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Caring Societies: The Future of Long-Term Care[1]

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Abstract

This discussion paper starts with a portrayal of key challenges connected to changes in the demand and supply of long-term care (LTC). In particular, we highlight changes in the quantity and quality of care needs, shortages in the LTC workforce as well as unfavourable working conditions in the sector, and challenges associated with informal caregiving. Subsequently, we summarise and discuss how policymakers have responded to these developments over the past few decades. We focus on developments in the funding of LTC, attempts to attract more workers to the sector, the diffusion of person-centred and integrated care approaches, the implementation of support for informal carers, and the hopes associated with digital technologies.

Against the backdrop of the normative concept of "the caring society", we advocate further efforts to develop integrated LTC systems that offer more equitable access to services and ensure the quality of life of both persons in need of care and their formal and informal carers over the life course.

1 This discussion paper was prepared for the Invitational Conference "The Future of Social Welfare Policy and Research" on the occasion of the 50th Anniversary of the European Centre. It focuses on one of the key areas of research and policy consultancy of the European Centre, aiming to highlight its achievements and discuss the way forward in future research strategies. We would like to thank Emma Dowling and Henk Nies as well as other participants at the Conference for their useful comments and suggestions. The authors would also like to thank Daria Jadric for proofreading and Anna Obernberger for the layout.

1 Introduction

In some form, receiving and giving care plays an essential role for almost everybody over the life course, and for the functioning of society as a whole. Caring, therefore, is one of the key factors for the (re-)production of the social fabric. However, its role for both the well-being of individuals and the thriving of societies they live in often remains unrecognised, unseen and undervalued. Care work makes up the largest part of non-paid work and entails care for children, persons with disabilities, persons with severe illness, and older adults with care needs. In this paper, we focus on long-term care (LTC) for older persons, although similar issues apply to all groups of persons with care needs and their carers.

The World Health Organization (WHO) defines LTC as care that is "provided over extended periods of time" either by informal carers, such as family members and friends, or professional carers. LTC encompasses "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) to maintain a level of functional ability consistent with their basic rights and human dignity" (WHO, 2022). Even if over 80% of care work globally is unpaid informal care (ILO, 2018), there is a general tendency toward the expansion of professional LTC services. This trend is driven by various factors, including the need to ensure high-quality care, reduce caregiving responsibilities of families, and facilitate the labour market participation of family members with care obligations. LTC has thus developed into one of the fastest-growing economic sectors and a distinct policy field over the past decades Addati et al., 2022; Leichsenring et al., 2013).

With the onset of the COVID-19 pandemic, care work became more visible and revealed that care is often performed by people who lack economic, social and political power (Leichsenring et al., 2023; Schilliger et al., 2022; Dowling, 2021). While care work remains undervalued, projections are that care needs will further increase (European Commission, 2024), resulting in a high demand for labour force, care services and funding. Care needs can also come with a huge financial and organisational burden on persons in need of care and their families, and significant inequalities in access to quality care continue to exist. In short, many societies are in the midst of a "care crisis" (Dowling, 2021) and are not fully aware of it due to the poly-crises with which they are confronted globally. The context of demographic change, global migration, digital transformation and climate change, therefore, must be kept in mind when we portray and discuss selected challenges and trends in LTC.

In this discussion paper, we portray key challenges in LTC and highlight solutions that have been promoted by research, policy and practice to counteract them. Our discussion of major trends in LTC is informed by the concept of the "caring society." The "caring society" has been described as a normative ideal in which care constitutes the fundamental principle for the political, economic and social organisation of society (Knobloch et al., 2022). More specifically, Knobloch and colleagues (2022) suggested that "caring societies" consist of three pillars: caring policies, a caring economy, and caring commons. Caring policies enable a just distribution of care work between the state, the third sector, the family, and the market, but also among different social groups, such as along

the lines of gender, ethnicity or socioeconomic status. They also foster the valuation of care work and shape the future-oriented organisation and delivery of care at the macro (systemic), meso (organisational) and micro (individual) levels. A caring economy places "care provision at the centre of economic thinking and aligns economic activity in all sectors with caring for others, but also for oneself, without neglecting the ecological context of providing for others" (Knobloch et al., 2022: 298; own translation). Finally, caring commons refer to care that is provided based on self-organisation and the creation of collective care infrastructures. Knobloch et al. (2022) argue that these structures may have transformative potential because they are an expression of fundamentally different perspectives on how care can be organised in a mixed economy of welfare that includes but also extends beyond the state, the market, the family or the non-profit sector.

In our understanding, the state and the expansion of public infrastructures play a crucial role in enabling a caring society, as the responsibility for creating such a society cannot be delegated to communities, even if they significantly contribute to its realisation (van der Knaap et al., 2019). Furthermore, while in a caring society everybody should receive the care they need such a society would also acknowledge and foster people's care-giving capacities. In the context of LTC, for example, this includes to recognise that also people who receive care may contribute to caring for others and are not "just" in need of care. Furthermore, we think that constituencies should be centrally involved in further defining and specifying what a caring society is and how it could look like.

The paper is structured as follows: Section 2 outlines challenges in the demand and supply of LTC. Section 3 portrays trends in policies and research that have been promoted and implemented to address these challenges. Finally, section 4 delineates the opportunities of working towards a "caring society" in the context of rising longevity.

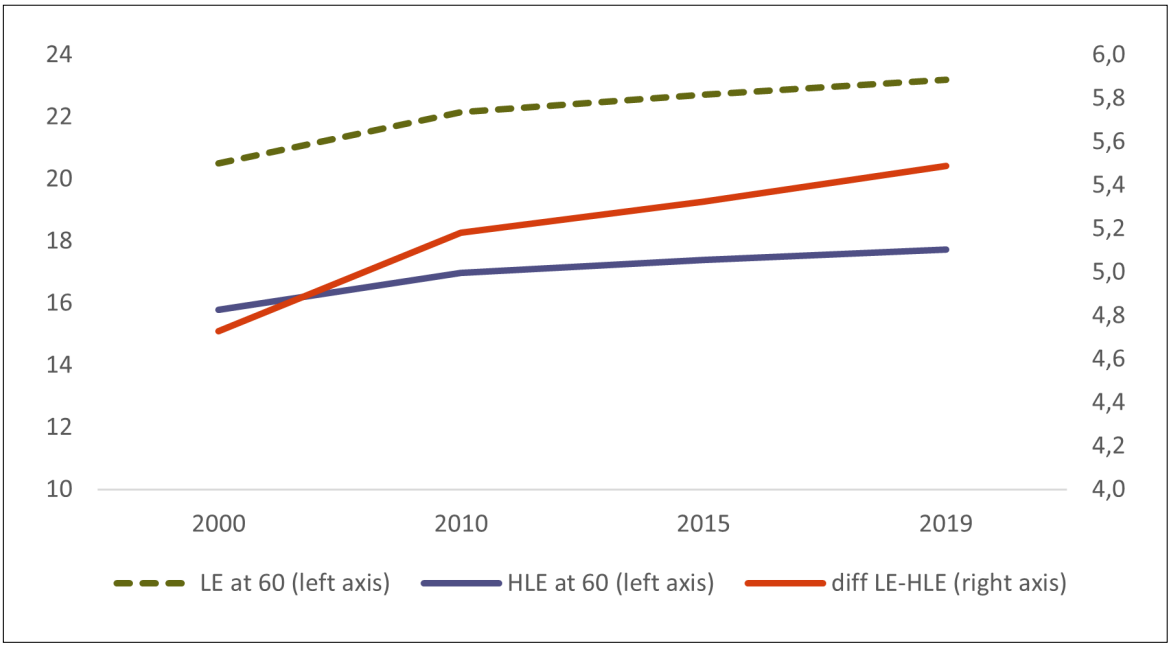
These reflections are based on a long track record of the European Centre's research and policy consultancy related to the developments of long-term care systems in the UNECE region. For the past 50 years, the European Centre's activities in this area have covered a wide range of dimensions from governance and financing, quality assurance and quality management, working conditions and employment in the care sector to social innovation, pilot projects and needs assessment. The European Centre also contributed to theoretical and conceptual debates on identifying LTC as a social risk (Evers & Novotny, 1987), to integrated LTC (Billings & Leichsenring, 2005; Leichsenring et al., 2013), care regimes, cultures of care (Nies & Leichsenring, 2018) and the welfare mix in LTC (Evers & Svetlik, 1993). This will be reflected in this discussion paper by referring to relevant European Centre publications and projects, respectively (we apologise for the lengthy self-referential list).

2 Challenges in demand and supply of long-term care

2.1 Changes in long-term care needs

Advances in medicine and health care have led to and will continue to contribute to rising longevity for a growing share of the population. This, however, will also lead to people living more years with more complex care needs, such as those resulting from multimorbidity and dementia. Indeed, Europe's mortality profile shows a historical progression from acute and communicable diseases to chronic and degenerative diseases: as of 2022, over half of deaths in the EU were attributable to cardiovascular diseases (32%) and cancers (23%), with accidents and infectious diseases (excluding COVID-19 cases after 2020) accounting for just under 5%. A notable consequence of this transition is the rising morbidity in older age. Available data suggests that life expectancy in good health, known as healthy life expectancy, is increasing at a slower pace compared to overall life expectancy (Figure 1).

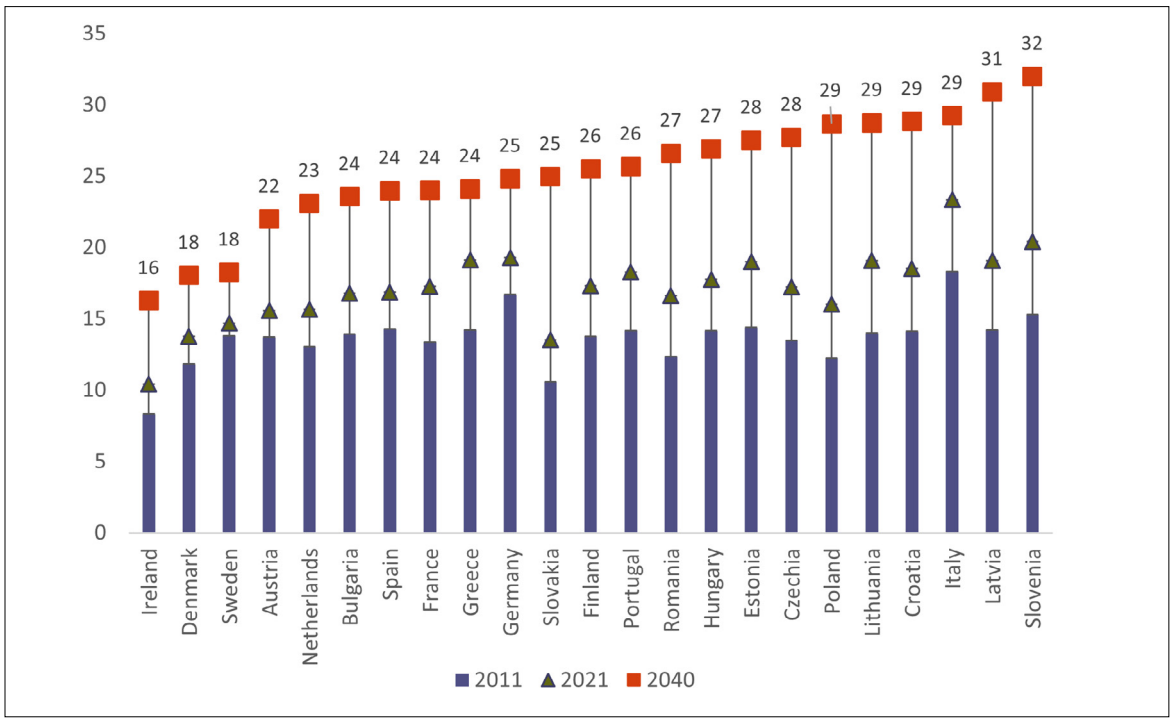
Figure 1: Evolution of life expectancy and healthy life expectancy at 60 (EU27), 2000-2019



Source: WHO, authors' own calculations. Notes: LE = life expectancy, HLE = healthy life expectancy.

With rising life expectancy and the prevalence of chronic diseases, multimorbidity becomes more common (Barnett et al., 2012), and care needs become more complex. Certain condition clusters, especially those involving mental health conditions, have been associated with more severe functional limitations (Tang et al., 2020). Indeed, dementia stands out as a separate spectrum of diseases and one of the greatest health and social care challenges linked to population ageing, underlining the rise and change of LTC needs. Throughout Europe, fatalities linked to dementia have been on the rise, with Alzheimer's disease alone representing over 60% of all cases. Countries with a larger proportion of older people, such as Italy, Germany, and Greece, show the highest dementia prevalence rates. Looking forward to 2040, dementia prevalence is expected to sharply increase across Europe (Figure 2).

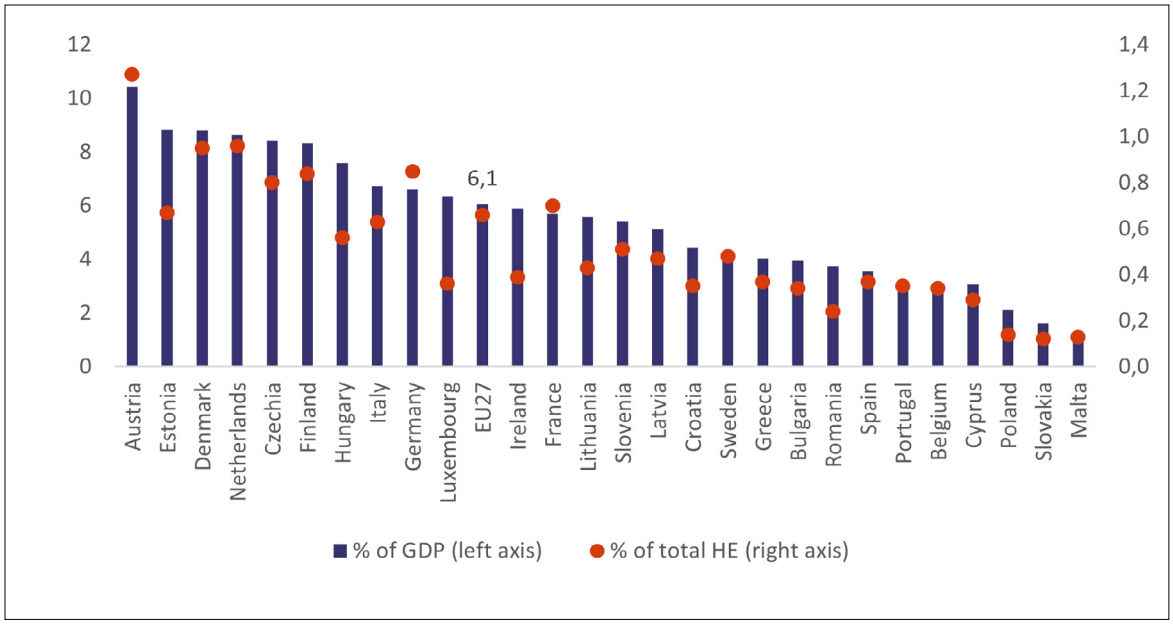
Figure 2: Dementia prevalence (per 1,000 population), 2011, 2021 and projections for 2040



Source: OECD, 2023a.

It can thus be concluded that there will be a further increase of care needs in quantitative terms and a change of LTC needs in qualitative terms with great variability in conditions, severity, and impact on the lives of those in need of care and their carers.

Figure 3: Expenditure on preventive care (% of GDP and % of total health expenditure), 2021



Source: Eurostat, System of Health Accounts.

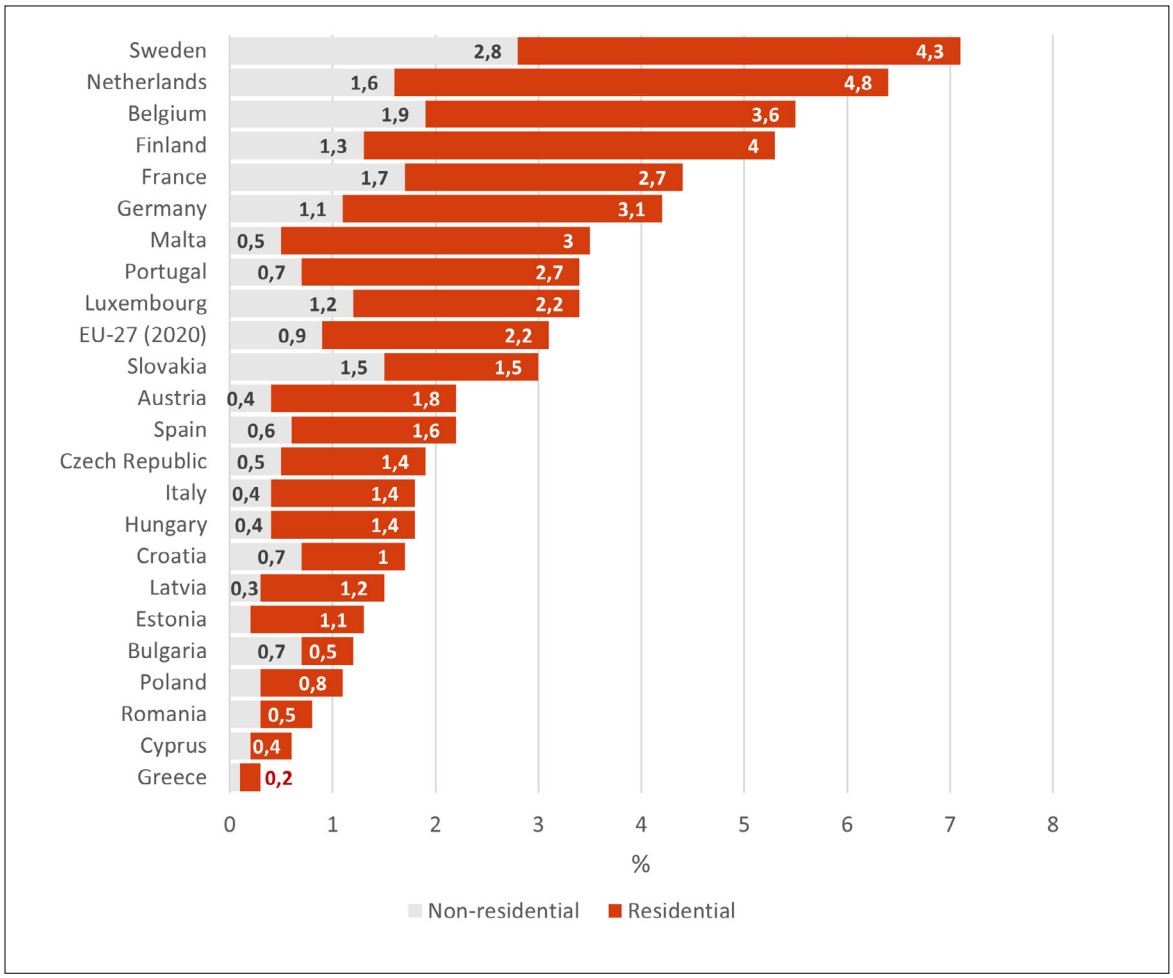
Despite the crucial links between LTC and preventive care, the two sectors are often addressed separately, undermining the potential for establishing more efficient and integrated healthcare systems. LTC should not be viewed in isolation but rather as part of the broader healthcare continuum. This would promote early medical intervention, continuity of care, better resource allocation, and more effective strategies for managing chronic diseases, ultimately leading to better health outcomes and reduced pressure on long-term care services.

Currently, the investment in preventive care within the EU27 remains critically low, with only 0.7% of GDP or 6% of total health expenditure allocated to prevention in 2021 (Figure 3). A more balanced approach – where preventive care and LTC receive adequate funding – would contribute to a more cost-effective and sustainable healthcare system capable of addressing the complexities of ageing populations.

2.2 Labour force shortages and poor working conditions in long-term care

To meet the increasing demand for LTC, an expansion of formal services and the labour force is crucial. Rising health and LTC needs have already triggered a steady growth in the supply of services and facilities in Europe, however, with differing trends in the various countries. The expansion of the formal LTC workforce can be used as an indicator of these significant cross-country differences. The LTC workforce grew from 4.7 million workers in 2009 to 6.3 million in 2020 (Eurofound, 2020), accounting for more than 3% of the entire EU-27 workforce. However, the proportion of formal workers in LTC is 7.1% of the total labour force in Sweden, while it amounts to 0.3% in Greece. Figure 4 informs about the situation in EU Member States and shows that in almost all countries, the majority of the LTC workforce is working in residential care settings (e.g., care homes).

Figure 4: LTC workers as a share of the total workforce by EU Member States, 2019



Source: Eurofound, 2020 (authors' calculations based on the LFS).

The huge differences among EU countries cannot be attributed to differences in care needs alone. Instead, they are most likely associated with differences in the labour market, cultural traditions and patterns in the provision of LTC, including the distribution between formal and informal care (Grages & Pfau-Effinger, 2022). Consequently, countries with a smaller formal workforce may experience higher unmet needs, private expenditures and indirect costs due to a higher share of informal care or undeclared labour in the sector.

Trends suggest that the development of the LTC workforce will likely continue its upward trajectory in the medium and long term in all countries. At the same time, staff shortages are already reported in many EU countries today. The list of challenges to be addressed in terms of working conditions, training, recruitment and retention of the LTC workforce is long and can be synthesized as follows:

- With 42%, part-time work is more common in LTC than among employees in general (19%). This is also because over 80% of workers in LTC are women. However, part-time work in LTC is often not voluntary and one reason why wages in LTC are often well below the national average (Eurofound, 2020).

- LTC workers tend to be older than the average workforce, with implications both for adapting workplaces to older workers' needs and for age management in general (Eurofound, 2020).
- Migrants play a bigger role in LTC than in the healthcare workforce. In particular, migrant live-in carers provide a large share of LTC in some countries, such as Austria and Germany, but often have little or no training and receive very low wages. In most countries, live-in care is not regulated (Leichsenring et al., 2022). In Southern European countries like Italy, Spain and Greece unregulated migrant labour is prevalent in the domestic live-in care subsector. A significant portion of this work remains undeclared and unprotected, exposing workers to precarious conditions and limited social protection (Eurofound, 2020).
- LTC workers often face shift work, requests to work at short notice, physically demanding work (e.g., lifting individuals), work hazards (e.g., exposure to biological agents causing infections), and may experience adverse social behaviour of care users (Eurofound, 2020).
- While almost three out of four LTC workers (71%) report that they have the feeling of doing useful work due to these demanding working conditions, about one-third report that they do not think to be able to continue their work until they reach the age of 60 (Bauer et al., 2017).
- In contrast to other sectors, LTC workers more often receive training that is paid for by their employer. However, they also express a stronger need for additional further training (Eurofound, 2020).

Changes in LTC needs will further contribute to the challenges in LTC work environments and reveal limitations such as general scarcity of resources, lack of management and leadership, inefficient organisation of work, lack of time for psychosocial care, and shortcomings related to role clarity, adequate training (e.g., for person-centred care) and professional development (Berta et al., 2022). It, therefore, comes as no surprise that the LTC sector has a negative image, with healthcare being perceived as a more attractive work environment in comparison. Improving working conditions in LTC is therefore crucial as imminent staff shortages already have detrimental effects on professional carers and negatively affect their capacity to provide high-quality care (Bauer et al., 2017).

2.3 The challenges of informal caregiving

Discussing developments in LTC also needs to consider the largest group of care providers, namely unpaid informal carers (also referred to as family carers).[1] Informal care is a key characteristic of LTC, as it is assumed that globally, at least about 80% of care is provided by this group (ILO, 2018). Other research found that about 34% of the population across selected European countries are providing care informally, again with significant differences across countries (Verbakel, 2018).

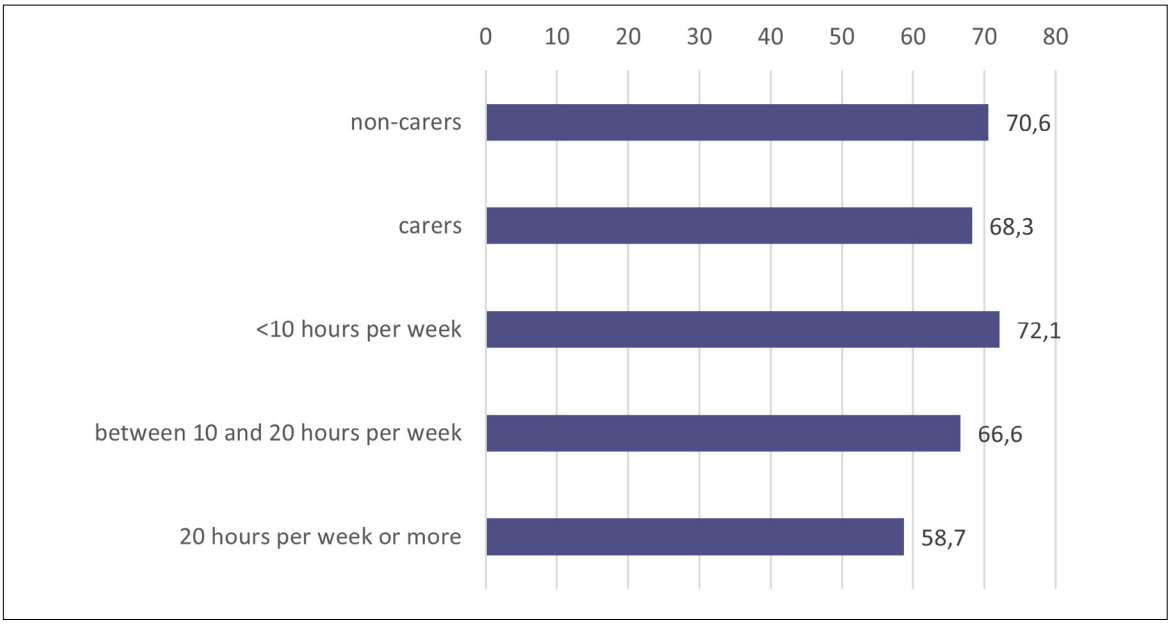
Important variation can also be observed in how much time informal carers spend to support and care for an older person and the physical and emotional burden this implies. While in some countries,

1 While we generally use to conceive informal carers as part of the LTC workforce we focus on informal carers in this section to acknowledge and highlight their specific needs and challenges.

informal caregiving is more prevalent in the population overall, in others it tends to be more time-intensive: informal care is more frequent in Nordic countries, but high-intensity informal caregiving is more frequent in Southern, Anglo-Saxon and Eastern countries (Verbakel, 2018). This demonstrates that in countries with generous formal LTC systems, more people engage in less intensive informal caregiving, whereas in countries with less generous LTC systems, fewer individuals provide more intensive support and hands-on care.

Many informal carers provide care because they choose to do so and because they want to provide care. Where informal carers are forced to provide care or provide very time-intensive or emotionally challenging care, informal caregiving can become a challenging experience. It is likely that particularly in those countries where there are more significant barriers to accessing professional services (e.g. in terms of availability, adequacy, accessibility, affordability), informal carers will find it difficult to stop providing care, even if they would want to reduce their involvement or are not able to sustain it over longer periods of time. An interesting finding is that providing low-intensity care – defined as 10 hours per week or less – may actually improve health and other outcomes for some groups of caregivers. However, this positive effect tends to reverse as the intensity of care increases, suggesting that the level of caregiving intensity is a crucial factor in the challenges informal carers face (Figure 5).

Figure 5: Share of persons self-reporting excellent/very good health status by carer status, EU-26, 2019



Source: authors' calculations based on EHIS microdata, wave 3 (2019)

Informal care provision becomes problematic when it reduces informal carers' life chances, has negative effects on their well-being and remains without social and economic acknowledgement. The current organisation of informal care tends to adversely affect the health of caregivers, in particular, if they provide intensive informal care (Bom et al., 2019). Moreover, it often has a negative impact on their financial situation (Lee et al., 2014) and their social connectedness, as informal caregiving is associated with higher levels of loneliness (Hajek et al., 2021). Against the backdrop that informal care

is more often provided by women (Ophir & Polos, 2022) and people of lower socioeconomic status (Quashie et al., 2021), the present distribution of informal care contributes to (re-)producing social inequalities.

A further group that warrants attention and protection are children, youth and young adults who provide informal care, so-called young carers (Kadi et al., 2023). Although here, too, there are significant differences between countries and particular age groups, it has been estimated, for example, that in England, 22% of 11 to 15-year-olds live together with a person with LTC needs, and 10% provide a high to very high degree of informal care (Joseph et al., 2019).

3 International trends in policy responses and solutions

The previous sections highlighted current developments and challenges in the demand and supply of LTC. Over the past few decades, there has been a general trend towards acknowledging the need for LTC as a social risk and a distinct policy field that calls for special attention. This has also been reflected in increasing research on LTC, for instance, on the definition and assessment of needs, the way in which LTC services are delivered and funded, and how care in the community – as opposed to care in institutions – can be promoted. The broader recognition of LTC can also be identified in the discourse on the societal impact of population ageing. While the concepts of Active Ageing (Walker & Maltby, 2012; Naegele, 2021) and Healthy Ageing have for a long time focused on the extension of the working life and preventative approaches based on individual lifestyle change ("successful ageing"), there is now decisively greater emphasis on addressing LTC and related societal challenges, including research on inequities and ageism (Sinyavskaya, 2024; WHO, 2020; Ayalon & Tesch-Römer, 2018).

In the following section, we summarise and assess international trends in how policymakers, researchers and practitioners in the UNECE region have responded to the challenges addressed above. Thereby, we highlight four developments:

- To address the increase in LTC needs, some countries have expanded funding and started to address the workforce shortage in the sector. Policies across the UNECE region are also marked by the rhetoric of "ageing in place," i.e. to enable older persons' care at home as long as possible. Active and healthy ageing is promoted to prevent or postpone the onset of LTC needs (Foster & Walker, 2021; Walker, 2019). These trends and strategies, however, are implemented with huge variations and differences in governance (Leichsenring et al., 2013; Kröger, 2024).
- In further developing LTC systems and responding to changing LTC needs, international research and practice has focused on the implementation of person-centred care that is underpinned by coordination and integration of LTC with the healthcare and social protection system (Leichsenring et al., 2013; WHO Europe, 2022; OECD, 2023b).
- As LTC is largely provided by informal carers, LTC policy has gradually started to also acknowledge and address the needs of informal carers. In various countries – although to different extents

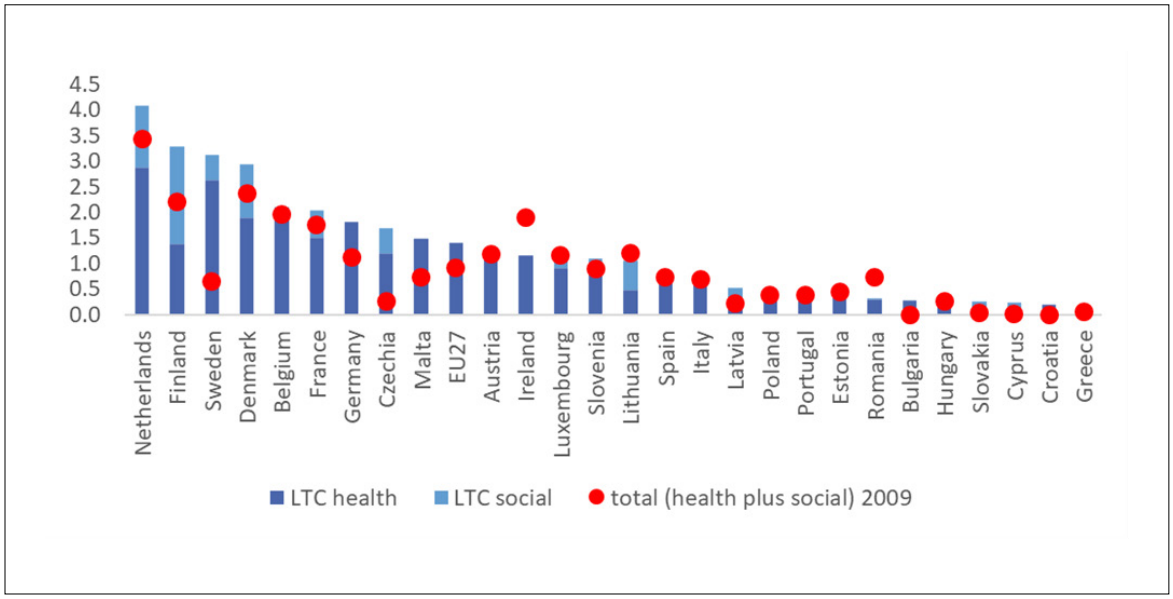
– support measures for informal carers have been implemented (Courtin et al., 2014; Rocard & Llena-Nozal, 2022). Yet, these policies are often not sufficient to attenuate the social risks associated with informal caregiving.

- Policymakers and other stakeholders have started to herald the development and implementation of digital technologies as a potential solution for several of the challenges discussed above, including improving access and quality of LTC, addressing worker shortages and supporting formal and informal carers (EHTEL, 2024; Zigante, 2020). However, respective strategies have been shown to be incomplete (Valokivi et al., 2023), and practical experiences also paint a more nuanced picture of the value of digital technologies for LTC (Hellstrand et al., 2024; Kaihlanen et al., 2023).

3.1 Investing in long-term care and addressing workforce shortages

The most significant indicator of the status of LTC and the political will to establish LTC systems and address increasing LTC needs is public spending (Figure 6). Remarkably, public expenditure in countries that started from higher shares of spending on LTC in 2009 further increased up to 4.1 of GDP in 2021 (Netherlands). Countries at the other end of the spending chart remained hesitant to significantly raise public expenditure from even the lowest levels, such as, for instance, Greece or Slovakia, still lagging behind with only 0.1%. Overall, data from 2021 indicates that public LTC spending in at least 13 EU countries was below 1% of GDP, suggesting significant room for expansion.

Figure 6: Public LTC expenditure as a % of GDP, 2021 (by component) vs. 2009 (total)



Source: Eurostat, SHA.

This variation is even more striking when considering the level of out-of-pocket (OOP) payments of households, i.e. private outlays. Indeed, countries with a relatively high share of LTC spending as a percentage of GDP exhibit lower levels of OOP payments and vice versa (Rodrigues et al., 2024). OOP payments can also push older individuals into financial or asset-based poverty, particularly when

needs are high, and care is provided for extended periods. Means-testing and asset-testing used to target public support can help allocate limited resources but may inadvertently penalize those with modest savings (OECD, 2020). Universal benefits are superior in addressing these issues by ensuring that all individuals have access to necessary care while reducing the risk of impoverishment.

Research has shown, however, that public expenditure on LTC, rather than being considered as a mere fiscal expense, needs to be reframed as an investment and pivotal tool for enhancing social and economic cohesion (Greve et al., 2017; https://sprint-project.eu/). Investing in LTC has multifaceted benefits: it enhances the quality of life for older persons and people with disabilities, fosters improved health outcomes for them and diminishes the strain on healthcare systems by preventing avoidable acute care admissions. Moreover, it can stimulate economic growth by creating more jobs and improving working conditions for people already employed in the sector. Current levels of LTC spending in many European countries may not be sufficient to meet current needs and future demand (European Commission, 2024), and they do not sufficiently reflect the indirect costs in terms of caregivers' employability, pension gaps, health, and general well-being.

Framing LTC spending as an investment not only aligns with demographic and socioeconomic trends but also with the real needs of citizens across Europe. Some 70% of European citizens would favour an increase in public funding for LTC, even if it would require higher taxes and contributions on their part. The proportion of individuals that would like their government to spend "totally more" on LTC varies from 92% in Greece to 57% in Belgium, reflecting, among other factors, differing levels of financing and provision gaps across the EU (European Commission, 2022).

Mutual learning, particularly from governments that have invested heavily in LTC over the past decade, can play an important role in making social investment strategies in LTC more widespread across the UNECE region:

- Since 2017, Germany has been implementing the largest care reform since the introduction of LTC insurance in 1994. The government introduced a fundamentally new definition of LTC needs and increased contributions to LTC insurance to fund measures enabling persons in need to remain in their familiar surroundings for as long as possible (Rothgang & Müller, 2021).
- In the Netherlands, the LTC Act of 2015, with the main objective of reducing expenditure and making funding sustainable (Alders & Schut, 2022), increased the thresholds for moving into residential care and established specialised nursing homes for people suffering from dementia. Housing for older persons with LTC needs was reorganised. Concomitantly, a new movement of local citizens' initiatives (cooperatives, but also informal groups) has evolved over the past two decades to organise health and social care in the community bottom up to respond to care gaps and the shortcomings of the LTC Act (van der Knaap et al., 2019).
- In Italy, the EU Recovery and Resilience Facility was explicitly used to launch an important care reform in the aftermath of the pandemic. The aim is to develop community care within the local health authorities by improving coordination, intermediate care and prevention (Cinelli & Fattore, 2024).

- Finland is currently implementing the biggest health and social care reform across the UNECE region by establishing novel administrative entities (Health and Wellbeing Counties) that can pool and address health and social care risks in a self-sustaining way. This implies re-centralising responsibilities from small municipalities to larger counties and de-centralising responsibilities at the national level (European Observatory et al., 2023).

Beyond increasing funding for LTC, many countries such as Austria have addressed challenges concerning the LTC workforce that became apparent during the pandemic through reforms and measures to combat the shortage of labour, the ageing of the care workforce and better support for informal carers (Kadi et al., 2023). National policymakers and managers of LTC services have responded to the increasing demand for LTC staff hitherto with different strategies to recruit, retain and reactivate staff. These include subsidising education and training, increasing wages, image campaigns, and improving working conditions to reactivate those who left the sector and/or to attract workers from other sectors. Enhancing earnings and working conditions for LTC workers can increase the attractiveness of the sector and contribute to reducing the gender wage and pension gaps, as well as gender inequality.

The European Care Strategy has also put the improvement of working conditions at the centre of attention when it comes to recruiting and retaining care staff, for instance, by promoting national social dialogue and collective bargaining, ensuring the highest standards in occupational health and safety, and by addressing the challenges of particularly vulnerable workers such as domestic, live-in and undeclared workers. However, these commitments have yet to be put into practice. For example, the employment of migrant live-in carers (Leichsenring et al., 2021; 2022; 2023), which is common practice in some countries, calls for further action as it masks some fundamental issues of the economy of care work – lack of regulation, bogus self-employment, lack of training, burden of care for individual carers in social isolation, and precarious working conditions (Aulenbacher et al., 2021).

Another approach to address labour shortages has been the international recruitment of LTC workers. This practice takes place under conditions of global competition and raises political, cultural and ethical issues. Even if such recruitment strategies were compliant with the WHO Global Code of Practice (WHO, 2010), they might result in care gaps in the countries of origin and are likely to pose challenges to the receiving countries in terms of care workers' social integration and the quality of care. Research is needed to identify successful and fair strategies for attracting care workers (ILO, 2018), as well as to understand the wider social implications and side effects of these policies (Eaton et al., 2023).

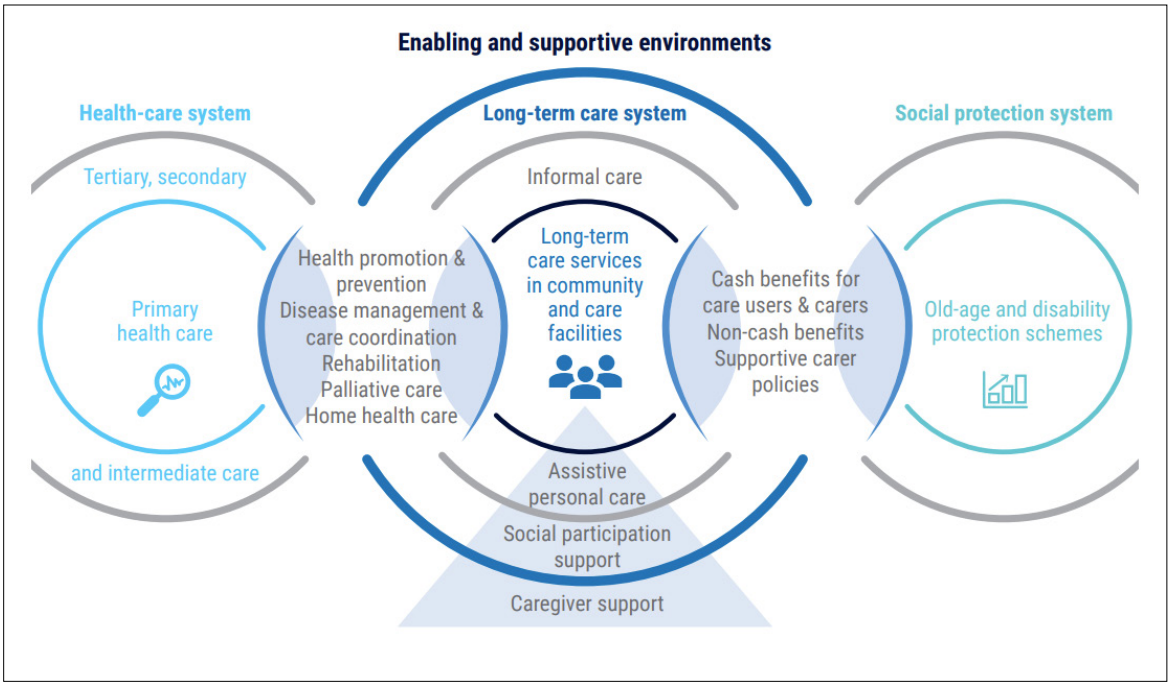
Issues of a potential upward convergence in LTC policies are an important part of the debate on welfare regimes – with findings suggesting that such convergence is happening at a very slow pace, with piecemeal reforms in most countries, and rather towards a middle ground (Kröger, 2024). The comprehensive LTC reforms undertaken in some countries, despite their embeddedness in cultural norms, institutional arrangements and care regimes, provide opportunities for international collaboration and the adjustment of good practices to the respective contexts. Policymakers will have to make choices in a complex area such as LTC with competing (policy) aims and solutions that are interfering with a wide range of policies, ranging from employment and housing to transport, technology and environmental affairs. Looking forward, however, it could be helpful to think one step ahead about how societies would need to get organised that put care at the centre of social policies, the economy and intergenerational solidarity.

3.2 Towards person-centred integrated LTC systems

As a reaction to the changing needs and demands in LTC, reforms in Central and Western Europe, as well as in the Nordic countries since the 1980s, were guided by debates on de-institutionalisation and the concept of "care chains," i.e. the necessity to provide the right type of care at the right place and time by the right person. These reforms were, however, taking place in the context of New Public Management and market-oriented governance (Rodrigues et al., 2014), which led to increased market shares of commercial providers, particularly in residential structures (e.g. in Germany, the UK, France, Sweden). Our studies have shown that this restructuring contributed to further fragmentation and new challenges for quality assurance (ESN, 2021; Rodrigues et al., 2014; Leichsenring et al., 2013).

To overcome the issue of fragmentation, intergovernmental organisations such as the WHO intensified their endeavours to promote integrated and person-centred[2] LTC (WHO, 2007; WHO, 2022; see Figure 7 below). The vision of integrated care promotes the development of LTC as a distinct system to facilitate appropriate services and mechanisms at the interface between health care systems and the social care system. Thereby, the provision of services in the community is at the centre of integrated LTC, which, furthermore, needs to be underpinned by enabling and supportive environments around care receivers and their carers. For example, better emphasis on prevention (as discussed in section 2.1) is one aspect where stronger links between LTC and health care can be created.

Figure 7: Integrating long-term care in health and social care delivery



Source: WHO Regional Office for Europe; 2022. Licence: CC BY-NC-SA 3.0 IGO

2 We refer to the term person-centredness, while the WHO uses the term people-centredness and others have suggested terms such relationship-centredness. While these different terms have different connotations, they are similar, in the sense that they all refer to providing services in line with the needs and wishes of those affected (e.g. Sturgiss et al., 2022).

Besides its organisational dimension, the vision to integrate LTC with the health and social protection system also has a normative dimension. This means, among other things, to consider access to LTC as a social right and part of universal health coverage. At the level of the EU, LTC has been included in the "European Pillar of Social Rights" that underlines the importance of investing in "universally accessible, affordable, high-quality childcare and long-term care," including by guaranteeing workforce professionalisation and fair working conditions. This approach was elaborated in the European Care Strategy (Council of the European Union, 2022). Although not legally binding, this declaration and similar policy statements are examples to foster "upward social convergence" among EU member states.

Implementing person-centred LTC encompasses multiple dimensions (e.g. Sturgiss et al., 2022). A key issue in this regard is the assessment of people's individual care needs, which has significant consequences on the quantity and quality of entitlements and benefits. There is a wider consensus that care needs stem from limitations in performing activities of daily living (e.g. personal hygiene, toileting, eating) and support needs with instrumental activities of daily living (e.g. housekeeping, managing finances, preparing food). However, needs and related eligibility criteria for care are defined and assessed by means of schemes that vary widely among jurisdictions and rely on diverse indicators and definitions.

For instance, in the course of the latest re-definition of care needs in the German LTC insurance previous needs definitions that focussed on physical needs were extended to now also include needs associated with cognitive and mental health issues (Bundesministerium für Gesundheit, 2016). This contributed to a sharp rise of beneficiaries from 2.7 million in 2015 to 4.9 million in 2022 (Bundesministerium für Gesundheit, 2024). While the German reform can be seen as a development towards person-centred LTC, people with cognitive and mental health needs are still excluded from LTC benefits in many other countries due to definitions and assessment schemes that focus mainly on physical disabilities and related impairments. Advances can also be reported regarding the recognition of citizens' social participation as an element of LTC needs. This means that the voice and preferences of persons in need of LTC are gaining ground in efforts to strengthen person-centredness in LTC provision (González-Ortiz et al., 2018).

These examples show how policymakers have adapted definitions of care needs to changing disease profiles but, for example, also normative debates about the social participation of older people. Further research is, however, needed to facilitate and manage rights-based access to LTC (Birtha et al., 2019), and to develop person-centred care in appropriate care eco-systems with an appropriate mix of contributions by public, private, civil society and individual (household) stakeholders (Ilinca et al., 2021). Furthermore, as the definition of what constitutes a care need is a political decision, care receivers, carers and the wider public should be included in negations of what constitutes legitimate care needs and person-centred care. The same should apply for defining and assessing quality in LTC.

3.3 Reframing unpaid care work

LTC reforms have also promoted the ageing-in-place approach to enable older persons to live at home as long as possible. This, however, can come at the cost of family members and friends, in particular, if such approaches are not backed by sufficient formal care staff working in non-residential settings (see Figure 3). For a better understanding of the prevalences and dynamics of informal care provision as well as the experiences of informal carers, better-coordinated strategies for data collection are needed because existing surveys are characterised by inconsistencies in definitions, methods and results (Tur-Sinai et al., 2020; Kadi et al., 2023).

In terms of policy responses to informal care, various countries in Europe and beyond have implemented support measures for informal carers, such as carer allowances, social security contributions or care leaves (Courtin et al., 2014; Rocard & Llena-Nozal, 2022). Some progress has also been made in recognising the needs of informal carers in existing care arrangements (Carers UK, 2024). The EU Care Strategy (Council of the European Union, 2022) has also provided some guidance for Member States by calling on them to identify informal carers, facilitate their cooperation with professional carers as well as improve access to training, counselling, respite care and social protection and financial support without deterring those at working age from participating in the labour market. While support measures for informal carers currently tend to focus on the group of informal carers in employment or of working age, there is a more general need to expand support to all groups of informal carers, independent of their position on the labour market.

More generally, with the rising complexity of needs, multimorbidity and extended duration of care needs, unpaid care work has become more visible, and the necessity to acknowledge unpaid social support has gained ground. The COVID-19 pandemic also contributed to making invisible care work more visible (Leichsenring et al., 2023). However, unpaid care work and related policy responses must be discussed in a wider context, namely as a field of tension in capitalist societies that conceive employment as the main source of income and social inclusion, often ignoring the necessity of unpaid care work.

Notwithstanding the necessity to further expand professional LTC services, the bulk of care will continue to be provided by spouses or other kin, mainly women in the family, based on notions of duty, altruism and familial responsibility. Being grounded in the "moral economy of care," i.e. the complex amalgamates of the social value of care, obligations, and expectations for reciprocity, rather than profit maximisation (Näre, 2011), informal care is not monetised and based on the assumption that women, in particular, are capable of providing this type of care "on the side." However, feminist scholars analysing the political economy of care have pointed out that unpaid care work is a fundamental element of social welfare production and – as a consequence of the gendered division of labour and patterns of domestic care provision – of social inequality affecting mainly women's life-chances (England, 2005; Tronto, 1993; 2005). As unpaid care work is considered "unproductive" by mainstream economics, it is ignored in economic equations, the calculation of GDPs and the entire economy (Himmelweit, 1995; Dowling, 2021). Policies to support informal carers, therefore, have

to be assessed against their ability to include unpaid care work in the economy, as part of the social security system, and as an important aspect of creating social solidarity and more equal societies.

3.4 Expectations around digital technologies in long-term care

As part of the general development towards digitalisation, respective technologies have also entered the field of LTC. While some digital technologies are well established in LTC (e.g., electronic patient records, smartphones, digitally operated wheelchairs), others are being implemented but not yet as widely used (e.g., smart home technologies, ambient assisted living devices, service robots). Yet other technologies, for example "autonomous" care robots, may also play a role in the future, but their development and large-scale implementation are not imminent (Leite et al., 2023). Policymakers and other stakeholders have embraced the development and implementation of digital technologies in health and LTC, as they have been associated with meeting some of the pressing challenges in the sector (EHTEL, 2024).

More specifically, digital technologies are considered to improve access to and quality of LTC by enabling better communication, documentation, monitoring, and coordination between care providers. They have also been associated with improving the quality of life of people with care needs such as by assisting in daily tasks and reducing social isolation. Some expect that digital technologies will also imply changes for both formal and informal carers, for example, through digital education and training, the use of algorithms in recruiting or the planning and scheduling of care work. They may also free care workers from performing certain care tasks and reduce the intensity of care (Zigante, 2020).

One of the fundamental prerequisites for increasing access and quality of care through digital technologies is that people in need of care have access to these technologies and can use them. Much research on technology use in LTC is industry-driven. For many informal carers and care receivers, however, digitalization is a barrier already at the point of accessing information about care. Awareness about inequalities in digital infrastructures and access to digital technologies has been identified as a gap in policy documents that promote digital technologies in LTC. Similarly, it has been shown that policy strategies are often based on a "limited understanding of the complexity […] of caring for older adults" (Valokivi et al., 2023: 835). Empirical research has also indicated that implementing digital technologies may lead to "core values of care being lost" (Frennert, 2019: 635) because knowledge resulting from digital technologies risks devaluing and replacing tacit knowledge resulting from the relationship between care receivers and caregivers. This also risks that practices directed at improving patients' quality of life may be overshadowed by attempts to improve measurable health parameters (Hellstrand et al., 2024). Studies also paint a nuanced picture of the impact of digital technologies on care work. For example, a Finnish study showed that the implementation of digital technologies reduced some tasks for LTC workers while at the same time introducing new ones (e.g., instructing care receivers how to use technologies) and overall increasing their workload (Kaihlanen et al., 2023).

Against this backdrop, critical commentators have contended that policy strategies concerning digital technologies in LTC are characterised by an undue "techno-enthusiasm" (Valokivi et al., 2023). It has

also been observed that presenting technologies as solutions allows policymakers to avoid addressing the causes of current problems in LTC while at the same time creating opportunities for tech businesses to "extract value from a crisis" (Johnston & Pratt, 2024). While the political economy of digitalisation is crucial for understanding future developments in LTC, digital technologies may, nevertheless, benefit caregivers and receivers if designed and implemented well. Therefore, ethical and regulatory issues must be considered as well to ensure technologies – from care robots to administrative software – are effective and safe and do not worsen existing inequities, for example, due to built-in biases. Policymakers should integrate these technologies within a broader strategy that aims at meeting care needs comprehensively, improving the quality of care, enhancing working conditions for formal carers, and support for informal carers, and is based on the involvement of care recipients and carers.

4 From care regimes to a caring society?

4.1 Different care regimes as a starting point

The framework of "care regimes" was triggered by the salient debate on "welfare regimes" (Esping-Andersen, 1990; Aspalter, 2021), which has been used over the past decades in comparative research to cluster groups of countries with similar structures and approaches to care, synthesising an intensive debate about suitable variables and definitions (Bettio & Platenga, 2004). Leichsenring (2021) proposed clusters that are formed by a range of dimensions that are relevant for LTC systems, in particular, drawing on the gendered division of work and the degree of "defamilialisation" that plays a decisive role in defining care regimes in analogy to the "decommodification of work" that plays a crucial role in Esping-Andersen's typology of "welfare regimes" (Esping-Andersen, 1990).

In Table 1, these ideal-typical clusters are listed as (a) rights-oriented, (b) subsidiary, (c) emerging market and (d) rudimentary LTC regimes. Countries have been allocated as examples, even if a clear demarcation line cannot always be defined. For instance, the strong labour market participation in the Netherlands is linked to a very high share of part-time work, not all East European countries have defined statutory care obligations for family members such as Hungary (Addatti et al., 2022), and not all subsidiary LTC regimes do provide cash benefits for LTC.

Given the challenges, however, that can and will emerge over the next two decades in rapidly ageing emerging markets and rudimentary LTC regimes, new priorities will push LTC to the centre of attention – and campaigns such as the WHO Decade of Healthy Ageing 2020-2030 help to promote LTC policies in these countries (WHO, 2020). In this context, two sets of questions are to be tackled. First, can and should there be an upward convergence in LTC policies, e.g. regarding the gendered division of labour? And, how can different political traditions and cultural approaches (family ethics) be considered rather than bluntly copying trajectories of other LTC regimes? Second, is there a political will to invest in LTC systems rather than just following a policy of muddling through by relying on unpaid care in the family?

Table 1: Ideal-typical long-term care regimes in the UNECE Region

Dimension	Rights-oriented LTC regime	Subsidiary LTC regime	Emerging market LTC regime	Rudimentary LTC regime
Family ethics	Focus on individual rights	Implicit reliance on family care	Explicit reliance on family care	Family as exclusive care institution
Gendered division of (care) work	Strong labour market participation of women	Rising share of women's labour market participation	Active role of women in the labour market, but continuing household responsibilities	Traditional gender roles in care
Commodification and professionalisation of care work	Important share of the labour force, esp. women in LTC and health	Rising share of employment in LTC, increasing provision; migrant carers	Marked steps to organise LTC facilities and services, training	First attempts to organise LTC services, caregiver training
Defamilialisation	No recourse for family members to pay for formal care	Recourse on assets, including next-of-kin, family in charge; migrant carers as functional equivalent	Family in charge, implicitly or even explicitly (morally and legally); migrant carers as an option	Family (women) explicitly in charge, but perceived weakening of family support systems
Political economy of care	High share of public and/or non-profit providers, but growing privatisation	Mixed economy of care, tradition of private provision, market governance, public funding rising, user choice	All types of provision, third-party support (international organisations), "illegal" private provision	First initiatives (often with third-party technical assistance)
Acknowledgement of LTC as social risk	Yes, with defined rights for LTC; public LTC expenditure >3% of GDP	Yes, but based on social assistance rationale; public LTC expenditure 1-3% of GDP	First signs and legal regulations; public LTC expenditure <1% of GDP	No, negligible LTC expenditure
Access to LTC	Established rules and infrastructure, benefits in kind, de-institutionalisation; "targeting"; facilitation of commercial providers' market access	Defined access, rationing of services, balancing residential and community care; Strong reliance on cash benefits	Discretionary, limited supply structures, de-institutionalisation as a goal; cash benefits	Very much restricted or not available
Agency of stakeholders	Increasing user choice and market access; ombudsperson for care	Market-oriented governance; users as customers with related rights	Restricted user rights; partly unregulated markets	Restricted
Degree of social/ health care coordination	Fragmented, individual coordination programs	Widely fragmented with increasing efforts	Recognised health care system, separated LTC (social care)	Basic health care as challenge; no LTC
Countries (examples)	Denmark, Sweden, The Netherlands, Norway	Austria, Canada, Germany, France, UK, US, Israel, Italy, Spain, Switzerland	Czech Republic, Slovakia, Poland, Hungary, Turkey, Greece, Western Balkan countries, Ukraine, Moldova	Azerbaijan, Uzbekistan

Source: adapted from Leichsenring, 2021.

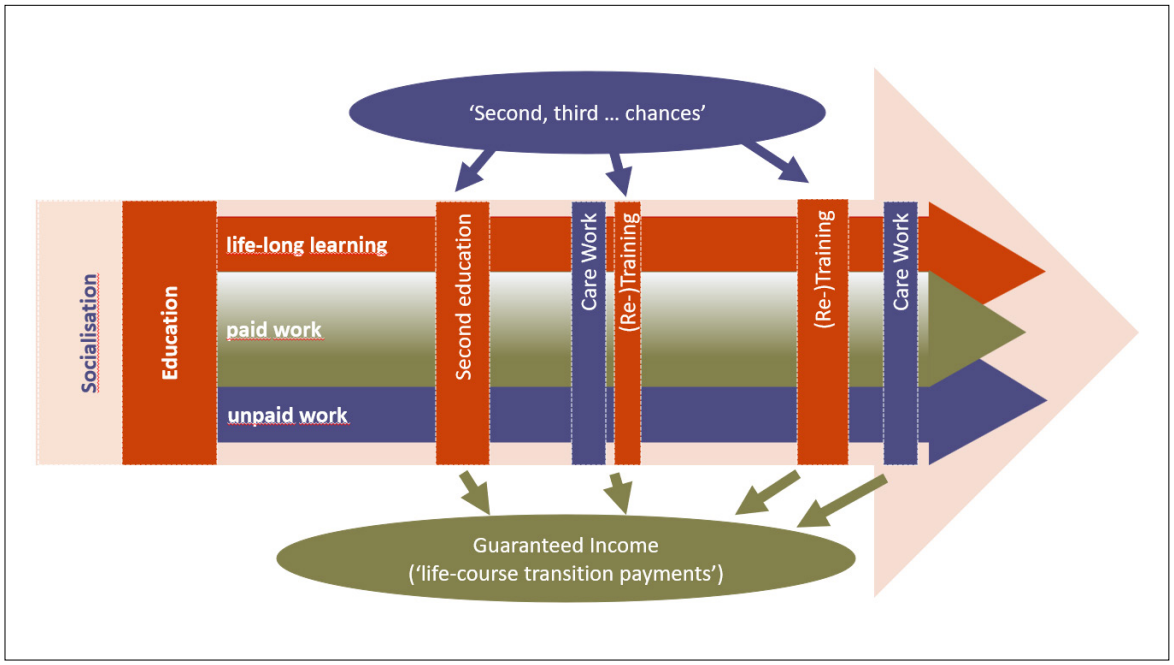
Policymakers will have to deal with these complex issues of providing resources and creating legal frameworks to establish and govern LTC systems that respond to the challenges and expectations described above. Research can underpin the decision-making process at several stages with empirical findings and methodological guidance, for instance regarding future needs, alternative funding (Simmons et al., 2024) and quality assurance mechanisms (Leichsenring et al., 2013), or to strengthen the participation of persons in need of care, their families and other important stakeholders in co-designing care policies (Kayran & Kadi, 2023; JFCSSR, 2022; Ilinca et al., 2021; Schulmann et al., 2019). Apart from this kind of policy advice, however, social research also has the task of proposing normative ideas and broader visions of social welfare policy.

4.2 Towards the caring society in the context of rising longevity

In the context of rising longevity and increasing care needs, it stands to reason to work toward a "caring society" and new ways to design social security and welfare from a life-course perspective. The issues discussed above are building blocks for such an undertaking, but such a society would, above all, allocate a prominent place to care work and the sustainable use of scarce caring resources. This certainly encompasses investments in supporting the care workforce, including informal carers, and extending the LTC infrastructure, e.g. by rolling out multi-functional health, social and LTC centres that integrate health and social care services at the local level. Another aspect of the "caring society" in the context of digital transformation will be to develop strategies on how to include the different groups of older persons in need of LTC in technological innovation (Peine et al., 2024).

The "caring society" with populations that enjoy increasing longevity will also need to develop new types of social policies that respond to specific life events and transitions over the life course with a focus on care tasks – from education to work, from work to periods of care and vice versa, including periods of (re-)training etc. One way to support the emergence of "caring societies" in the context of demographic change would be to facilitate a more integrated life-course perspective with respective changes in social security institutions and schemes such as "life-course transition payments" as a conditional basic income (Molina-Millán et al, 2019). Figure 8 depicts this approach promoted by the European Centre to contribute to debates about combating ageism, cumulated inequalities over the life course, and getting rid of chronological age boundaries, e.g. in pension and other social security schemes (Leichsenring & Sidorenko, 2024; Leichsenring, 2018).

Figure 8: Underpinning caring societies through an integrated life-course perspective



Source: Leichsenring, 2018; Leichsenring & Sidorenko, 2024.

Table 2 informs about some key features of an envisaged "caring society" along the dimensions of existing LTC regimes. Rather than categorising care regimes, we envisage future research to measure the distance between reality and an ideal type of "caring society." We underline that defamilialisation will certainly be an important factor in a better distribution of care among citizens, supporting those with excessive burdens and acknowledging unpaid care as a significant contribution to the social fabric and the economic functioning of societies. Existing research has shown that in countries with generous formal LTC systems, informal care work is better distributed, as more people tend to engage in less intensive informal caregiving (Verbakel, 2018). A "caring society" should consider informal carers as part of the LTC workforce and ponder the repercussions of care work on inequities, the participation (of women) in the labour market, and the acknowledgement of care work over the life course. This would contribute to reducing cumulative inequalities over the life course and offer new opportunities for social inclusion and equal chances.

Furthermore, a "caring society" would acknowledge that, while older people may be in need of care in some regards, they may also be able to provide forms of care for others. For example, communal housing projects for older citizens support mutual help among older people and transgenerational (co-)housing projects offer opportunities for different generations supporting each other. This means that a "caring society" fosters intergenerational solidarity and recognises that older people are not just beneficiaries but can significantly contribute to such arrangements.

It might be a long way to go to change existing care regimes into a "caring society" through respective initiatives in policy, research and practice because LTC is currently not at the centre of digital, demographic and ecological transformations. However, a broad debate is needed to avoid the further expansion of inequalities and create social buffers to the societal consequences of these

transformations. This also includes a better understanding and reflections about obstacles in working towards a "caring society". For example, as LTC is considered a major "growth sector," there is a need for better understanding the mechanisms and consequences of commercialisation and privatisation in LTC and the detrimental effects this can have on quality of care, access to services and working conditions.

Table 2: Dimensions of the "caring society" and issues to be addressed in policy and research

Dimension	Issues to be addressed in policy and research
Family ethics	• Distributing care across society relieves families from being the main provider of care • Analyse inequalities in LTC provision and the potential of care eco-systems
Gendered division of (care) work	• Work towards gender balance, facilitating the care responsibilities (and professional perspectives) for men • Qualitative studies about (paid and unpaid) care work by men and the potential of local eco-systems
Commodification and professionalisation of care work	• Investment in education and training in LTC and attractive new jobs, integrated care services and facilities • Analyse the potential of new job profiles in LTC and the potential for professionalisation, incl. digitalisation, action on climate change and the social return on investment of preventative measures
Defamilialisation	• Developing alternatives to isolated care in the family, waiver of asset-based out-of-pocket payments by family members • Participative research to develop local care networks, housing alternatives and partnerships with local stakeholders in LTC
Political economy of care	• Moving care at the centre of a mixed economy of care, including private non-profit, commercial and public providers • Analysing the preconditions of a mixed economy of care based on national traditions and potentials for social innovation, including in terms of working conditions and quality of life
Acknowledgement of LTC as social risk	• Securing sufficient funding for LTC services and facilities, gauging alternative payment mechanisms (integrated care organisations), and considering funding of care activities over the life course • Analysing incentive structures and behavioural change
Access to LTC	• Securing equal access to high-quality services and facilities in local LTC eco-systems, including prevention and re-ablement • Participative studies on how to improve acceptance and the distribution of information on LTC eco-systems, including the role of digital support
Agency of stakeholders	• Establish rights for users and carers, with checks and balances, including quality assurance • Monitor rights-based approaches to LTC and evaluate the impact of user rights on quality of life (of users and carers)
Degree of social/health care coordination	• Facilitate the coordination and integration of health and social care as well as formal and informal care • Participative research with stakeholders on how to improve interprofessional working, the involvement of relevant agents, and to create and scale up local LTC eco-systems

5 Conclusions

This discussion paper has gauged trends and opportunities to develop a "caring society" in the context of ongoing transformations due to demographic change, rising longevity and growing care needs. We observed massive challenges and a range of concomitant, partly contradictory and conflicting goals that need to be addressed, namely the need for investment in LTC as against voices of unsustainability, high expenditures for residential care against the rhetoric of "ageing in place," or the exploitation of unpaid care work as against the general goal in employment policy to increase the labour market participation (of women).

We advocate further efforts to advance "caring societies" with integrated LTC systems that offer more equitable access to services and appropriate technologies, ensure the quality of life for both persons in need of care and their carers, and are governed by sustainable strategies.

Public discourse on social investment in the LTC sector needs to be guided by evidence on integrated care and related conceptual approaches (Mohr & Dessers, 2019), outcome-oriented financing (Simmons et al., 2024) and community-based services that result in improved quality of life. For instance, the implementation of digital technologies in LTC needs to be embedded in a broader strategy that aims at meeting people's care needs, improving the quality of LTC delivery, enhancing the working conditions for formal carers as well as providing support for informal carers (Zigante, 2020). Care recipients and carers need to be involved in decision-making processes on these issues. Future research on these topics is certainly needed (see also Lamura & Nies, 2024) but so is awareness that the dynamics that shape LTC partly also lie beyond LTC. LTC is affected by societal development such as austerity politics, general labour market dynamics, housing and transportation, education, digitalisation, and gender inequalities. Researching and addressing these issues more generally, will also be important for fostering and improving LTC.

6 References

Addati, L., Cattaneo, U., Pozzan, E. (2022). *Care at work: Investing in care leave and services for a more gender equal world of work*. Geneva: International Labour Office.

Alders, P., Schut, F.T. (2022). Strategic cost-shifting in long-term care. Evidence from the Netherlands, *Health Policy* 126(1): 43-48.

Aspalter, C. (Ed.) *Ideal Types in Comparative Social Policy*. London: Routledge.

Aulenbacher, B., Lutz, H., Schwiter, K. (Eds.) (2021). *Gute Sorge ohne gute Arbeit? Live-in-Care in Deutschland, Österreich und der Schweiz*. Weinheim: Beltz Juventa.

Ayalon, L., Tesch-Römer, C. (2018). *Contemporary perspectives on ageism*. Cham: Springer.

Bauer, G., Rodrigues, R., Leichsenring, K., Six, M. (2018). *Arbeitsbedingungen in der Langzeitpflege aus Sicht der Beschäftigten in Österreich. Eine Untersuchung auf Basis der internationalen NORDCARE-Befragung*. Wien: European Centre.

Barnett, K., Mercer, S.W., Norbury, M., Watt, G., Wyke, S., Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet*, 380: 37-43. https://doi.org/10.1016/s0140-6736(12)60240-2.

Belgian Presidency of the Council of the European Union (2024). La Hulpe Declaration on the Future of the European Pillar of Social Rights, available at https://belgian-presidency.consilium.europa.eu/en/events/european-pillar-of-social-rights-the-la-hulpe-declaration-on-the-future-of-social-europe/ (last accessed: 15 July 2024)

Berta, W.B., Stewart, C., Baumann, A. (2022) What is old is new again: global issues influencing workers and their work in long-term care, *Healthcare Policy* 17.

Bettio, F., Plantenga, J. (2004). Comparing Care Regimes in Europe. *Feminist Economics*, 10(1), 85-113. https://doi.org/10.1080/1354570042000198245

Billings, J., Leichsenring, K. (Eds.) (2005). *Integrating Health and Social Care Services for Older Persons. Evidence from Nine European Countries*. Farnham (UK): Ashgate.

Birtha, M., Rodrigues, R., Zólyomi, E., Sandu, V., Schulmann, K. (2019). F*rom disability rights towards a rights-based approach to long-term care in Europe: Building an index of rights-based policies for older people*. Vienna: European Centre for Social Welfare Policy and Research.

Bom, J., Bakx, P., Schut, F., van Doorslaer, E. (2019). The Impact of Informal Caregiving for Older Adults on the Health of Various Types of Caregivers: A Systematic Review. *Gerontologist*, 59(5), e629-e642. https://doi.org/10.1093/geront/gny137.

Bundesministerium für Gesundheit Deutschland (2016). Neuregelungen im Jahr 2017 im Bereich Gesundheit und Pflege, https://www.bundesgesundheitsministerium.de/ministerium/meldungen/2016/dezember-2016/neuregelungen-2017 (last accessed: 24 June 2024)

Bundesministerium für Gesundheit Deutschland (2024). Pflegeversicherung, Zahlen und Fakten, https://www.bundesgesundheitsministerium.de/themen/pflege/pflegeversicherung-zahlen-und-fakten (last accessed: 16 June 2024)

Carers UK (2024). Having a carer's assessment, https://www.carersuk.org/help-and-advice/practical-support/carers-assessment/ (last accessed: 24 June 2024)

Cinelli, G., Fattore, G. (2024). The 2022 community-based integrated care reform in Italy: From desiderata to implementation, *Health Policy*, 139: 104943, https://doi.org/10.1016/j.healthpol.2023.104943.

Council of the European Union (2022). Council Recommendation on access to affordable, high-quality long-term care, 2022. Available at: https://data.consilium.europa.eu/doc/document/ST-13948-2022-INIT/en/pdf

Courtin, E., Jemiai, N., Mossialos, E. (2014). Mapping support policies for informal carers across the European Union. *Health Policy*, 118(1): 84-94. https://doi.org/10.1016/j.healthpol.2014.07.013

Dowling, E. (2021). *The care crisis: What caused it and how can we end it?* London: Verso.

Eaton, J., Baingana, F., Abdulaziz, M., Obindo, T., Skuse, D., Jenkins, R. (2023). The negative impact of global health worker migration, and how it can be addressed, *Public Health*, 225: 254-257, https://doi.org/10.1016/j.puhe.2023.09.014.

EHTEL (European Health Telematics Association) (2024). Vision and mission. https://ehtel.eu/about/vision-and-mission.html (last accessed: 25 July 2024)

England, P. (2005). Emerging theories of care work. *Annual Review of Sociology*, 31: 381-399, https://doi.org/10.1146/annurev.soc.31.041304.122317

Esping-Andersen, G. (1990). *The three worlds of welfare capitalism*. Princeton: Princeton University Press

Eurofound (2020). *Long-term care workforce: Employment and working conditions*, Publications Office of the European Union, Luxembourg.

European Commission and High-level Expert Group (2023). *The future of social protection and of the welfare state in the EU*. Brussels: DG Employment.

European Commission (2022). Special Eurobarometer 529: Fairness, inequality and inter-generational mobility in 2022. Retrieved from: https://ec.europa.eu/social/main.jsp?langId=en&catId=89&furtherNews=yes&newsId=10509

European Commission (2024). *2024 Ageing Report, Economic and budgetary projections for the EU Member States (2022-2070)*. Luxembourg: Publications Office of the European Union.

European Observatory on Health Systems and Policies, Tynkkynen, L.-K., Keskimäki, I., Karanikolos, M., Litvinova, Y. (2023). *Finland: Health system summary*, 2023. Copenhagen: World Health Organization. Regional Office for Europe.

European Social Network (ESN) (2021). *Putting Quality First. Contracting for long-term care*. Brussels: ESN.

Evers, A., Nowotny, H. (1987). *Über den Umgang mit Unsicherheit*. Frankfurt/M.: Suhrkamp.

Evers, A., Svetlik, I. (Eds.) (1993). *Balancing Pluralism. New Welfare Mixes in Care for the Elderly*. Aldershot: Avebury.

Foster, L., Walker, A. (2021). Active Ageing across the Life Course: Towards a Comprehensive Approach to Prevention. *Biomed Res Int.* 3:6650414. https://doi.org/10.1155/2021/6650414

Frennert, S. (2019). Lost in digitalization? Municipality employment of welfare technologies. Disability and Rehabilitation, *Assistive Technology*, 14(6): 635-642. https://doi.org/10.1080/17483107.2018.1496362

Grages, G., Pfau-Effinger, B. (2022). *Gaps in the provision of long-term care across Europe*. EUROSHIP Working Paper No. 14. Oslo: Oslo Metropolitan University. DOI: 10.6084/m9.figshare.19328912.

Greve, B., Lopes, A., Richards, A. (2018). *Social Investment Criteria in the Field of Long-term Care*. Brussels: SPRINT Working Paper D4.1, SPRINT.

González-Ortiz, L.G., Calciolari, S., Goodwin, N., Stein, V. (2018). The Core Dimensions of Integrated Care: A Literature Review to Support the Development of a Comprehensive Framework for Implementing Integrated Care. International Journal of Integrated Care, 18(3): 10, https://doi.org/10.5334/ijic.4198

Hajek, A., Kretzler, B., König, H.H. (2021). Informal Caregiving, Loneliness and Social Isolation: A Systematic Review. *Int J Environ Res Public Health*, 18(22), 12101. https://doi.org/10.3390/ijerph182212101.

Hellstrand, M., Kornevs, M., Raghothama, J., Meijer, S. (2024). Tensions between real-world practices and the digitalization paradigm for data-driven services in eldercare: Observations from an ethnographic study in Sweden. *BMC Geriatrics*, 24(1): 98. https://doi.org/10.1186/s12877-024-04693-z

Himmelweit, S. (1995). The Discovery of 'Unpaid Work': The Social Consequences of the Expansion of Work. *Feminist Economics* 1(2): 1-19.

Hoffmann, F., Rodrigues, R. (2010). *Informal carers: who takes care of them?* European Centre Policy Brief Series https://www.euro.centre.org/downloads/detail/1256

Ilinca, S., Simmons, C., Zonneveld, N., Benning, K., Comas-Herrera, A., Champeix, C., Nies, H., Leichsenring, K. (2021). *Social Innovation in LTC in Europe: Towards a common narrative for change. InCARE Short Report no.1.* Vienna: European Centre.

International Labour Office (ILO) (2018). *Care work and care jobs for the future of decent work*. Geneva: ILO.

Johnston, C., Pratt, G. (2024). Automating adult social care in the UK: Extracting value from a crisis. Geoforum, 151. https://doi.org/10.1016/j.geoforum.2024.103997

Joint Forum of Civil Society and Scientific Research (JFCSSR) (2022). Declaration – a fulfilling life throughout the life-course: A joint effort of civil society and research in policy making, https://unece.org/

Joseph, S., Kendall, C., Toher, D., Sempik, J., Holland, J., Becker, S. (2019). Young carers in England: Findings from the 2018 BBC survey on the prevalence and nature of caring among young people. *Child: care, health and development,* 45(4): 606-612. https://doi.org/10.1111/cch.12674

Kadi, S., Pot, M., Simmons, C., Leichsenring, K., Staflinger, H. (2023). *Young Carers und Young Adult Carers in Oberösterreich. Status quo, Handlungsfelder und Lösungsansätze (Young Carers and Young Adult Carers in Upper Austria. Current situation and needs for action)*. Linz und Wien: Arbeiterkammer Oberösterreich & Europäisches Zentrum für Wohlfahrtspolitik und Sozialforschung. Available online: https://www.euro.centre.org/publications/detail/4746

Kaihlanen, A. M., Laukka, E., Nadav, J., Närvänen, J., Saukkonen, P., Koivisto, J., Heponiemi, T. (2023). The effects of digitalisation on health and social care work: A qualitative descriptive study of the perceptions of professionals and managers. *BMC Health Services Research*, 23(714). https://doi.org/10.1186/s12913-023-09730-y

Kayran, E.N., Kadi, S. (2023). Piloting Social Innovation in Long-Term Care: Application of Theory of Change and Lessons Learnt. *InCARE Policy Brief*, Nr. 10. Vienna: European Centre.

Knobloch, U., Theobald, H., Dengler, C., Kleinert, A.-C., Gnadt, C., Lehner, H. (Eds.) (2022). *Caring Societies – Sorgende Gesellschaften*. Weinheim Basel: Beltz Juventa.

Kröger, T. (2024). Towards the caring or the uncaring state? A social policy perspective on long-term care trends, pp. 203-220 in Leichsenring, K., Sidorenko, A. (Eds.) *A research agenda for ageing and social policy*. Cheltenham: Edward Elgar.

Lamura, G., Nies, H. (2024). Longer lives with long-term care needs: research needed to tackle the care gap, pp. 183-202 in Leichsenring, K. & Sidorenko, A. (Eds.) *A research agenda for ageing and social policy*. Cheltenham: Edward Elgar.

Lee, Y., Zurlo, K.A. (2014). Spousal caregiving and financial strain among middle-aged and older adults. *Int J Aging Hum Dev*., 79(4): 302-321. https://doi.org/10.1177/0091415015574181.

Leichsenring, K. (2021). Applying Ideal Types in Long-Term Care Analysis, pp. 187-206 in Aspalter, C. (Ed.) *Ideal Types in Comparative Social Policy*. London: Routledge.

Leichsenring, K. (2018). Ageing 4.0 – New approaches to population ageing. *Policy Brief, October*. Vienna: European Centre.

Leichsenring, K. Billings, J., Nies, H. (2013) *Long-term care in Europe – Improving policy and practice*. Cheltenham: Palgrave Macmillan.

Leichsenring, K., Kadi, S., Simmons, C. (2022). Making the Invisible Visible: The Pandemic and Migrant Care Work in Long-Term Care. *Social Sciences*, 11: 326. https://doi.org/10.3390/ socsci11080326

Leichsenring, K., Kadi, S., Schmidt, A.E., Staflinger, H. (2023). The Covid-19 Pandemic in Austria: With Special Reference to Migrant Care Workers, pp. 275-294 in Aspalter, C. (Ed.), *Covid-19 Pandemic. Problems Arising in Health and Social Policy*. Singapore: Springer.

Leichsenring, K., Schmidt, A.E., Staflinger, H. (2021). Fractures in the Austrian model of long-term care: What are the lessons from the first wave of the Covid-19 pandemic? *Journal of Long-Term Care*, 33-42. https://doi.org/10.31389/jltc.54

Leichsenring, K., Sidorenko, A. (Eds.) *A research agenda for ageing and social policy*. Cheltenham: Edward Elgar.

Leite, H., Hodgkinson, I.R., Volochtchuk, A.V. (2023). New development: Digital social care—the 'high-tech and low-touch' transformation in public services. *Public Money & Management*, 43(2): 183-186. https://doi.org/10.1080/09540962.2022.2140897

Mohr, B.J., Dessers, E. (Eds.) (2019). *Designing Integrated Care Ecosystems. A Socio-Technical Perspective*. Cham: Springer Nature.

Molina Millán, T., Barham, T., Macours, K., Maluccio, J.A., Stampini, M. (2019). Long-term impacts of conditional cash transfers: Review of the evidence, *World Bank Research Observer,* 34(1): 119–59.

Naegele, G. (2021). *The potentials of research and policies on Active Ageing: From MOPACT and EXTEND to EIWO.* Linköping: Linköping University Electronic Press.

Näre, L. (2011). The Moral Economy of Domestic and Care Labour: Migrant Workers in Naples, Italy. *Sociology*, 45(3): 396-412, https://doi.org/10.1177/0038038511399626

Nies, H., Leichsenring, K. (2018). Concepts and strategies of quality assurance in care for older people, pp. 347-372 in Boll, T., Ferring, D., Valsiner, J. (Eds.) *Cultures of care in ageing*. Charlotte: IAP.

OECD (2023a). *Health at a Glance 2023: OECD Indicators*. Paris: OECD Publishing, https://doi.org/10.1787/7a7afb35-en.

OECD (2023b). *Integrating Care to Prevent and Manage Chronic Diseases: Best Practices in Public Health*. Paris: OECD Publishing, https://doi.org/10.1787/9acc1b1d-en.

Oliveira Hashiguchi, T., Llena-Nozal, A. (2020). *The effectiveness of social protection for long-term care in old age: is social protection reducing the risk of poverty associated with care needs?* Paris: OECD Publishing (OECD Health Working Papers, No. 117).

Ophir, A., Polos, J. (2022). Care Life Expectancy: Gender and unpaid work in the context of population aging. *Population Research and Policy Review*, 41: 197-227. https://doi.org/10.1007/s11113-021-09640-z

Peine, A., Meissner, A., Wanka, A. (2024). Digitalisation and population ageing: Social Policy Dimensions of the digital divide and innovation, pp. 131-150 in Leichsenring, K. & Sidorenko, A. (Eds.) *A research agenda for ageing and social policy*. Cheltenham: Edward Elgar.

Plank, L., Volmary, H., Blaas, W., Krenn, M. (2023). *Shareholderorientierte transnationale Investoren in der kritischen sozialen Infrastruktur*. Wien: Verlag Arbeiterkammer Wien.

Quashie, N.T., Wagner, M., Verbakel, E., Deindl, C. (2021). Socioeconomic differences in informal caregiving in Europe. *Eur J Ageing*, 19(3): 621-632. doi: 10.1007/s10433-021-00666-y.

Rocard, E., Llena-Nozal, A. (2022). *Supporting informal carers of older people: Policies to leave no carer behind*. Paris: OECD Health Working Papers, No. 140. https://doi.org/10.1787/0f0c0d52-en

Rodrigues, R., Leichsenring, K., Winkelmann, J. (2014). *The 'Make or Buy' Decision in Long-term Care: Lessons for Policy*. Vienna: European Centre.

Rothgang, H. & Müller, R. (2021). *BARMER Pflegereport 2021. Wirkungen der Pflegereformen und Zukunftstrends*. Berlin: BARMER (Schriftenreihe zur Gesundheitsanalyse – Band 32).

Schilliger, S., Schwiter, K., Steiner, J. (2023). Care crises and care fixes under Covid-19: the example of transnational live-in care work, *Social & Cultural Geography*, 24(3-4): 391-408, https://doi.org/10.1080/14649365.2022.2073608

Schulmann, K., Reichert, M., Leichsenring, K. (2019). Social support and long-term care for older people: The potential for social innovation and active ageing, pp. 255-286 in Walker, A. (Ed.) T*he future of ageing in Europe – Making an asset of longevity*. Singapore: Palgrave Macmillan.

Simmons, C., Pot, M., Lorenz-Dant, C., Leichsenring, K. (2024). Disentangling the impact of alternative payment models and associated service delivery models on quality of chronic care: a scoping review, *Health Policy*, 105034. https://doi.org/10.1016/j.healthpol.2024.105034

Sinyavskaya, O. (2024). The future of active ageing and related needs for research, pp. 83-98 in Leichsenring, K. & Sidorenko, A. (Eds.) *A research agenda for ageing and social policy*. Cheltenham: Edward Elgar.

Sturgiss, E., Peart, A., Richard, L., Ball, L., Hunik, L., Chai, T., ... Stewart, M. (2022). Who is at the centre of what? A scoping review of the conceptualisation of 'centredness' in healthcare. *BMJ Open*, 12(5), e059400. https://doi.org/10.1136/bmjopen-2021-059400

Tang, L.H., Thygesen, L.C., Willadsen, T.G., Jepsen, R., la Cour, K., Frølich, A., Møller, A., Jørgensen, L.B., Skou, S.T. (2020). The association between clusters of chronic conditions and psychological well-being in younger and older people – A cross-sectional, population-based study from the Lolland-Falster Health Study, Denmark. *Journal of Comorbidity*, 10, https://doi.org/10.1177/2235042X20981185.

Tronto, J.C. (1993). *Moral Boundaries: A Political Argument for an Ethic of Care*. New York: Routledge.

Tur-Sinai, A., Teti, A., Rommel, A., Hlebec, V., Lamura, G. (2020). How many older informal caregivers are there in Europe? Comparison of estimates of their prevalence from three European surveys. *International Journal of Environmental Research and Public Health*, 17(24): 9531. https://doi.org/10.3390/ijerph17249531.

Valokivi, H., Carlo, S., Kvist, E., Outila, M. (2023). Digital ageing in Europe: A comparative analysis of Italian, Finnish and Swedish national policies on eHealth, *Ageing & Society*, 43(4): 835-856. https://doi.org/10.1017/S0144686X21000945

van der Knaap, T., Smelik, J., de Jong, F., Spreeuwenberg, P., Groenewegen, P.P. (2019). Citizens' initiatives for care and welfare in the Netherlands: an ecological analysis, *BMC Public Health*, 19: 1334, https://doi.org/10.1186/s12889-019-7599-y

Verbakel, E. (2018). Informal caregiving in Europe. *Scandinavian Journal of Public Health*, 46: 436-447.

Walker, A. (ed.) (2019). *The future of ageing in Europe. Making an asset of longevity*. Singapore: Palgrave Macmillan.

Walker, A., Maltby, T. (2012). Active Ageing: A strategic policy solution to demographic ageing in the European Union. *International Journal of Social Welfare*, 21: S117-S130.

WHO (2007). *People-centred health care: A policy framework*. Manila: WHO Western-Pacific Region.

WHO (2010). *The WHO Global Code of Practice on the International Recruitment of Health Personnel*. Geneva: WHO.

WHO (2020). UN Decade of Healthy Ageing: Plan of Action 2021–2030, available at https://cdn.who.int/media/docs/default-source/decade-of-healthy-ageing/decade-proposal-final-apr2020-en.pdf?sfvrsn=b4b75ebc_28 (last accessed: 28 June 2024)

WHO Europe (2022). *Rebuilding for sustainability and resilience: strengthening the integrated delivery of long-term care in the European Region*. Copenhagen: WHO Regional Office for Europe.

Zigante, V. (2020). *The role of new technologies in modernising long-term care systems: A scoping review*. Luxembourg: European Commission.

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