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## *Introduction*

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### 1.1 Introduction

Societies are ageing. Everywhere. The age-mix of populations is always shifting due to variations in numbers of births and deaths, as well as immigration and emigration, but the next few decades will see dramatic shifts. In many developed nations, the segment of the population aged 65 and over will grow considerably. By 2050, for instance, nearly one-third of the European Union's population will be above 65 years old, and in much of Europe, the population over the age of 85 is projected to more than triple by the end of the century. Meanwhile, in less developed settings currently viewed as having a 'young' demographic, improvements in health care and economic growth will result in a notable surge in older age groups.

To the extent that population ageing results from people living longer lives, it is a marker of progress in areas like health care, nutrition and living conditions. Rather than viewing an ageing population as a problem, we should recognise and celebrate the myriad ways in which older individuals enhance community life. Through their work, financial decisions and social relationships, they play integral roles in our societies. As grandparents, they often provide invaluable support to families, offering care, love and a bridge to cultural and familial traditions. Intergenerational bonds foster mutual respect and understanding, as the older generation share their insights and guidance, enriching the fabric of communities.

But population ageing also brings challenges. It stokes policy makers' fears in several ways, not least for fiscal reasons. Rising pension costs, health care costs and the erosion of the workforce as older people retire make policy makers cautious about additional entitlement spending linked to population ageing. As societies grow older, there is likely to be an accompanying surge in the prevalence of chronic conditions and disabilities, whether driven by increases in the

number of older people or in the incidence of disease at older ages. Crucially for the focus of this book, population ageing is expected to contribute to additional need for health care and long-term care in countries at all levels of income and at different stages of the demographic transition. Addressing this need will require countries across the income spectrum to afford higher priority, and more resources, to historically neglected long-term care systems, but this will not happen by default or without concerted action from policy makers.

Long-term care often falls by the wayside in national policy dialogues for a range of reasons. In some countries there are cultural norms that compel families to look after older people at home. This, combined with a lack of understanding and awareness about long-term care among both policy makers and the public, means that a formal role in supporting long-term care is not perceived to be within the remit of governments. Current levels of public investment in long-term care in many countries both reflect and reinforce these norms. Some may simply look at rising health care costs and feel as though the public sector cannot shoulder more care responsibilities, and the alternative is that these responsibilities should be borne by individuals and families. This is likely to prove unsustainable, considering concurrent trends of declining fertility and increasing female workforce participation that place families with caring responsibilities – and especially women – under increasing pressure.

Public long-term care systems are in many ways best placed to meet the care needs of older people. Yet despite concerns about a ‘demographic timebomb’ overwhelming publicly financed health and care systems, population ageing has a modest and gradual effect on health expenditure forecasts when compared to conventional cost drivers such as technological innovation and price growth. The challenge is to enable people to remain healthy and independent for as long as possible, and long-term care systems themselves have a vital role to play in this. To the extent that population ageing will place additional stress on health systems, strong long-term care services can offer a crucial means of alleviating pressure on acute services. In many cases, they are also better able to provide the specialised support that older people may need.

In many countries, this potential has yet to be realised. Chronic underinvestment has left many formal long-term care systems bereft of the resources needed to meet existing needs, let alone those of the future. This was made apparent during the Covid-19 pandemic when

long-term care recipients living in institutional settings experienced disproportionately high mortality rates in many countries. A failure to protect vulnerable groups, including older people in general and care home residents in particular, has emerged as a significant factor in post-Covid-19 inquiries (Dyer, 2022; Claeson & Hanson, 2021). Far from being a distant concern for future generations, the pandemic has laid bare the urgency of addressing the gaps and weaknesses in long-term care systems. Against this backdrop, the purpose of this volume is to set out the arguments, grounded in theory and evidence, for increased public investment in high-quality, universally accessible long-term care. Taken together, they provide a compelling case for why and how governments can (and should) take action.

### *Should governments support long-term care?*

Government spending on long-term care has historically been low as a share of economic resources, even in countries with mature welfare states. At the same time, public expenditure on long-term care in European countries is projected to almost double by 2070. This may appear concerning, but must be put in perspective: public expenditure on long-term care is starting from a low base in most countries, with families bearing the majority of the burden. Even if public expenditure on long-term care was to double (or even treble) from current levels, it would still account for a small share of economic resources relative to other areas of social expenditure such as health care and labour market policies (European Commission, 2018).

If long-term care does not pose a singular challenge to fiscal sustainability, some may still argue that it is a sector best left to the markets, where those who can afford to pay for it do so, and those who cannot are looked after by family. Even putting aside the equity implications of this, private insurance markets for long-term care are still very limited, in part because those who perceive themselves to be at low risk of needing long-term care are unlikely to enrol, leading to a high concentration of risks among enrollees and consequently high premiums. Even in countries where cultural norms lead families to provide most long-term care, government has a vital role to play in ensuring that caregiving does not impoverish or otherwise burden families unduly, and in ensuring that those requiring care receive the care they need, regardless of whether it is provided formally or informally.

### *Consequences of underinvestment in long-term care*

The cascading effects of underinvestment in long-term care are profound and far-reaching. A principal consequence is a lack of access to quality long-term care: there may simply not be enough facilities or caregivers to meet the demand. The implications of this shortfall are stark: extended wait times, limited choices for those in need of care, and individuals who require care not being able to access it at all. Inadequate funding leads to insufficient staffing, low pay for caregivers, lack of training and limited resources, all of which detrimentally affects the standard of care provided. A lack of public funding for long-term care also contributes to high out-of-pocket (OOP) expenditures, which prove financially debilitating for many families and also engender poor health outcomes. Those who cannot afford to pay for private care find themselves disproportionately affected, leading to an increase in inequality in access to care and in health outcomes.

Inadequate access to care (or access to only inadequate care) leads to avoidable health complications and a deterioration of overall well-being. This not only negatively impacts the individuals receiving care and their families, but has a direct impact on the wider health system. Hospitalisations and acute care, in general, are significantly more expensive than preventive and long-term care. Consequently, a health care system may face exacerbated strain, causing a surge in health care costs. Without sufficient investment in the long-term care workforce, caregivers may find themselves overworked and underpaid, which can result in high levels of burnout and turnover, resulting in a shortage of qualified caregivers, and by extension, a further decline in the quality and availability of care. The strain also extends to informal caregivers, typically family members, who are compelled to fill the gaps left by insufficient professional care. The responsibilities they shoulder often go beyond their capacities, leading to physical, emotional and financial stress. Moreover, the additional burden on caregivers might affect their career prospects and their ability to care for younger generations (for example, their children or grandchildren).

As the high number of deaths in care homes in many countries during Covid-19 (Comas-Herrera et al., 2020) revealed, long-term care is simply not fit for purpose in many countries. The existing deficit is so great that even a doubling of public expenditure as a share of GDP by 2070 may not be sufficient to meet the growing needs of older

individuals or protect them from the potential burden of catastrophic expenditure associated with household spending on long-term care.

The core argument of this volume is twofold: firstly, it is imperative that public policies pertaining to long-term care are re-evaluated and revamped to ensure the wellbeing and financial security of both older individuals and their caregivers, while also mitigating the long-term societal costs associated with inadequate long-term care provision. Secondly, long-term care is itself a driver of economic growth, creating jobs and freeing up carers to return to the formal workforce. Accordingly, while significant public investment is needed, it should be seen precisely as such – an investment in the health, wellbeing and prosperity of our societies – rather than a cost. This volume provides an international evidence base to support this rethinking of long-term care and its role in our societies, and we hope it will be of practical value for those seeking to communicate the case for change.

### *What do we mean by long-term care?*

A range of long-term care definitions exists, many of which differ in terms of providers, care users, settings and the degree of formalisation they refer to (OECD, 2017; WHO, 2019; WHO, 2021). In this book, we largely subscribe to the definition proposed by the World Health Organization (WHO), which states that:

Long-term care 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. (WHO, 2022:3)

The WHO definition is broad. It includes both social and medical services, which constitute two key dimensions of long-term care, as well as care services provided formally and informally. The activities involved in long-term care range from services aimed at maintaining independence and social participation, from prevention and rehabilitation, to assistive support with activities of daily living, and palliative care. Government support for long-term care may be targeted to support family members and other unpaid carers. These services may vary in their aims: respite, psychological support and cash and other benefits aim to reduce the impacts and costs of caring experienced by carers,

while other services such as training aim to support the carers in their caring activities.

Depending on individual needs and the country context, long-term care can be provided at home or in the community, or in different kinds of facilities and institutions. Such facilities can comprise residential centres for assisted living, skilled nursing care facilities or community care centres, as well as health centres and hospitals. People that provide this care have a wide range of clinical and personal skills, and frequently involve teams of people with a range of qualifications. A great deal of long-term care is also provided by household members and people in the community.

The definition of long-term care used in this book does not generally include what has come to be called ‘post-acute’ care: physical and occupational therapy and skilled nursing care that typically are provided for a short period of time to help a person recover from an acute medical incident such as a stroke or surgery. Furthermore, although this book focuses primarily on long-term care needs for populations as they age and face functional decline, it is important to note that anyone with limitations in functional abilities, regardless of age, may require long-term care.

### *What is a ‘good’ long-term care system?*

As this book will discuss, the characteristics of formal long-term care systems can vary markedly across, and even within, countries. However, long-term care system should aim at reaching common goals and adhere to common standards and principles. The WHO Framework for countries to achieve an integrated continuum of long-term care describes the goal of long-term care systems as:

to ensure that an individual who has significant declines in physical or mental capacity can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfilment and human dignity. The goal of long-term care also includes the provision of comfort and well-being for individuals at the end of life and for their families. (WHO, 2021:7)

In order to reach such a goal, a long-term care system should have the objective of providing quality, sustainable and equitable services to older

people in need. It should be person-centred (aligned with the person's values and preferences), and proactive in optimising older people's functional ability and empowerment over time (compensating for the loss of intrinsic capacity). Finally, it should offer services that allow older people to live in their community for as long as possible, without compromising the wellbeing of informal carers and care workers.

As discussed throughout this volume, governments need to invest in key synergic elements to achieve the above objectives. These elements can be summarised as: governance, service delivery, financing, infrastructure including information systems and the care workforce. In particular, a good long-term care system needs solid governance to coordinate multisectoral stakeholders and accountability mechanisms, as well as legislation to enhance transparency, equality and effectiveness of service access and care quality. A long-term care system needs to establish clear definitions of the types of services that are offered, clear eligibility conditions based on applicants' needs, and an established quality management process to ensure good quality service provision. A long-term care system needs to be financially sustainable, meaning it can raise funds to ensure quality service provision and adequate coverage for the eligible population, thereby protecting older people from financial impoverishment associated with long-term care costs, while also incentivising efficiency in care provision and care utilisation and quality. A long-term care system needs infrastructure, including an integrated information system to inform providers and policy makers on the outcomes of care provision and to facilitate quality control. Finally, a long-term care system needs to support formal care workers in their training and socioeconomic wellbeing, as well as meeting the physical, emotional and financial needs of informal carers.

## 1.2 An overview of this volume

This book is structured in two parts. Part 1 (chapters 2 – 5) establishes the context and motivation of the book and explores 'what works' in designing long-term care systems and services, while part 2 (chapters 6 – 10) makes the case for investing in strong long-term care systems. It concludes with a chapter which brings the arguments together. Here we provide a brief summary of the contents and key arguments in each chapter:

*With demography driving increasing demand for care, policy makers need to rethink care mixes and invest in a sustainable and high-quality formal and informal workforce for future decades*

Chapter 2, by Bo Hu and Raphael Wittenberg, describes the drivers of the increase in the demand for long-term care around the globe, and what this means for economies, societies and public policy. Declines in infant mortality, fertility and premature death have enabled longer life expectancy in many countries. The number and share of older persons 65 years and older are gradually increasing, leading to an increase in the demand for long-term care in all countries, and proportionally more in countries with a currently younger population. Moreover, the authors note the increase of older people in need of dementia care, which is particularly intensive. Such rising demand for long-term care prompts the authors to reflect on the scope for more effective long-term care service mixes. The authors argue that policy should support the ongoing paradigm shift away from nursing home services and towards de-institutionalisation (support for ‘ageing in place’ home-based care, provided either formally or informally). They also demonstrate why it is vitally important to raise the awareness of long-term care as a social and human right and build a robust regulatory framework to continually monitor and improve the quality of care in the system. The authors warn that, with lower fertility and changes in labour market participation rates, policy interventions are needed to, on the one hand, keep an adequate supply of informal caregiving in place and, on the other hand, invest and develop the long-term care workforce to prevent shortages and maintain acceptable quality levels through training and career structures.

*Expanding long-term care eligibility rules can reduce inequalities and increase coverage and wellbeing*

Chapter 3, by Ludovico Carrino, Mauricio Avendano, Tiago Cravo Oliveira Hashiguchi, José Carlos Ortega Regalado and Ana Llena-Nozal draws from the experience and reforms in developed long-term care settings, to discuss features, limitations and consequences of legislation that regulates access to public long-term care resources. The



authors highlight that, to a greater extent than in health care settings, the lack of a common framework for measuring long-term care needs leads to large variation in the operational definition of eligibility rules, even among mature welfare systems. This raises equity concerns: otherwise similar individuals are eligible for very different long-term care benefits depending on the rules they are subject to, which translates into different care utilisation rates. The authors empirically show that policies which expand eligibility to domiciliary long-term care would lead to higher utilisation of home-based care and lower unmet needs. Furthermore, the authors argue that the effectiveness of long-term care rules depend also on their degree of transparency, with complex and intricate legislation contributing to access barriers vulnerable older people and their families. Finally, the chapter shows that by expanding eligibility rules and hence care use, governments can improve the mental health and wellbeing outcomes of older people. This suggests that a policy shift towards coverage for publicly funded home-based care may be justified in terms of increased societal welfare.

### *Improving access and efficiency in long-term care service delivery: recent trends*

Chapter 4, by Florian Tille, Astrid Eriksen, Stefania Ilinca and Ewout van Ginneken, illustrates country experiences in improving the efficiency of long-term care service delivery. The authors highlight several key trends in Europe to improve efficiency and access to required services. These include integrated delivery of health and social services, and a shift to de-institutionalisation towards home and community-based care. The authors also note a shift towards privatisation in the delivery of long-term care. Their analysis, based on case studies from Germany, Japan, Norway, Romania and Sweden, highlights the interdependence between the existing systems of long-term support in each country, the political pressure to act depending on the scale of the challenges, and the resources available. The authors conclude by stressing several critical factors that can facilitate better access and quality care, including investments in appropriate skills and numbers for the long-term care workforce and in digital technology.

*Public and private spending for long-term care is low given increasing care needs*

Chapter 5, by Adelina Comas-Herrera, Eva Cyhlarova, Ishtar Govia, Jayeeta Rajagopalan and Zhanlian Feng, discusses the multiple ways in which long-term care is financed around the world, for both emerging and mature long-term care systems. Funding sources range from unpaid, yet very valuable, informal support, to charitable support, to large private OOP payments, or to the yet relatively undeveloped insurance market. The authors then focus on public financing of long-term care (universal vs means-tested). Overall, multiple financing systems are involved in long-term care, although in low- and middle-income countries (LMICs) the role of the public sector is smaller and informal support is larger than in mature economies. While comparisons across the world are challenging, partly due to the difficulties in valuing informal care, public and private long-term care spending in mature economies (1.5% of their GDP) is low relative to health spending (9%). Increases in long-term care expenditure require unpopular increases in social insurance taxation or contributions. Low expenditure has hidden consequences for societies and economies.

*Levers for quality improvement are underdeveloped and require long-term investment and reforms*

Chapter 6, by Juliette Malley and Valentina Zigante, illustrates the major challenges and policy strategies adopted to monitor and improve quality in long-term care services at three different levels: individuals, care providers and care systems. The authors review government strategies to improve the quality of long-term care for care users and caregivers, by empowering care users: by giving them freedom and information to choose the care path they need, by investing in the skills of the existing workforce, and by establishing formal career structures which are currently only present in a few countries. The authors then argue that improving the quality of long-term care also requires governments to focus on care-providing organisations and the range of services they deliver. More long-term investment is needed to increase the quality of home care settings, in order for home care to constitute a solid and sustainable

alternative to institutional long-term care. Similarly, the authors review efforts to improve the quality of institutional long-term care by making its environment more home-like and person-directed, although such interventions are significantly costly. Moreover, the chapter elaborates on how new technologies can help organisations to deliver better and safer home-based or institutional long-term care, and argues that more research is needed to provide evidence-based recommendations. Finally, the authors focus on quality improvements from a system-wide perspective. To this end, the chapter discusses the role of legislation in limiting market failures by reducing asymmetric information and making care users more aware of their rights and their choices, imposing quality control procedures, and ensuring a higher degree of standardisation of care practices.

*An underfunded long-term care system undermines the sustainability of health care systems*

Chapter 7, by Gemma Frances Spiers, examines the relationship between long-term care and health systems. According to the author, the health and long-term care needs of older adults are interconnected. Systems that effectively support older adults to maintain independence are crucial for their overall health and the health of family caregivers. On the other hand, a lack of investment in long-term care can negatively impact older adults' ability to age with dignity and wellbeing. Hospitals are not appropriate settings for long-term care, and prolonged stays in hospitals can harm overall health and wellbeing. While measurement of the relationship has been challenged by methodological problems, some types of long-term care are associated with reduced use of secondary level health care. This implies that long-term care acts as a substitute for health care with the potential to lessen demand on hospital services, and correspondingly, that a failure to invest and develop long-term care systems can undermine efforts to contain health care costs. Issuing a note of caution on the prospects for 'quick wins', the author highlights the importance of sustained commitment from policy makers in order to realise the benefits of strong long-term care systems.

*More government support is needed as long-term care needs lead to impoverishment of individuals and families*

Chapter 8, by Ricardo Rodrigues, Cassandra Simmons and Kai Leichsenring, focuses on measuring the impact of the need for care on the finances of users and their families. They show that individuals and families in Europe make large contributions towards long-term care, in terms of OOP payments, depletion of savings, and time spent caregiving, and that these contributions substantially increase the risk of poverty for both care users and caregivers. The authors focus on Europe and report wide cross-country variation in OOP spending for home care services. Even within a context of relatively established long-term care systems such as in Europe, one out of four care users report catastrophic payments in some settings, and the heaviest burden is concentrated among households with the lowest incomes. The authors also highlight the financial situation of informal caregivers, many of whom are already below the poverty line before the onset of caregiving, and the long-lasting impact that caregiving can have on their incomes. Such effects are larger in countries with lower public coverage for long-term care, but they are still relevant even in countries with more generous long-term care systems. This highlights the existing failures by European governments to implement effective policies to address long-standing inequities besetting long-term care systems. That this is the case even in European countries with relatively strong long-term care systems underlines a near-universal need for more investments to bridge the gap in social protection that is even wider in other countries and regions.

*Investments in long-term care increase societal wellbeing through higher social justice, solidarity and innovation*

In chapter 9, Hee-Kang Kim highlights how investing in long-term care should be a priority for governments, as its social benefits go far beyond individual care recipients and caregivers. The author revisits the perception that investing in long-term care is inefficient because it only affects the welfare of care users and caregivers while requiring substantial funding through general taxation. Drawing on case studies from the United Kingdom (UK), the Republic of Korea, the Netherlands and Denmark, the author argues that long-term care is a means to respect the rights and

dignity of both older individuals and their caregivers. A stronger long-term care system would benefit society as a whole by enhancing social justice, strengthening social solidarity, promoting social innovation, and increasing overall social wellbeing, which can pave the way to sustained economic growth. While further research is needed to better quantify and characterise such benefits, the analysis offers powerful arguments for larger investments in long-term care system.

*Investment in long-term care is key, not a hurdle, to sustained economic growth in ageing societies*

Chapter 10, by Katherine Swartz, argues that forward-looking governments aiming to enhance and sustain economic growth should invest more, not less, in long-term care. Under the assumption that population ageing slows down economic growth, countries are concerned that investing in long-term care would further slow down growth due to the need to raise further resources through taxes or public spending cuts. However, the author argues, gaps in formal long-term care systems embed an implicit tax on the labour supply of family caregivers, who face huge work/family trade-offs to supply care that would not be provided by other sources. The lack of strong formal long-term care leads to insufficient and inefficient labour markets, especially for women, with lower than optimal investment in human and physical capital, which in turn reduces economic growth. Conversely, a stronger public investment in long-term care can enable informal caregivers to take jobs that are a better match for their skills, thus increasing long-run labour productivity and economic growth. The Covid-19 pandemic highlighted this argument, as economic growth slowed when substantial numbers of people with skills and experience left the workforce due to uncertainty about family responsibilities. Investing in long-term care can address this uncertainty and contribute to the growth of communities, economies and a resilient health sector.

*Towards universal, high-quality long-term care: conclusions and reflections*

In the concluding chapter of this book, the editors present a synthesis of the arguments put forth by the authors. Bringing together contributions from social scientists (including economists, demographers and sociologists) this book offers a multidisciplinary perspective on the

impact of ageing on economies, households, health systems and societies, and the centrality of long-term care systems to how we respond. Through a collective analysis of the authors' arguments, we establish that the interests of governments align with those of care users and caregivers. We contend that identifying and investing in a comprehensive array of services aimed at preserving health and functioning, while enabling individuals to remain at home for as long as possible, will yield numerous benefits at the individual, family and societal levels. This approach has the potential to reduce the strain on health care systems, stimulate economic growth, and ultimately decrease both present and future demands for long-term care.

Almost everyone will need long-term care at some stage of their lives, either for themselves or for a loved one. While policy makers, researchers, health care professionals and advocates are key target readers, this book is also an invaluable resource for anyone with a stake in building strong long-term care systems. The book equips readers with compelling arguments that can be used effectively to advocate for increased investment in long-term care. By making use of the evidence and reasoning presented in this volume, readers can articulate the significance of universally accessible, high-quality long-term care, and effectively advocate for augmented public funding. Additionally, readers will discover a wealth of ideas and insights to inform the development of effective policies and programmes in the realm of long-term care. While the book largely focuses on high-income countries, given their more mature long-term care systems, the principles and insights shared herein can be adapted and applied to various socioeconomic contexts. As the editors, we hope that the evidence and arguments presented in this book will empower policy makers to construct persuasive cases for the sustained commitment to building long-term care systems that will be necessary to meet the challenges of our ageing societies.

### 1.3 References

- Claeson, M., Hanson, S. (2021). COVID-19 and the Swedish enigma. *The Lancet*, 397(10271), 259–261.
- Comas-Herrera, A., Zalakaín, J., Lemmon, E., Henderson, D., Litwin, C., Hsu, A. T., et al. (2020). *Mortality associated with COVID-19 in care homes: early international evidence*. London: International Long-Term

Care Policy Network, Care Policy and Evaluation Centre, London School of Economics and Political Science. Available at: <https://ltccovid.org/wp-content/uploads/2020/05/Mortality-associated-with-COVID-3-May-final-5.pdf>.

Dyer, C. (2022). Covid-19: Policy to discharge vulnerable patients to care homes was irrational, say judges. *BMJ*, 377:o1098. doi: 10.1136/bmj.o1098. PMID: 35487509.

European Commission (2018). *The 2018 ageing report: economic and budgetary projections for the EU member states (2016–2070)*. Luxembourg: Publications Office of the European Union (Institutional Paper No. 79).

OECD (2017). Recipients of long-term care. *Health at a glance 2017: OECD indicators*. Paris, OECD Publishing.

WHO (2019). *Integrated care for older people (ICOPE): guidance for person-centred assessment and pathways in primary care*. Geneva: World Health Organization.

WHO (2021). *Framework for countries to achieve an integrated continuum of long-term care*. Geneva: World Health Organization. Licence: CC BY-NC-SA 3.0 IGO. p. 7

WHO (2022). *Rebuilding for sustainability and resilience: strengthening the integrated delivery of long-term care in the European Region*. Copenhagen: WHO Regional Office for Europe. Licence: CC BY-NC-SA 3.0 IGO.