to increase demand for care services, and subsequently additional care workforce. Barring productivity increases or that many countries' LTC workforce face chronic shortages, an additional 13.5 million care workers would be required by 2040 to maintain the current ratio of care workers (OECD, 2020). This figure is likely to be higher as the result of chronic shortages exacerbated by the Covid-19 pandemic (WHO, 2022b).

Precarious and unfavourable working conditions characterize the LTC sector, with low wages, non-standard working arrangements (i.e. part-time work, over-night, shift work), physically and mentally intensive work and adverse social behaviour (i.e. verbal abuse, physical abuse, threats, etc.) being common in the field (Martinez-Lacoba et al. 2021; Eurofound, 2020b). These precarious conditions have led to high staff turnover and low recruitment rates, also contributing to the chronic shortage of LTC workers across all countries in Europe threatening the sustainability of the LTC workforce to sufficiently meet the demand for services (Eurofound, 2020b). The undervaluing and insufficient support and protection provided to the LTC workforce were one of the key vulnerabilities of LTC systems in Europe, which left them unprepared and unable to respond in a timely and efficient fashion during the Covid-19 pandemic (WHO, 2020b). Closing these gaps and creating a sustainable care workforce that efficiently meets future demands for LTC services will require significant investment in three core areas: i) expanding

the size of the care workforce; ii) improving retention of care workers and iii) investing in developing the skill-mix of the care workforce.

One solution to expanding the care workforce has been to attract foreign workers, a strategy evident in the already high proportion of foreign workers working in LTC across EU countries. The intersection of LTC policy in terms of organization and financing in care, with employment and migration regimes has led to a number of models of migrant care (Simonazzi, 2009; Da Roit and Weicht, 2013). The provision of unconditional cash benefits in particularly have contributed to developing an informal market across some European countries where families buy cheap and flexible migrant labour (Martinez-Lacoba et al. 2021). In 2019, 7.9% of the LTC workforce in Europe were foreign workers (DG EMPL and SPC, 2021), 4.5% of which were born outside the EU and 3.4% within, although this number is likely underestimated as live-in carers, who are nearly entirely foreign-born, are not included. Research on foreign LTC workers has highlighted a gap in working conditions and wages in relation to native workers, suggesting they may face a more precarious position in LTC work (Simmons et al, 2022; Doyle and Timonen, 2009).

In a number of European countries (Austria, Cyprus, Germany, Greece, Spain, Italy and Malta), 24-hour live-in care has gained traction, where the LTC worker lives in the care recipient's home providing care around the clock, either full-time or in alternating rotations with another care worker. This "migrant-in-the-family" model has developed in part due to unrestricted cash-for-care programmes and development of underground care markets (Da Roit and Weicht, 2013; Martinez-Lacoba et al. 2021). While this solution provides a low-cost option for individuals with high and complex care needs who wish to remain in their home with limited alternative options, it is not without issues. Motivated by significant wage differentials and employment opportunities between the host and home country, live-in care is often characterized by unregulated and poor working conditions in tandem with a lack of enforceable labour rights, and consequently a compromise in quality of care (Eurofound 2020b; Aulenbacher et al. 2020). Furthermore, the recruitment of foreign workers and live-in carers contributes to the global issue of care drain and perpetuates global care chains, whereby women migrate to more developed countries to perform care work, often leaving a gap in care in their home countries where LTC services are underdeveloped or non-existent (Bauer and Österle, 2016; Lutz, 2018; DG EMPL and SPC, 2021). If foreign workers are to be a feasible solution to filling labour shortages, investment will be needed in regulating and regularizing live-in care, enforcing the labour rights of these workers, as well as improving the general working conditions of foreign care workers. Austria presents as one example where 24-hour care work was regularized (Österle and Bauer, 2016), and although not without its own issues, particularly surrounding the role of

intermediary agencies (Aulenbacher et al. 2020), regularization of 24-hour care has afforded these live-in cares some form of social protection (Österle and Bauer, 2016).

Significant investment will be required to expand the care workforce, namely through addressing working conditions (i.e. improving wages, career-development options, etc.), improving the attractiveness of the sector, as well as investing in the recruitment process itself and providing financial support/grants for LTC training (DG EMPL & SPC, 2021; Eurofound, 2020b; OECD, 2020). The demographic ageing of the LTC workforce will also require focusing on recruiting a more diverse workforce aside from the typical LTC worker profile (i.e. recruiting younger individuals/students and men) by improving career development prospects and tackling gender stereotypes (Eurofound, 2020b; OECD, 2020). Substantial investment will be needed to stabilize the LTC workforce by improving the retention of workers. Many of the aforementioned measures needed to improve recruitment will also be relevant for improving retention of care workers: improved working conditions, increased wages, more career development opportunities and improved perception and valuation of care work (OECD, 2020; Eurofound, 2020b; DG EMPL and SPC 2021). Finally, enhancing the productivity of the workforce through reskilling and upskilling so that LTC workers can provide care for more people without comprising on the quality of care, will also be key in creating an efficient and sustainable solution to the care workforce problem.

<b> Infrastructure to support informal caregivers

The economic value of informal care in European countries (2.4-2.9% of GDP) has been estimated to surpass total expenditure on formal care services by a considerable amount (European Commission, 2021). The tasks they carry out are often the same as those performed by formal carers, yet informal carers are typically unpaid and their work is unrecognized as a result. Spiritual and emotional support, as well as responsibility for making decisions, handling administrative processes and coordinating the person's care are also often part of an informal carer's role (Burch et al. 2019). There is clear evidence that people who provide large amounts of informal care experience negative impacts in terms of wellbeing, health and income (Brimblecombe et al, 2018 and Korfhage, 2019). The COVID-19 pandemic has exacerbated the challenges faced by informal carers, with additional financial and health challenges, and in most countries very little support and guidance. The limited measures adopted to support informal carers through the pandemic reflect, not only a lack of awareness of the role and needs of informal carers, but also a lack of infrastructure to identify and reach informal carers and monitor their situation (Eurocarers/IRCCS-INRCA, 2021; Lorenz-Dant and Comas-Herrera, 2021). In fact, most countries in Europe do not have processes to identify informal carers and their needs (Courtin et al, 2014).

Half of all informal carers in the EU are aged 65 or over and, on average, women provide care more often and for longer hours than men (European Commission, 2021). While most informal carers of working age combine care provision with paid work, the employment rates of carers decrease with the intensity of care provided. There is evidence that, in countries with public care systems that are more generous in terms of formal services provision, fewer family carers need to provide high-intensity support (Verbakel et al., 2017; Bom et al., 2019). It is also important to note that unpaid carers are more likely to be women who are not economically active and have lower levels of education (Spain by Zueras et al., 2018), indicating a selection effect, which, combined with the potential negative health and financial impacts of providing care, may exacerbate existing inequalities (Spijker et al., 2020)

There is great diversity in both the characteristics of carers and their needs, therefore support for informal caregivers can take many different forms. Brimblecombe et al (2018) distinguish between indirect support (services for the care-recipient), direct support (such as psychological therapies), work conditions and combinations of these. A complementary classification of informal carer support mechanisms was proposed by Wieczorek and colleagues (2021), differentiating between measures focused on compensation and recognition of informal care (e.g. cash benefits and carer's allowance), labour market policies and regulations (i.e. care leave, care leave benefits and flexible work arrangements) and measures to improving carers' physical and mental wellbeing (e.g. respite care, counselling and training services).

Indirect support services typically involve substitute or complementary formal care, which may be regular (for example day care, home, care, personal assistance), or sporadic (respite care). These services benefit informal carers through being protected from the negative consequences of providing large amounts of informal care and having the opportunity to rest, maintain their professional and social activities and look after their own health (van den Broek and Grundy, 2018). Services that are directly provided to carers include education and training on providing care and care for oneself, psychological therapy and support groups (in-person or remote/online). Despite successful demonstration projects, in most European countries the capacity to offer direct support to carers is very limited and considerably undersized with respect to estimated demand (Spasova et al., 2018) and the majority of informal carers in Europe do not receive any themselves (European Commission, 2021). Finally, Burch et al (2019) and Spann et al (2019) highlight the numerous ways in which workplace policies can support informal carers, ranging from flexible work arrangements and work schedule control, to organizational and employer support, including line manager training, to a supportive work culture and accessible information on entitlement and availability of support and benefits. There is growing policy attention to measures linked to work

conditions. For example, the EU Directive on work-life balance for parents and carers[2] adopted in 2019 requires Member States to ensure carer's leave of at least five working days per year and enshrines the right of informal carers to flexible working arrangements.

Considering the sizeable economic and societal contribution of informal caregivers, it is very easy to make the business case for increasing investment in social infrastructure in support of informal caregivers. Estimates based on 2016/2017 data suggest that informal caregiving in European is equivalent to 3.6% of GDP, or 576 billion euros (Peña-Longobardo and Oliva-Moreno, 2021). Even abstracting from the clear preference expressed by most for informally provided care, it is unthinkable under current cost containment pressures that informal caregiving can be replaced by formal services. It is therefore all the more urgent to invest in developing and adequately resource the necessary support programs in order to facilitate families to keep providing needed care and ensure sustainability of care systems.

It is also important to consider the long-term fiscal implications of high reliance on informal care. The negative impact of providing care on employment can persist even after the caring spell has ended, resulting in lower lifetime earnings and pension entitlements for informal carers, which also have fiscal implications due to reduced social insurance contributions (Korfhage, 2019). Zigante (2018) argues that policies that recognize informal carer's needs as early as possible, formalizing their care provision through training, legal rights and social security and ensuring they have access to supportive services is key to ensure the sustainability of informal care provision. Such findings underline the urgency to invest in development of social infrastructure to support informal caregivers, throughout Europe and particularly in those member states where reliance on informal carers is very high while support systems remain underdeveloped (Spasova et al, 2018).

Political awareness of the importance of supporting carers is also growing throughout Europe and some countries have already begun to lay the foundations of carer-friendly societies (Eurocarers, 2020). In September 2022, the European Council adopted a Recommendation pressing member states to "establish clear procedures to identify and support informal carers", enjoining them to facilitate carers' cooperation with LTC workers, ensure they have access to training, counselling, healthcare, psychological support and respite care, work-life balance measures, as well as social protection and adequate financial support

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

(European Council, 2022). Efforts to which member states commit on this aspect will be backed by the European Commission with the tools at its disposal (monitoring, awareness raising campaigns, mutual learning programme, funding programmes, etc) as announced in the European Care Strategy adopted by the European Commission in 2022.

<b> Strengthening information systems and data infrastructure for LTC

Planning, monitoring and evaluation of LTC services are crucial mechanisms for developing a strong evidence base that can support informed policy decisions. Appropriate quality projections based on data are essential for policy-makers as they consider alternative courses of action and reform plans, but the analyses can only be reliable as long as the available data on which they are based are both sound and comparable. In order to ensure LTC service quality and capacity, care policies should be informed by a thorough and dynamic understanding of population needs, system dynamics and community strengths and weaknesses. Slow and inadequate responses in LTC settings during the Covid-19 pandemic have revealed the enormous gaps in information systems and data infrastructure for LTC throughout Europe, which predated the pandemic and have been highlighted more generally through this chapter. Strong information systems, including capacity for data capture, surveillance and monitoring, are not only a basic

requirement for a coordinated response to public health crises, but they are also essential for the efficient management of scarce resources and the sustainability of care systems.

<c> The weak basis of hard data: Low data comparability as a barrier to informed decision-making

The weak basis of available data and the difficulties it raises for LTC policy-making can be exemplified by a study of three high LTC spending Northern European countries (Denmark, Sweden and the Netherlands) commissioned by the Dutch Parliament (Pomp, Zonneveld and Nies, 2020). The study aimed to identify useful elements from Scandinavian LTC policies that could inform LTC interventions in the Dutch context. At first sight, the data from comparative OECD and EU databases revealed significant differences between Denmark, Sweden and the Netherlands. As a second step, data from multiple sources (EU, OECD and national data, reports and expert interviews) were analysed, to substantiate hypotheses and to explain the apparent differences in LTC spending between these three countries. User manuals and metadata for comparative datasets were analysed and the data were compared with existing national and, where applicable, local data sources. Where significant underreporting in LTC spending appeared to be the case, other sources were consulted to validate the differences. Hypotheses for differences or data gaps were discussed with national experts. The analyses demonstrated that the health care component of the OECD LTC data is to some extent comparable across these countries. The social care component within the LTC data, however, are more ambiguous – and in a number of cases lacking. Expenditure was underreported by more than 1% of GNP, whereas the health-related expenditures add up to 2.3 to 2.7 of GNP. This emphasizes that data for LTC as presented in international databases are at best incomplete and at worst, misleading. In particular social care data within LTC are often incomplete or unavailable, and therefore appear to be a weak basis for comparisons between countries. Although the three countries chosen for comparison in the study are recognized as front-runners in health and social care information systems in Europe, the reliability of available data remains a significant concern.

Monitoring and quality assurance mechanisms in the LTC sector vary widely between countries in Europe, but by and large, the lack of a regular and detailed stream of data limits quality assurance measures to the setting of minimum requirements for inputs and structure-oriented indicators (Ces and Coster, 2019). Process or outcome indicators, where they exist, suffer from patchy and unsystematic data collection, which makes it difficult to reflect on and intervene to improve the quality of care services and satisfaction with care. Furthermore, information systems in LTC are often developed separately from existing health information systems and have low inter-operability. The inability to link data between sectoral databases and to exchange information swiftly among care providers in the health and social sector fragments care, duplicates costs and negatively impacts the experience of care. A front-runner in this regard is Denmark, which stands out for its highly developed information exchange platform (Danish Health Care Data Network) that pools personal and clinical data from laboratories, pharmacies, GPs, municipal, regional and national authorities (WHO, 2019). In addition, Danish authorities regularly monitor user satisfaction

with care providers and services as part of the national quality assurance mechanism for LTC and collect data on experiences of care transitions on a yearly basis - asking care users to rate the level of collaboration between the hospital units and locally provided home and nursing care services (WHO, 2019). An orientation of quality mechanisms towards care outcomes, supported by strong investment in data collection infrastructure and highly developed IT platforms for information exchange, contribute to improving the experience and continuity of care in Denmark.

The low availability and reliability of data on LTC needs and key system performance measures remain a significant challenge across Europe, although progress is being made in some countries. There is a pressing need to increase investment in LTC data infrastructure at local, regional and national level, as well as to improve international coordination and efforts to harmonize data collection and reporting. In order to design and implement better care services, to plan for an uncertain future and to respond successfully to public health emergencies, policy-makers need timely, reliable and quality economic and financial projections. This will crucially depend on the ability of countries to strengthen data infrastructure in LTC and to successfully link it with available health information systems.

<b> Coordinated action and local empowerment: a pathway to sustainable LTC development

Throughout this chapter, we have summarized the evidence for marked gaps in social infrastructure for LTC throughout Europe. While different countries find themselves at different points in LTC system development, under-investment in tangible and intangible care infrastructure remains a common challenge. Current care service capacity is insufficient to meet the needs of the older population and it will be impossible to respond to growing care needs in the future unless investment in the sector is stepped-up significantly. The investment in LTC infrastructure needed to address these shortages has been estimated at 50 billion Euros per year across EU countries and urgency to commit these resources has only grown in the aftermath of the Covid-19 pandemic. The areas most in need of increased and sustained investment are: i) strengthening provision of community-based care with a focus on addressing geographic and socio-economic inequalities in access; ii) investing in training, supporting and stabilizing the LTC workforce; iii) enhancing support for informal caregiving and iv) developing data infrastructure for LTC.

Addressing these gaps moving forward will require not only the elaboration of a coordinated national agenda for social infrastructure development at European and national level, but also the empowerment

and engagement of local communities and local governments. Strengthening local agency in social infrastructure development for LTC will require the development of a flexible and supportive governance network, but will ensure resources are invested in projects that reflect community goals and build on their capacities.

European experiences over the last decades have proved that LTC systems do not lend themselves well to “one-size fits all” policy and development approaches. Rather than working against the decentralized governance structures prevalent in LTC in Europe, we propose a social infrastructure investment agenda that supports the development of “best fit for purpose” solutions in each local context (Ilinca et al, 2021). Care users, their families, communities and local actors are best positioned to identify optimal social infrastructure investment opportunities, and their support for such initiatives is key to their success. At the same time, the support of national and international bodies is essential to finance, support implementation, develop scale-up plans and ensure sustainability of social infrastructure for LTC. A social innovation agenda for the future of LTC in Europe must be built on a partnership model between local communities and national and supra-national bodies and should start with investment in enabling such partnerships to form.

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