

European Observatory on Health Systems and Policies

The Care Dividend

Why and How Countries Should Invest in Long-Term Care

Edited by Jonathan Cylus, George Wharton,
Ludovico Carrino, Stefania Ilinca,
Manfred Huber and Sarah Louise Barber

CAMBRIDGE





The Care Dividend

Long-term care often falls by the wayside in national policy dialogues. As populations age around the world and the prevalence of chronic conditions increases, greater numbers of people will need care and support, putting added pressures on acute-care facilities, communities, and families, among others. This increase in demand for long-term care raises questions about the capacity of governments to provide access to needed care, how these services will be properly resourced and who should receive these benefits. *The Care Dividend* provides a roadmap for investing in long-term care systems. It argues for increased public investment in high-quality, universally accessible long-term care and explains why these systems benefit everyone: households, health systems, economies, and societies. Bringing together a team of academics and policy experts from around the world, this book explains why and how governments can, and should, take action. This title is also available as Open Access on Cambridge Core.

Jonathan Cylus is the head of the European Observatory on Health Systems and Policies' London Hubs and a Senior Health Economist in the WHO Barcelona Office for Health Systems Financing. His main research is on health systems, focusing primarily on health financing policy, health economics and health system performance, as well as on the economics of population ageing. He has worked on these topics in a wide range of countries, as well as with the European Commission, OECD and WHO.

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European Observatory on Health Systems and Policies

The volumes in this series focus on topical issues around the transformation of health systems in Europe, a process being driven by a changing environment, increasing pressures and evolving needs.

Drawing on available evidence, existing experience and conceptual thinking, these studies aim to provide both practical and policy-relevant information and lessons on how to implement change to make health systems more equitable, effective and efficient. They are designed to promote and support evidence-informed policy-making in the health sector and will be a valuable resource for all those involved in developing, assessing or analyzing health systems and policies.

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European Observatory on Health Systems and Policies



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The European Observatory on Health Systems and Policies supports and promotes evidence-based health policy-making through comprehensive and rigorous analysis of health systems in Europe. It brings together a wide range of policy-makers, academics and practitioners to analyse trends in health reform, drawing on experience from across Europe to illuminate policy issues.

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1 *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 enrolees 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.

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2 *Historical and future drivers of long-term care demand*

BO HU, RAPHAEL WITTENBERG

2.1 Introduction

This chapter provides an overview of the key drivers of demand for long-term care. Research on this topic has proliferated in the past few decades, and there are good reasons for this. Identifying the drivers of care demand helps in understanding and determining the required distribution of long-term care resources in the population and can aid the detection and minimisation of any potential inequality in care utilisation and social injustice. In the context of global population ageing and a changing pattern of morbidity and disability in later life, the demand for long-term care will continue to rise and become more complex and differentiated across the world. Research on the drivers of care demand sheds light on how demand is likely to change in the future. Equipped with an understanding of the drivers of demand, policy makers and practitioners will be better prepared for any upcoming turbulence and able to make informed decisions about resource allocation. Moreover, people prefer to receive care from different sources such as professionals or family caregivers, which leads to different patterns of long-term care utilisation. A good understanding of the drivers of demand is a crucial step towards the provision of personalised care that caters for the recipients' preferences. Furthermore, understanding what drives demand for care can help guide more effective prevention initiatives and the development of targeted strategies to help contain the foreseen rise in demand.

This chapter describes how declines in infant mortality, fertility and premature death have enabled longer life expectancy in many countries. The numbers and proportion of older persons (65 years and older) are gradually increasing, which is leading to an increase in demand for long-term care in all countries, and proportionally more in countries with a currently younger population. Moreover, we note the prominent increase of older people in need of dementia care, which is

particularly intensive. Such rising demand for long-term care prompts reflection on new, more effective long-term care service mixes. As well as the necessity of an overall increase in expenditure on long-term care, we argue that policy should support the ongoing paradigm shift away from nursing home services and towards de-institutionalisation (that is, support for ‘ageing in place’ home-based care, provided either formally or informally). We 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. However, with lower fertility and changes in labour market participation rates, policy interventions are needed to, on the one hand, ensure an adequate supply of informal caregiving and, on the other hand, invest in and develop the long-term care workforce to prevent shortages and maintain acceptable quality levels through training and career structures.

The chapter is organised as follows. [Section 2.2](#) discusses the established theories that aim to explain why people use care or how they choose from different sources of care. These theories provide a useful ‘roadmap’, which has been tested and refined in empirical research. [Sections 2.3–2.6](#) review the empirical evidence on the key drivers of long-term care demand. The discussion focuses on the extent to which different factors are associated with care demand, how they have changed in the past, and what their impacts on care demand may be in the future. Drawing on empirical data, [section 2.7](#) brings together the individual drivers discussed in [sections 2.2–2.6](#) and presents the results regarding their joint and relative importance. [Section 2.8](#) reviews the existing research on the projections of long-term care demand. [Section 2.9](#) concludes this chapter with a focused discussion on the policy implications.

2.2 Theoretical perspectives

Theories of long-term care utilisation and demand have a long history. Andersen and colleagues (Andersen & Newman, 2005; Andersen et al., 1975) proposed a behavioural model of health care utilisation, which has since been used as a theoretical framework for long-term care research (Bradley et al., 2002; Burnette & Mui, 1995). According to the original behavioural model, the drivers of long-term care utilisation can be divided into three groups: predisposing factors, need factors and

enabling factors. Predisposing factors are the individual-level characteristics, such as age, gender and ethnicity, that affect people's propensity to use long-term care and are in place prior to the onset of care needs. Later, it was argued that psychosocial factors such as the expectation of receiving care, preference for self-independence, and concerns about privacy factors mediate the relationship between the predisposing factors and care utilisation (Bradley et al., 2002; Jacobs et al., 2016).

The concept of care needs takes a central role in the behavioural model as the most immediate reason for using care. Theoretically, there is a distinction between perceived needs and evaluated needs (Andersen, 1995). The former is a social construct based on people's own views and influenced by social status and health beliefs, whereas the latter is largely based on an assessment of people's health conditions by care professionals as well as on eligibility rules embedded in legislation (Brugiavini et al., 2017). A thorough discussion on the alternative concepts of care need, as well as the implementation of policy through eligibility rules, is included in [chapter 3](#) of this volume.

Enabling factors refer to the means and know-how that allow people to access care (Andersen, 1995). These include the availability and proximity of formal and informal care providers (Martikainen et al., 2009; Pickard et al., 2012), and the financial resources such as income and insurance that people can mobilise to purchase care. In the digital era, the internet provides another important channel through which people access information about public services. IT knowledge and skills, as an important form of human capital, are increasingly recognised as another enabling factor for care utilisation (Hu et al., 2020).

A recent development of the behavioural model has been an emphasis on the impact of societal factors on individual behaviour (Andersen and Newman, 2005). It has been pointed out that the propensity to use long-term care is strongly influenced by social norms or values. In countries or regions where family members are expected to take caregiving responsibilities, people attach great stigma to care home admissions because they are considered as the abandonment of care recipients by their family members. As a result, people are not willing to move to a care home even though their care needs can be fully met there, and they can afford the services (Shi and Hu, 2020).

The economic model of long-term care demand (henceforth 'economic model') builds upon the Grossman model of health demand (Grossman, 1972). In this model, long-term care is conceptualised as

a service that people with care needs consume to maximise their utility subject to income constraints. Demand for long-term care, therefore, is driven by a person's income, the price of services, the price and quality of close substitutes or complementary services, and the person's preferences (Kemper, 1992; Van Houtven & Norton, 2004).

Like the behavioural model, the economic model recognises the important role of care needs. However, there is a subtle difference: the economic model explicitly distinguishes between care need and care demand, with the latter taking account of a person's inherent ability and willingness to purchase services. In other words, demand arises when a person with long-term care needs seeks long-term care and is prepared to pay when the price is right. Despite this difference, there is a great overlap between the behavioural model and the economic perspective in terms of the proposed drivers of long-term care demand. In some cases, this may simply boil down to a 'labelling' issue. For example, predisposing factors in the behavioural model are considered as preference factors in the economic model. Socioeconomic characteristics and service prices, which are captured by care affordability in the economic model, are treated as enabling factors in the behavioural model.

The concept of demand for long-term care has little meaning if there is no or insufficient potential supply, although it is important to recognise that care needs persist irrespective of supply availability. Both the behavioural and economic models recognise that there are multiple sources of supply of long-term care. In many high-income countries, people may choose between formal and informal care. By comparison, formal care systems are underdeveloped in most LMICs, with the result being an overwhelming reliance on informal care. In both cases, spouses, adult children, relatives, neighbours and friends may all be potential caregivers under the umbrella of informal care.

Researchers have devoted a great deal of attention to understanding the factors influencing people's choice of either formal or informal care. Two theories, the hierarchical-compensatory theory (Cantor, 1979; Shanas, 1979) and the task-specific theory (Litwak, 1985; Messeri et al., 1993), have been proposed to explain the selection behaviour. The hierarchical-compensatory theory posits that older people's selection of caregivers follows an ordered preference based on the proximity of the relationships between older people and caregivers. The spouse is often the first choice for caregiving. In the absence of a spouse, older

people will turn to their next of kin such as adult children and other relatives. When family members are unavailable, they will seek help from friends, neighbours or formal caregivers.

The task-specific theory argues that the selection of caregivers is driven by the nature of the tasks. For example, help with personal care tasks such as eating and dressing requires frequent personal contact and a shared lifestyle between caregivers and care recipients, so the spouse is the most suitable caregiver. In comparison, help with domestic tasks such as managing finances or shopping for groceries is needed at longer intervals and can in some cases be provided remotely. Children and other family members may be better positioned to assist with these tasks. By and large, the choice between different sources of care is based on the comparative advantages of caregivers in assisting with different tasks, making care arrangements between caregivers and recipients not a random process but one strongly driven by an efficient division of labour.

Many of the theories reviewed in this section were developed in the very specific situations of a few high-income countries with distinct system characteristics. Although theories are powerful tools to guide long-term care research and inform policy making, there are debates about the extent to which these theories are applicable when our attention turns to long-term care systems outside those countries. In the next few sections, we will provide an overview of the empirical evidence in the literature and discuss the extent to which these theories are supported by the findings reported in different parts of the world.

2.3 Population ageing as a driver of long-term care demand

Older people are the main users of long-term care due to increased rates of morbidity and disability and declines in functionality as people age. A sustained increase in long-term care demand is therefore a direct result of the profound changes in the population structure in recent decades (Brändström et al., 2021; Hu & Ma, 2018; Hu et al., 2022b; Hu et al., 2022c; Kemper, 1992; Murphy et al., 2015; Suanet et al., 2012). Population ageing is a global phenomenon. There has been a continued increase in the number as well as the proportion of older people in developed and developing countries alike. It is projected that the number of older people aged 60 and over will increase by 116 per cent between 2017 and 2050, from 962 million to

2,081 million (United Nations, 2019). The demographic structure within the older population is also changing. As life expectancy continues to rise, especially in developing countries, the proportion of very old people (those aged over 85) increases much faster than the older population in general (United Nations, 2019). People of very old age are also the most intensive users of long-term care (Hu, 2020).

Population ageing is driven by decreasing fertility and mortality rates. A decline in fertility rates takes place in the context of (post-) industrialisation where the pursuit of education, employment and other personal life goals leads people to have fewer children, or to have children later in life. In some cases, government policy also plays a decisive role. For example, the One Child policy pursued by the Chinese government in the late 1970s restricted parents to having a single child, and the fertility rate has stayed low ever since (Feng et al., 2012). Lower fertility rates do not directly affect demand for long-term care but exert an indirect influence through a reduction in the number of younger adults and the availability of caregivers, which affects supply-induced demand. This will be discussed in more detail in [section 2.5](#).

Recent decades have seen an overall decrease in the mortality rate in most parts of the world, driven by improvements in living standards, advancements in medical sciences and improvements in the quality of health care. In addition, a well-designed social insurance or social security system ensures that life-saving health care services are accessible and affordable to most members of society. Reduced mortality rates contribute directly to an increase in life expectancy. As shown in [Figure 2.1](#), the life expectancy of the world population increased from 47 years in 1950 to 72 years in 2020. People in Northern America and Europe have the highest life expectancy, which stood at 79 years and 78 years respectively in 2020. Meanwhile, life expectancy in Africa and Asia has been catching up quickly. Although regional differences in life expectancy remain, those differences have diminished in both relative and absolute terms. In 1950, life expectancy at birth in Northern America was 69, compared to 37 in Africa – almost double. By 2020, the difference in life expectancy had declined to 16 years.

While population ageing is a universal trend, the population of older people increases at markedly different rates between countries and regions. Such variation is illustrated in [Table 2.1](#). It is projected that the numbers of older people in Africa and Latin America and the

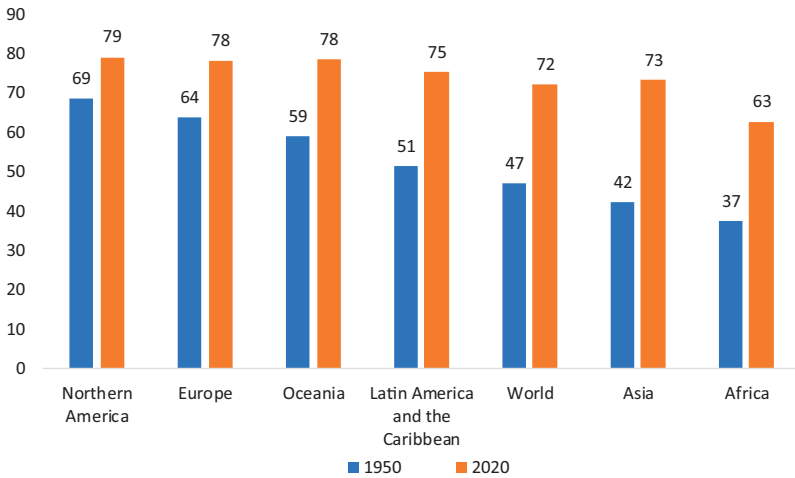


Figure 2.1. Life expectancy at birth across different regions in 1950 and 2020 (years)

Source: United Nations (2019)

Caribbean will increase by 229 per cent and 167 per cent respectively in the next three decades, faster than any other world regions. In comparison, although Europe and Northern America currently have the highest proportion of older people in their populations, this proportion is only projected to increase by 35 per cent and 57 per cent respectively by 2050. There is no doubt that governments in Europe and Northern America are currently facing much higher demand for long-term care than other regions, but it seems that Africa, Latin America and the Caribbean and Asia will be the main driver of a worldwide increase in demand for long-term care in the decades to come.

It is important to note that these population projections are based on specific assumptions about future fertility and mortality rates. There are ongoing debates about what the most appropriate assumptions are, and official statistics released by different countries show that projected numbers of older people are normally sensitive to different assumptions. In the case of the Republic of Korea, for example, in the medium population scenario the number of people aged 65 or over is projected to increase from 8.1 million in 2020 to 17.2 million in 2040 (Table 2.2). By contrast, under the high population scenario (which assumes a higher fertility rate, higher life expectancy at birth and higher net immigration

Table 2.1. *Number of persons aged 60 years or over in 2017 and 2050*

	Number of persons aged 60+ years in 2017 (millions)	Number of persons aged 60+ years in 2050 (millions)	Percentage change between 2017 and 2050	Distribution of persons aged 60+ years in 2017 (percentage)	Distribution of persons aged 60+ years in 2050 (percentage)
World	962.3	2080.5	116.2	100.0	100.0
Africa	68.7	225.8	228.7	7.1	10.9
Asia	549.2	1273.2	131.8	57.1	61.2
Europe	183.0	247.2	35.1	19.0	11.9
Northern America	78.4	122.8	56.6	8.1	5.9
Latin America and the Caribbean	76.0	198.2	160.8	7.9	9.5
Oceania	6.9	13.3	92.8	0.7	0.6

Source: United Nations (2017)

Table 2.2. *Projected number of people aged 65 years or over in Republic of Korea under different demographic assumptions, 2020–2040 (millions)*

	2020	2030	2040	% increase 2020–2040
High population	8.1	13.2	17.8	120%
Medium population	8.1	13.0	17.2	112%
Low population	8.1	12.7	16.6	105%

Source: Statistics Korea (2019)

than in the medium scenario) the projected number of older people in 2040 is 17.8 million. Under the low population scenario (lower fertility, lower life expectancy and lower immigration), the projected number of older people in 2040 is 16.6 million. The uncertainties in future

population projections will affect the precision of our projections for long-term care demand, a topic we will revisit in [section 2.8](#).

2.4 Definition of long-term care needs and demand for long-term care

Long-term care needs arise when people experience a sudden loss of, or a gradual decline in, functional capacity to perform daily tasks. Indeed, the ability to perform activities of daily living (ADL) is one of the most common measures of functional disability and long-term care needs. An important policy question is: how should this capacity and thus the level of need be defined and measured? Historically, the measurement of care needs had a strong focus on personal care. Katz et al. (1970) proposed a six-item scale, which includes eating, bathing, dressing, using the toilet, moving in and out of a bed or a chair, and continence. Meanwhile, Mahoney and Barthel (1965) developed an inventory of ten ADLs. As well as the six items in Katz et al.'s (1970) measure, they included grooming, ambulation and climbing stairs, and controlling bowels and bladder, which were treated as two separate ADLs. Functional capability to perform instrumental activities of daily living (IADL), which focus on domestic tasks, is another common measure of long-term care needs. Spector et al. (1987) pointed out that IADLs include people's ability to adapt to a changing environment. Lawton and Brody (1969) proposed an eight-item scale of IADLs which encompass using the telephone, shopping, food preparation, housekeeping, laundry, using transportation, taking medication and managing finances.

Any discussions of long-term care needs are incomplete without mentioning the environmental settings. Functional capability and environmental requirements define each other. A person can live in a house or a community comfortably and independently only when the functional capability of the person meets the requirements of the physical environment (Lawton, 1983). The extent to which the person has sufficient functional capability depends on the housing characteristics or accessible features in the neighbourhood. A house with assisted living facilities or adaptations (e.g., a lift or accessible rollator) greatly reduces the requirements imposed on older people with ADL limitations so that they can accomplish the tasks necessary for daily living themselves or with some extra help from care workers (Ball et al.,

2004). Otherwise, people living alone and with severe functional disability have no other choice but to move into a nursing home.

In addition to functional ability, it has increasingly been recognised that the onset of mental illness or cognitive impairment may trigger long-term care needs. Measurements such as the Interval Need scale (Isaacs & Neville, 1976; Willis et al., 2019) and Bristol Activities of Daily Living (BADL) scale (Bucks et al., 1996) have been designed to capture these additional dimensions. The Interval Need scale distinguishes between long, short and critical interval needs according to the intervals elapsing between the need for help. Severely mentally disturbed persons who are not responsible for their actions and who may endanger themselves or others are graded as having a critical interval need. Orientation in time and space is a key component of the BADL scale in evaluating the care needs of people living with dementia. The implication is that care professionals and policy makers should turn their attention to different measurement scales according to the specific care needs of the groups that their interventions and policies target. Additionally, as models of care evolve there is a growing recognition of the importance of holistic approaches that consider the whole person, not just their clinical or physical needs. In practice, while clinical needs and ADLs are primary factors in long-term care assessments, some countries also consider factors like social participation to provide a more comprehensive picture of an individual's needs. The policy implications of needs assessments in designing public programmes of long-term care will be explored in [chapter 3](#).

Given the multi-dimensionality of the concept, it is unsurprising that the estimated number of people needing long-term care varies according to the definitions of need. If the definition is confined to functional disabilities in ADL tasks, it is estimated that 20 million community-living older people aged 60 and over in China have long-term care needs (Hu, 2019). Another 40 million will be added to the estimate if functional disabilities in IADL tasks also count towards long-term care needs. Similarly, Kaye et al. (2010) estimated that the older population (aged 65 and over) with long-term care needs in the United States is around 2.5 million using an ADL-based definition. This rises to 5.0–5.4 million if an ADL/IADL-based definition is adopted.

The number of older people with long-term care needs in the future hinges upon two factors. The first is the age composition of the older population. The severity of functional limitations or the level of care

needs is positively correlated with age (Hu et al., 2022a; Singer et al., 2019; Zimmer et al., 2012). Therefore, as the number of older people and the proportion of older people in higher age groups rise, so will the number of people with care needs. The second factor is the age-specific prevalence of care needs. As the world population continue to enjoy added years of life in the future, debates emerge about the possible health profiles of people in those years. The morbidity compression hypothesis posits that the time people spend with diseases will be compressed to a very short period of time at the end of life (Fries, 1980, 1983). In comparison, the morbidity expansion theory argues that technological advances and modern medicine reduce mortality by helping people with poor health survive longer, which implies an increase in the prevalence of morbidity over time (Gruenberg, 1977). The dynamic equilibrium hypothesis provides a more nuanced perspective: delayed disease progression means that people will spend less time in the more severe stages of a disease or disability but more time in the less severe stages (Manton, 1982).

Studies have been conducted to examine how the prevalence of care needs has changed over time. There is evidence that the prevalence of ADL disability in the United States increased steadily and that of IADL disability decreased between 1995 and 2004. Evidence from England shows a reverse pattern: a decrease in ADL disability and an increase in IADL disability between 2002 and 2008 (Chatterji et al., 2015). Jagger et al. (2016) compared the proportion of life free of disability in the older population in England in 1991 and 2011, and identified a dynamic equilibrium: the proportion of years of mild disability increased by 5.6% for men and 9.4% for women, whereas the proportions of moderate or severe disability decreased by 0.2% for men and 0.1% for women. A recent study comparing seventeen countries across the globe between 2004 and 2014 showed a significant increase in the prevalence of ADL disabilities in Belgium, the Czech Republic and Mexico, and a significant decrease in Denmark, England, Greece, the Republic of Korea, Poland and Sweden (Lee et al., 2020).

The evidence suggests divergent trends in the prevalence of long-term care needs across countries. The evidence from some countries supports the disability expansion theory, while in others it supports the dynamic equilibrium theory. To policy makers and researchers, the implication is

that there are great uncertainties regarding the age and gender-specific prevalence of care needs in the future. Under the assumption of an unchanged age and gender-specific prevalence of care needs, Wittenberg et al. (2018) projected that the number of older people with ADL limitations in England will increase from 1.75 million in 2015 to 2.95 million in 2040. In comparison, the number will increase to 3.33 million in 2040 if an annual increase of 0.5% in age-specific prevalence is assumed, and to 2.62 million in 2040 with an annual decrease of 0.5% (see Figure 2.2). As mentioned before, the exact measures of care needs matter. Using interval needs as the measurement, Kingston et al. (2018) projected that the number of older people in the United Kingdom with care needs will increase by 32 per cent, from 4.2 million in 2015 to 5.5 million in 2035. In most cases, it is highly debatable what the most appropriate assumption about future prevalence of care needs should be. One possible approach to addressing these uncertainties is for policy makers and researchers to consider a wider range of plausible assumptions and look at a range of estimates, rather than sticking to a particular set of assumptions.

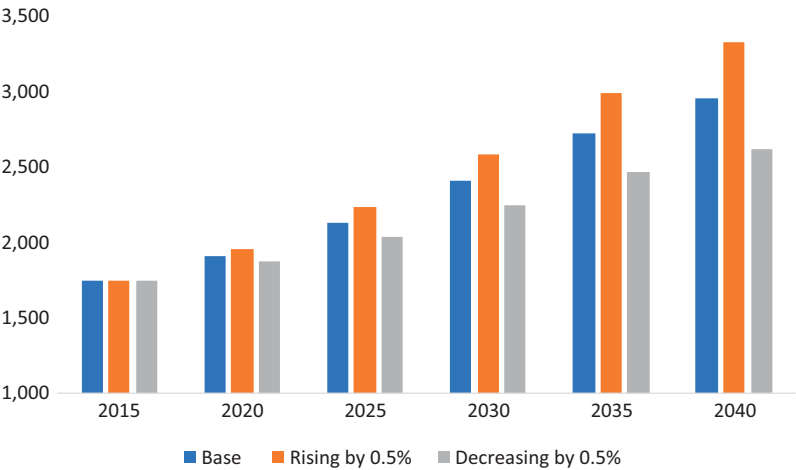


Figure 2.2. Projected number of ADL-disabled older people in England 2015–2040 under different assumptions of prevalence of disability in England (in thousand persons)

Source: Wittenberg et al. (2018)

2.5 The availability of caregivers affects the demand for long-term care

Demand for long-term care is preconditioned by the availability of caregivers. Long-term care demand is a latent construct that often cannot be observed directly. What can be observed is the utilisation of long-term care, which represents a state of equilibrium where demand matches supply. Serious policy concerns regarding unmet needs will arise where the supply of care cannot keep up with the demand. Recent policy debates on inadequate care provision have pointed to the possible consequences for care poverty (Hu & Chou, 2022; Kröger, 2022; Kröger et al., 2019).

It is useful to make a conceptual distinction between two types of caregivers: unpaid (or informal) caregivers and professional (or formal) caregivers. Unpaid caregivers such as family members, friends and neighbours assume the majority of the care responsibilities for older people in a country. Spouses are often the main caregivers of older people with care needs and play a crucial role in maintaining older people's wellbeing. This is most common among people with personal care needs (see [section 2.2](#)). Yet access to spouse care is a gendered issue. It has been widely observed that females have a higher life expectancy on average than males (Van Oyen et al., 2010). This implies that females are more likely than males to lose access to spousal care and to seek alternative care arrangements. This is especially the case for people in very old age (aged over 85). The good news is that this gender imbalance is changing. Recent evidence suggests that the gap in life expectancy between men and women has been decreasing, which is partly attributable to changed life habits and consequently a reduction in preventable deaths among males (Pattison et al., 2012). One example is the reduction in the prevalence of lung cancer as increasing numbers of men stop smoking. Improved availability of care provided by husbands is likely to boost the demand as well as the receipt of long-term care by older females.

Adult children are also important caregivers. Older people living with their children are more likely to receive care or more hours of care than those living away from their children because the costs and time associated with caregiving increase in the latter case, sometimes significantly. In LMICs, economic development has a profound impact on family structure and household composition. For example,

traditional values in China such as filial piety have been weakened as a result of rapid industrialisation and urbanisation, and nuclear families are increasingly common (Hu & Ma, 2018). As a consequence, the average household size and the proportion of older people living with their children have been declining (Zeng et al., 2008). This poses a serious threat to older people's access to care provided by their children.

Meanwhile, it should be stressed that the impact of economic development on living arrangements and care access may not fully offset those associated with culture and social norms. In the Republic of Korea, which is a high-income economy, 14 per cent of older people (aged over 65) are estimated to be single and living alone (Jang & Kawachi, 2019). This is far below the level in England, which is 34 per cent. In addition, it has been reported that 54 per cent of older people in Taiwan, China would prefer to live with their children or children's families, but only 34 per cent actually do so (Ministry of Health and Welfare, 2017). The key message is that the cultural context and informal institutions still play a visible role in shaping preferences in care arrangements, which should be duly accounted for when governments set out to design or reform long-term care systems.

Family bonds are an important but often overlooked factor in the quality of care. While marital status and living arrangements indicate the availability of an older person's support network, family bonds reflect the quality of the network. A study conducted by Silverstein et al. (1995) shows that adult daughters who feel close to their older parents and communicate well with them are more likely to provide care. Hu and Wei (2021) found that older people who are satisfied with their relationships with their spouses and children are more likely to receive adequate care and less likely to have unmet care needs.

Formal care provided by professional caregivers is an integral part of the long-term care system in many high-income countries. There is a sustained debate in the literature about the relationships between formal and informal (or unpaid) care. On the one hand, ample evidence suggests that there is a substitutive relationship between informal and formal care. A number of studies conducted in the United States and Europe show that the availability of informal care alleviates the demand for formal care (Bolin et al., 2008; Bonsang, 2009; Gannon & Davin, 2010; Van Houtven & Norton, 2004). There is also emerging evidence that the availability of formal care reduces the demand for

informal care (Hollingsworth et al., 2017; Kim & Lim, 2015). On the other hand, subgroup analysis reveals that the level of substitution between these two types of care may vary. Carrino et al. (2018) have shown how an increase in the public provision of formal care to older people with unmet needs would also lead to an increase in the utilisation of informal care. Bonsang (2009) reported that the substitutive relationships between formal and informal care disappear in older European people with a higher level of care needs. Bolin et al. (2008) found that the substitution effect is stronger in South Europe than in Central and North Europe. The relationship between formal and informal care becomes less clear-cut once we shift our lens of investigation to particular groups of older people.

2.6 Socioeconomic status as driver of long-term care demand

Socioeconomic status is an especially important driver of long-term care demand in countries with a well-developed formal care sector. Formal care is often not free-of-charge at the point of use but may require substantial user contributions towards care costs. In the United Kingdom, for example, financial support from the government is only available to older people with eligible care needs, and the receipt of formal care is subject to means testing which the government uses to decide on the level of user contribution. Therefore, the affordability of formal care depends on the financial resources of the person with care needs and the generosity of government support. A study conducted in the United States showed that people living in states with more generous Medicaid home care programmes are less likely to have unmet personal care needs (defined as not receiving any help with ADL tasks in the presence of ADL care needs (Kemper et al., 2008)). In contrast, evidence from China suggests that where the formal sector is still under development and not widely available to the older population, preferences and demand for formal care may be less sensitive to financial indicators such as income than to other factors (Shi & Hu, 2020).

That socioeconomic status is at the centre of academic debate is also due to its close connection to social equality and distributive fairness. There is a growing body of literature investigating the distribution of long-term care resources among older people with varying levels of income and wealth. The studies conducted in Europe all confirm that the distribution of formal and informal care is more concentrated in

older people with a lower level of income or wealth (Carrieri et al., 2017; García-Gómez et al., 2015; Ilinca et al., 2017; Rodrigues & Glendinning, 2015; Tenand et al., 2020). This is largely because older people with a lower level of income or wealth are more likely to have a higher level of long-term care needs and demand. However, when it comes to long-term care inequity, namely the distribution of care resources for people with similar levels of need for care, great variations across countries start to emerge. After controlling for care needs, paid domestic help and home-based nursing are found to be more concentrated among the rich in Southern and Continental Europe, whereas countries in Northern Europe do not demonstrate significant care inequity (Carrieri et al., 2017). These findings largely resonate with the clustering of welfare states by researchers studying the typology of welfare state regimes. Nordic countries, which typify ‘social democratic’ regimes, are characterised by more state involvement in welfare provision and more progress in the reduction of inequity than countries with ‘conservative’ regimes (Aspalter, 2017). Provision of long-term care under different welfare state regimes will be discussed further in [section 3.3](#).

2.7 The joint and relative importance of demand drivers: an empirical application

As well as investigating each driver of care demand separately, it is equally useful to understand the joint importance of all drivers or the relative importance of one driver against another. Their joint importance indicates whether all of the main drivers of care demand have been considered or whether any important drivers are still missed out in the analysis. This is a crucial step that needs to be taken before we can make any reliable projections and forecasts of long-term care demand. Their relative importance helps researchers identify the structure and hierarchy of long-term care drivers. This is especially useful to policy makers and practitioners who have limited resources and thus want to prioritise their interventions for a selected number of the most important drivers. There are different approaches to quantifying the joint and relative importance of a group of drivers. One approach is by looking at whether they can accurately predict the outcome of interest. This involves using the drivers of interest and adopting the machine learning approach to build a prediction model (see [Box 2.1](#)) and then comparing the predicted outcomes with the actual outcomes shown in the data.

Box 2.1. Machine learning methods for prediction models

Machine learning is considered a branch of artificial intelligence research where algorithms are used to enable computers to learn from data and make predictions (Casanova et al., 2020; Qin et al., 2020). Machine learning has strong connections with, but is different from, mathematical statistics. It is increasingly popular due to its capability to uncover complex patterns in data and make accurate predictions. Compared with linear or logistic regression models, machine learning models can automatically capture the non-linear relationships between variables, which provides a time-efficient way to improve prediction accuracy (Hu, 2020). The commonly used machine learning models or algorithms include: random forests, XGBoost, support vector machine (SVM), Naïve Bayes, and artificial neural networks (ANN). The deep learning algorithm, which is highly effective in processing unstructured data such as text, images and videos, is a subset of the ANN where there are multiple layers of network representations (Collet & Allaire, 2018).

In this section, we present the results of a prediction analysis and report on the joint and relative importance of the demand drivers for long-term care utilisation in the older population in England. Our data came from the English Longitudinal Survey of Ageing (ELSA), which collected ageing and health-related information from a nationally representative sample of individuals aged over 50 in England (NatCen Social Research, 2020). We used data from the pooled sample for community-dwelling older people aged 65 and over in waves 6–9, covering the period from 2012 – 2019 (N=22,054).

We used the Extreme Gradient Boosting (XGBoost) algorithm to build the prediction models. The XGBoost algorithm, an efficient variant of the gradient boosting machine algorithm, is increasingly used in predictive analytics and machine learning research (Chen & He, 2016). Apart from automatically capturing non-linear relationships between the predictors and the outcome variable, it has repeatedly outperformed other machine learning algorithms such as logistic regression and support vector machines in terms of prediction accuracy.

The targets of our prediction were three binary outcome variables: (1) using informal care vs no care; (2) using formal care vs no care; and

(3) using informal care vs formal care. This meant a total of three prediction models. We examined the following demand drivers: age, gender, marital status, whether or not living with children, the number of functional limitations, living with dementia, education, housing tenure, and equivalised income. The relative importance of one predictor against another was derived by calculating their contribution to the prediction accuracy, which was normalised on a scale from 0 (least important) to 100 (most important). The cross-validation technique was applied: we built the prediction model using the randomly selected training set (70 per cent of the sample) and tested the model performance using the validation set (30 per cent of the sample). This was to detect and avoid overfitting of the prediction models.

The prediction performance of our models is presented in [Figure 2.3](#). Our model has a prediction accuracy of 0.90 for informal care vs no care. This means that the drivers correctly predict the use of informal care or no care for 90 per cent of cases. Functional capability is the most important driver. Indeed, it has such a predominant position in terms of its contribution to prediction accuracy that the importance of the other predictors looks relatively trivial. The prediction model for formal care vs no care has a prediction accuracy of 95 per cent. Functional capability is still the predominant predictor, but the contributions of the other drivers in the formal care model, especially age, are comparably larger than those in the informal care model. The policy implication is that intervention or prevention measures that focus on delaying the onset or progression of functional limitations should be very effective in alleviating the demand for formal or informal care – and arguably more effective than many other policy measures. We will discuss this point in more detail in [section 2.9](#).

Our last model predicts whether a person will use informal or formal care. This model has a prediction accuracy of 75 per cent. The relative importance of the drivers in this model is more balanced than in the other two models. It is notable that marital status is the most important predictor, which points to the central role of spousal care when people choose between informal and formal care. Functional capability is still an important predictor, but it is only half as important as marital status. Income, living with children and level of education all have a non-trivial contribution to the prediction accuracy.

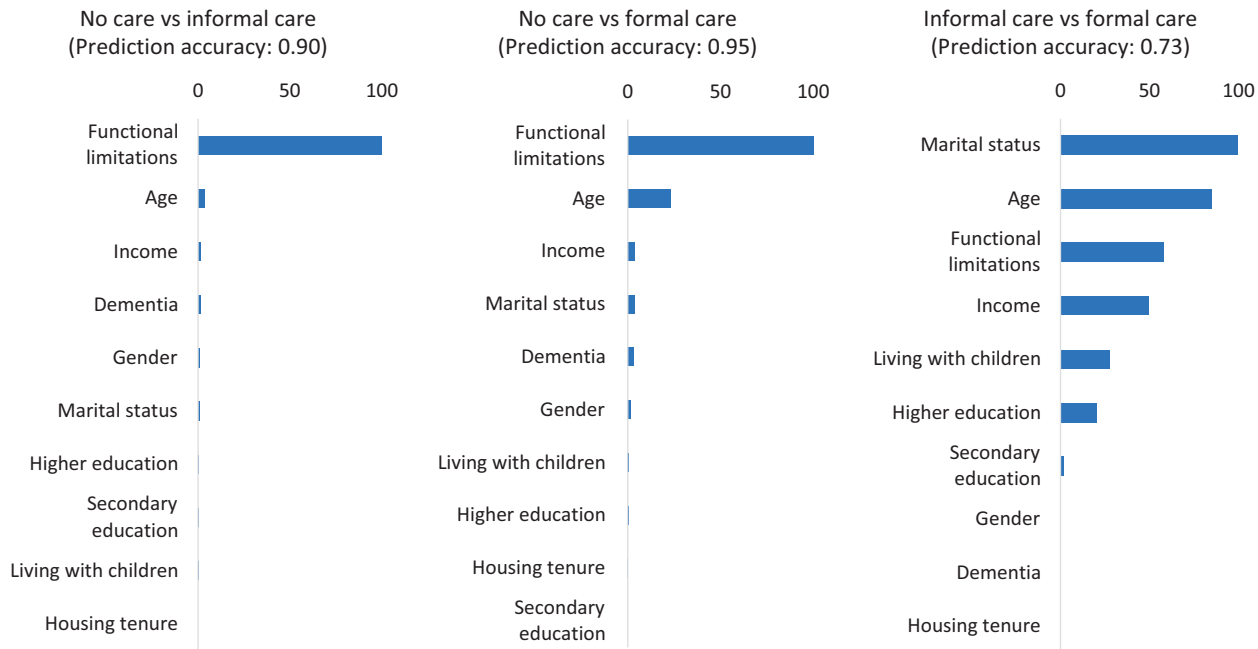


Figure 2.3. Relative importance of drivers of long-term care demand

Guided by the relative importance of the drivers shown in [Figure 2.3](#), we next used the ELSA data to look at the utilisation of formal or informal care in a selection of groups of older people, defined as follows:

- Group 1: 1–2 functional limitations, aged below 75, married;
- Group 2: 3–7 functional limitations, aged between 75 and 85, married;
- Group 3: eight or more functional limitations, aged between 75 and 85, single, living with children;
- Group 4: eight or more functional limitations, aged over 85, single, living alone, above median income;
- Group 5: group 4, living with dementia.

This provides another angle to understand how different factors combine to drive long-term care demand. As shown in [Figure 2.4](#), there are wide inter-group variations in terms of care utilisation. Eighty-five per cent of those in the first group did not use any care, 13 per cent used informal care and 2 per cent used formal care. This stands in

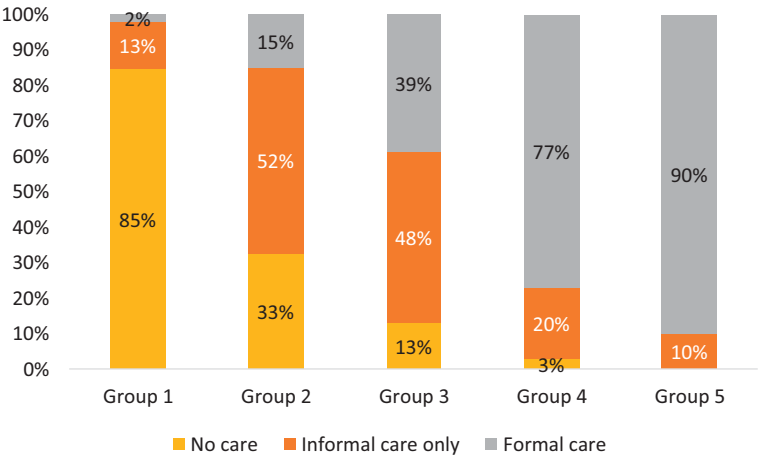


Figure 2.4. Variations in the proportions of older people using informal or formal care

Notes: Group 1: 1–2 functional limitations, aged below 75, married; Group 2: 3–7 functional limitations, aged between 75 and 85, married; Group 3: 8 or more functional limitations, aged between 75 and 85, single, living with children; Group 4: 8 or more functional limitations, aged over 85, single, living alone, above median income; Group 5: group 4, living with dementia

marked contrast to those in group five. They were all care users: 10 per cent used informal care and 90 per cent used formal care. It should be pointed out that the results presented in this section are based on data collected in England. The relative and joint importance of the demand drivers are likely to differ in other contexts.

2.8 Projecting future demand for long-term care

Projections of demand for long-term care and associated expenditure are valuable for budgeting and planning services at the local level and for developing policies at the national and local levels. They have been produced to guide reforms of long-term care systems and to assess the sustainability of current or proposed systems. The Brookings Institution produced projections for the United States when reforms were under consideration there (Wiener et al., 1994). In 1998, the London School of Economics and Political Science (LSE) produced projections for the United Kingdom when a Royal Commission was preparing proposals for reforming long-term care in the United Kingdom (Witttenberg et al., 1998). In 2006, updated projections were produced for the United Kingdom and new projections were produced for three other European countries – Germany, Spain and Italy (Comas-Herrera et al., 2006). Projections have also recently been produced for Hong Kong (Chung et al., 2009) and mainland China (Xu & Chen, 2019). The European Union Economic Policy Committee's Ageing Working Group regularly produces economic and budgetary projections for member states, which include long-term care as well as other services affected by population ageing (European Commission, 2018). What all these projections have in common is a marked increase in needs and demand for care, even under conservative assumptions.

These projections need to be distinguished from forecasts. They comprise estimates of future demand for long-term care on the basis of a set of assumptions about trends in the drivers of demand and about future patterns of care. Projecting the numbers of people needing care involves assumptions about future mortality rates and disability rates by age and gender. These may be drawn from demographic and epidemiological modelling by government statistical offices or research centres. Projections of numbers of service users require analyses or assumptions about trends in socioeconomic drivers of demand such as income and household composition. They also require assumptions

about whether the balance between unpaid care, community-based services and residential care will change or remain constant over time. Finally, if expenditure is projected, an assumption is needed regarding the future wages of social care staff. These factors are likely to be affected by government policies. Projections have generally been produced on the basis of unchanged policies and specified changes in policy that governments may be considering.

It has been projected that the number of older people receiving formal long-term care in England will rise from 0.66 million in 2015 to 1.18 million in 2040. Public expenditure on social services for this group has been projected to rise from around 0.45% of gross domestic product (GDP) in 2015 to 0.75% of GDP in 2040 (Wittenberg et al., 2018). Older people with dementia are among the most intensive users of long-term care. The costs of formal care for older people with dementia in England have been projected to rise by 300 per cent, from £9.8 million in 2015 to £39.2 million in 2040 (Wittenberg et al., 2020). It is worth noting that these projections are sensitive to assumptions about future trends in mortality and disability rates and in the real unit costs of care. Older people in other countries or regions may follow different trajectories of mortality and disability rates in the long run, so the projected increase in long-term care expenditure is likely to differ markedly from that in England. Furthermore, the rising demand for better-quality care and the recognition that professional caregivers should be better rewarded and paid will increase the unit costs of care, which in turn will elevate the projected costs of care.

2.9 Conclusion and policy implications

Demand for long-term care for older people is projected to rise worldwide over the coming decades due to rising numbers of older people, and especially rising numbers surviving to late old age when the need for care is highest. Population ageing could in principle be offset, at least partially, by declining rates of disability in old age, but it is very doubtful that disability rates will fall sufficiently to fully offset the rise in the numbers of older people.

To fully understand the implications of population ageing for long-term care demand, it is useful to distinguish between absolute and relative growth in demand. Countries with an advanced level of

population ageing face great challenges because the absolute level of care needs in older people is already enormous. Even a small proportionate increase in care demand will translate into a big rise in absolute terms. Meanwhile, countries with a younger population structure normally have a lower level of care needs in the older population in absolute terms, but this does not necessarily mean that the long-term care system is free of pressure because the relative growth in care demand may be substantial in the future.

The implications are twofold. First, countries at different stages of population ageing all need to plan for rising expenditure on long-term care and rising numbers of people working in the care sector. This requires that an increasing proportion of the economy's resources (GDP) be devoted to long-term care and a higher proportion of the workforce in the care sector. Second, long-term care policies should be carefully designed to ensure equitable access to long-term care for all older people with care needs. 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.

In the health care sector, it is well known that the supply of hospitalisation may induce its own demand where a third party provides financial support for usage. This is known as Roemer's Law, namely 'a built bed is a filled bed' (Roemer, 1961). It can be argued that this supply-induced demand also applies to nursing home utilisation and thus constitutes another driver of long-term care demand and expenditure. Use of nursing home services when this could be avoided may also be the result of how public support is set up, availability of benefits and the necessary co-payments, rather than the available supply. In addition, residential care remains the final safety net for low-income individuals in many countries with well-developed long-term care systems. To address this issue, it would be useful for policy makers to optimise the mix of services. This would involve a paradigm shift away from nursing homes and a call for heightened support for unpaid caregivers and home care services. Treating the de-institutionalisation of long-term care as a long-term goal and identifying new, innovative forms of 'institutional' care should be at the top of the government agenda.

There is evidence that policies and technologies that encourage ageing in place help people maintain their social networks and continuity in life, bringing down the long-term care costs (Graybill et al., 2014)

and improving older people's wellbeing (Wiles et al., 2012), even though ageing in place may not be suitable for every older person (Fernández-Carro, 2016). All in all, a crucial question we must address in the context of population ageing is: what mix of services best preserves health and functioning and enables people to stay at home for as long as possible and in that sense minimises current and future long-term care needs? The components of good quality rehabilitation – access to assistive devices, good nutrition, fall prevention, home adaptations and reablement services – are the key here. Policy choices should also be based on an understanding of how demand patterns may change in the future as preferences for different types of care evolve. From this perspective, more needs to be done to understand and reflect people's preferences for care, moving away from the tendency of long-term care policies to consider preferences to be of secondary importance at best, and certainly much less important than costs and efficiency considerations.

Rising demand for long-term care also has important policy implications for the workforce and the labour market. The majority of long-term care for older people is provided by unpaid carers. If the availability of unpaid care does not rise in line with the demand for care, this will place additional pressure on the demand for formal services. Rates of childlessness are rising in some countries and the average family size is falling in many countries. If the supply of unpaid care is to keep pace with rising needs, a higher proportion of people will need to provide unpaid care for a longer period. Changes in society, including rising female labour market participation and both internal and external migration, suggest that it is doubtful that the supply of unpaid care will rise in line with demand. It is therefore important that countries provide support to unpaid carers both to support their wellbeing and to enable them to combine caring with other aspects of their lives including, in many cases, employment and/or child care responsibilities (Colombo et al., 2011). This support can include information and training about caring, respite care to allow carers to take a break, financial support for carers and labour market flexibilities. It is also important to encourage the division of care responsibilities within families and communities, to reduce reliance on primary caregivers. This is crucial not only from a gender perspective but also in order to protect the health and wellbeing of caregivers.

Countries that have developed long-term care systems frequently face workforce shortages and challenges with recruiting and retaining sufficient staff to provide quality care to those who need it (Colombo et al., 2011; OECD, 2020). Countries that are developing their long-term care systems will need to recruit and retain substantially greater numbers of care staff. These two dynamics are not independent: richer countries, with more developed health and long-term care systems, continuing to recruit trained personnel from lower-income countries is exacerbating shortages in the sending countries. A global discussion around ethical recruitment in health and long-term care is long overdue and rendered more urgent by the Covid-19 pandemic.

Finally, care workers tend to be low paid and to have low qualifications and limited career prospects in the care sector. Wages for care staff may need to rise faster than wages in other sectors in order for sufficient staff to be recruited and retained. At least as importantly, the status of care staff needs to be raised, training and qualifications for care staff need to be increased, and career structures for carers need to be introduced (OECD, 2020). Given that the care workforce, both formal and informal, is overwhelmingly female, it is vital that these interventions prioritise gender equity.

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3 *Who should be eligible for long-term care in older age? Policy trade-offs and implications for coverage, equity and wellbeing*

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3.1 Introduction

The demand for long-term care is expected to rise dramatically over the next decades due to rapid population ageing. While most high-income countries have developed a system of long-term care to respond to increased demand, there are important variations in their approach to defining eligibility, coverage and equity. In low and middle income countries (LMICs), on the other hand, long-term care continues to be a largely neglected or low priority policy issue (Lloyd-Sherlock, 2014). LMICs will experience fast population ageing and will face a steep increase in the demand for long-term care in the next decades, which will require effective policy responses (OECD, 2019). Establishing a long-term care system for older people should therefore be a major policy priority for countries across the globe. An important number of older people will not be able to perform basic ADLs and will need support with them, such as getting in and out of bed, getting dressed, going shopping, doing laundry, and going out to meet friends. They will also require support with more complex tasks including managing medical care for multiple, chronic conditions.

As explained elsewhere in this volume, the first and most common source of long-term care support for older people worldwide is commonly known as *informal care*, typically provided by a spouse or adult child, or in some cases, a friend or neighbour (Colombo & Mercier, 2012). However, informal care may not be always available or may not be the preferred option. This might happen, for example, when needs are – or have become – too severe and require more intensive long-term care; when informal carers are not willing and/or able to provide support, often due to work-related time or geographical constraints; or when the person in need simply does not have an adequate social network from which to seek support (Carrino et al., 2022). In these cases, *formal care* may be necessary, that is, care provided by professional carers such as nurses, personal carers and personal assistants. While in principle people seeking formal long-term care have the option to purchase services from private providers, the costs of private formal long-term care of an acceptable quality can prove unaffordable

for people in high-income countries, and prohibitive for people in LMICs, especially if support is required for continued, recurrent or extended periods. An alternative strategy would be to purchase long-term care insurance earlier on in life but, for reasons explored in [chapter 4](#), both demand and supply of private insurance is still very limited in most countries.

Due to the fact that most older individuals will not be able to cover the full costs of long-term care, or lack insurance for long-term care costs, many countries have established local public institutions and services that are in charge of financing, organising and/or providing, at least to some extent, long-term care services. However, people seeking public support for formal long-term care will often find the process more complex than for health care. While the exact procedures differ from country to country, most systems involve a set of needs assessment tools and eligibility rules for publicly financed and/or publicly provided long-term care services. As this chapter shows, procedures can be intricate, may differ from region to region within a country, and typically involve many stakeholders as well as numerous rules with sometimes complicated calculations. People in need of long-term care and their relatives and friends may find it difficult to predict what services they are eligible for and how much these services will cost them. Moreover, as with private provision, local supply of public formal long-term care may also be constrained, for example due to shortages in skilled workers and/or low public spending.

In this chapter, we focus on the challenges that arise with the measurement of long-term care needs to determine eligibility for long-term care, as well as on the outcomes of eligibility rules on access to care and wellbeing. We focus our analysis on the case of European countries with well-established long-term care systems as they have extensive experience with the use of eligibility rules, but our aim is to draw lessons from these countries for other countries around the globe in the process of setting up long-term care systems.

Eligibility rules impact how much and what type of care individuals receive. They are useful tools to identify persons with the greatest need for care, and to ensure resources are distributed in a way that best addresses equity. And yet, we document that defining eligibility for long-term care is fraught with challenges arising from the lack of a universally agreed approach to measuring the concepts that define health and social need for long-term care, and difficulties in linking

different levels of need to the right amount and type of long-term care. As a result of the design of eligibility rules, some people with functional or cognitive limitations may either be ineligible for publicly financed and/or publicly provided long-term care, or, despite being eligible, receive an amount of support that is insufficient, and/or face additional unaffordable OOP costs of care. This may lead them to rely exclusively on informal care when this may not have been their preferred option, or go without care altogether. Living with unmet needs not only reduces their ability to live independently but may also put them at higher risk of avoidable and costly hospital care. Systems may therefore develop eligibility rules that are consistent with the objectives of the long-term care system to improve coverage and equity, while at the same time maintaining efficiency.

We argue that policy makers should consider expanding eligibility rules for long-term care. We show that existing eligibility rules are an effective policy tool to increase older people's access to care, although they are less effective for lower socioeconomic groups (e.g., lower educated groups). We also show that these rules reduce the risk of extreme poverty resulting from care costs and they improve wellbeing and quality of life.

Finally, we argue that governments around the world ought to reflect carefully about their criteria to define eligibility rules, as they are crucial to achieving key goals of the system such as universal long-term care coverage, effectiveness, people-centredness, accessibility and financial sustainability.

This chapter is organised as follows. In [section 3.2](#) we introduce the policy challenge of defining need for long-term care. [Section 3.3](#) then explores how countries in Europe undertake assessment of long-term care needs, how they differ and what the implications are for individuals in need of care. [Section 3.4](#) then provides an examination of the complexities of measuring need for long-term care, introducing concepts of disability, dependency, frailty and independence, exploring how these concepts are operationalised in needs assessments. [Section 3.5](#) goes on to look at the question of whether the availability of informal care should be taken into account in needs assessments. [Section 3.6](#) examines the effects of different eligibility rules on rates of coverage in a population, while [section 3.7](#) looks at their implications for the intensity of coverage. [Section 3.8](#) explores the role of means testing in determining eligibility. [Section 3.9](#) discusses the implications

of eligibility rules for utilisation of long-term care and the wellbeing of older people. In concluding, [section 3.10](#) draws the arguments together, highlighting key takeaways for policy makers based on our analysis.

3.2 Defining ‘need for long-term care’ is a policy challenge

A key step in determining eligibility for public formal long-term care is establishing the *need for care*. While health policy is often concerned with the question of how to deliver care based on need as determined by a medical diagnosis, the definition of need for long-term care rests on multiple contested concepts such as *frailty*, *disability*, *dependence* and *autonomy* (Brugiavini et al., 2017; Colombo & Mercier, 2012). The definition of these concepts is the subject of decades of debates in clinical gerontology, geriatrics, nursing, biodemography and sociology. Operationalising these concepts raises challenging questions for societies and governments: can populations agree on a list of tasks defined as basic or essential to maintain independent living and human dignity, and if so, how can these tasks be measured? Should an individual’s self-reported ability to perform tasks be considered among the criteria, or should other external assessments (e.g., physical performance) be required to establish a person’s ability to perform tasks? Should factors other than needs – such as financial means or availability of informal care – be considered when determining eligibility, especially in the context of tight fiscal conditions in most countries around the world? What other factors should be considered, given that governments have many competing objectives, including efficiency, equity and quality?

The question of who should be eligible for long-term care touches on critical questions about the role of the state when individuals need support with their functioning in daily life. For example, in Nordic European countries, advanced social insurance systems confer an important role on the state in financing, organising and/or providing long-term care. By contrast, in the United States, long-term care is often the responsibility of individuals and their families, except for cases of extreme poverty where Medicaid may step in to cover the costs of long-term care. When establishing the rules for eligibility, governments may have in mind specific objectives and values that respond to different concepts of the role of the state. The WHO health system framework

states that a health policy should aim to ensure universal health coverage, access and financial protection (WHO, 2007a), while the OECD health framework highlights the importance of effectiveness, people-centredness, accessibility and financial sustainability of health systems (Carinci et al., 2015).

In achieving these objectives, countries designing long-term care systems may need to take into account three important dimensions: *efficiency* in the use of limited resources; distribution according to some principle of *equity* or *social justice*; and preservation of *individual freedom* (Barr, 2012). Although most countries may agree on the importance of all three aims, they differ in the definition and weight they assign to each of them, resulting in significant variations in long-term policy. Underlying these variations are deep political and ideological debates. From a utilitarian perspective, for example, the aim of long-term care policy may be to maximise total welfare (for older people, their carers and society as a whole). In contrast, it has been increasingly argued that freedom of choice is essential for any long-term care policy, and many countries have moved towards providing more choice in the type of care received, for example through the use of cash for care programmes (Gori, 2012). The definition and weight given to each of these aims imply a normative judgement, one that requires substantial political debate.

The definition and quantification of need ultimately have important implications for one of the key tasks of any long-term system: establishing *eligibility* for publicly funded long-term care services. Most social benefits are dependent on well-defined criteria to define eligibility, such as a specific age threshold (e.g., reaching the age of 65 for pensions), being below a certain level of income (e.g., for social assistance programmes), or having contributed to an insurance programme for a defined period and experienced a well-defined shock (e.g., unemployment insurance). On the one hand, eligibility criteria are a mechanism by which governments regulate the number of beneficiaries, control costs and plan for the resources required to run the system (Buscher et al., 2011). On the other hand, eligibility criteria are also deeply rooted in complex concepts that signal whether individuals need government intervention. In this chapter we will argue that eligibility criteria for long-term care have an impact on coverage and accessibility, but they are also inherently linked to concepts related to functional

capacity, the ability to live independently, and the potential to prevent decline or compensate for the loss of function.

In the context of limited resources, several factors come into play to shape the way governments determine eligibility for publicly funded long-term care. First, the definition and quantification of need establishes whether and to what extent individuals face limitations in functioning. However, not all individuals in need will be automatically eligible for public support, and individuals with different levels of need may be assigned different levels and types of care. Typically, governments define thresholds based on some consensually agreed level of need above which individuals are considered to face difficulties in functioning independently.

Second, some governments may consider that need itself is not sufficient and incorporate some assessment of the ability to pay in the form of *means testing* based on income and/or wealth. By targeting those on the lowest incomes, governments may wish to address equity objectives under the assumption that those with enough resources will be able to purchase care in the market. Governments would therefore provide support for essential care tasks, leaving individuals to co-pay the costs of board and lodging.

Third, in defining eligibility for long-term care, a few countries consider whether individuals in need have a partner or adult child who can support them. The assumption is that family members will perform at least some of the care for their older relatives.

These differences result in varying models of long-term care provision and financing. Recent classifications (see, for example, Fernández et al., 2009; Gori and Fernández, 2015; and Barber et al., 2020) distinguish between countries that minimise state intervention and provide support only to the lowest-income subgroups in the population (*safety net* systems, such as in Australia, England and the United States); countries with a *universal* approach that aims to provide equitable access based on health needs (e.g., Denmark, Japan, the Netherlands), and *mixed systems* which combine universal entitlements with a means-tested approach (e.g., Austria, Belgium, France). As we shall see, eligibility rules and their outcomes are not necessarily homogeneous even within these typologies.

Finally, governments face a trade-off between the transparency of long-term care eligibility rules and their effectiveness in matching resources to needs, as thoroughly discussed by Fernández et al.

(2009). On the one hand, transparent and easily interpretable rules are desirable as they facilitate individuals' care allocation planning, as well as public auditing. Long-term care systems can be broadly split between those adopting algorithm-based eligibility rules, and those adopting a case-managed approach to determine eligibility. Algorithm-based systems are more transparent, as they include an explicit list of measurable tasks and thresholds that characterise the eligibility score (examples are France, Germany, Japan, Spain). Case-managed systems determine eligibility on a case-by-case basis: front-line workers (the case managers) exercise significant discretion in determining individuals' entitlement to long-term care, and the evaluation of need most often includes individual or contextual characteristics not easily measurable, such as the quality of the informal care support (examples are England, Denmark, Sweden). Case managers often follow an official guideline which does not include an explicit threshold or algorithm. Case-managed systems are therefore deemed less transparent and more complex. On the other hand, a long-term care system is more effective in matching care packages to individuals' needs if it allows for an assessment of needs that accounts for the complex interaction of the applicant's multiple circumstances, such as, for example, physical and mental wellbeing, attitudes, income, family context and support network. An algorithm-based system, although more transparent, is less effective in matching resources to needs than case-managed systems, which are more flexible and comprehensive in the evaluation of individual circumstances.

3.3 Assessment of needs and eligibility rules: how to do it and what are the consequences?

In most OECD and EU countries, a resident can apply for public long-term care services and support, but geographical coverage is not always comprehensive, coverage may not be ensured in all cases, and older people, their relatives and their advocates might find the application processes – with multiple eligibility criteria, numerous stakeholders and intricate rules – difficult to navigate.

In countries with well-established long-term care systems, eligibility is typically determined through so-called *long-term care needs assessments*, which are used to determine whether an older person is eligible for public support and services. This would ideally enhance

governments' ability to maximise access, affordability, equity (i.e. the most vulnerable are adequately protected) and efficiency (i.e. the desired level of results is achieved at the lowest cost to the public purse). One way in which needs assessments do this is by determining eligibility based on a minimum level of needs, and by associating higher intensity of care with higher severity of needs. The exact procedures employed in different countries are very heterogeneous, as detailed in recent reviews such as Gori and Fernández (2015), Oliveira Hashiguchi and Llana-Nozal (2020) and Brugiavini et al. (2017). As already discussed, eligibility rules differ, for example, depending on who conducts the assessment, which types of limitations and needs are included, the way different limitations are scored to determine overall severity of needs, whether social structures (e.g., adult children) are considered, and finally how the results from needs assessments determine eligibility for specific levels of long-term care support and services (Table 3.5 in the chapter appendix provides an overview of needs assessments in different countries).

The types of limitations and difficulties that are considered relevant in needs assessments differ from country to country. In what follows, we will mostly concentrate on countries that adopt algorithm-based eligibility rules, where the process of assessment of need is explicitly defined in the legislation. A frequent element across countries' rules is the focus on ADLs, with many programmes also including IADLs (introduced in chapter 2). However, as shown in Brugiavini et al. (2017), the way in which such difficulties are operationalised may vary greatly: for example, several countries do not include all IADLs (such as in major programmes in Italy and France, whereas in Germany IADLs are included in the assessment but not in the eligibility algorithm), and others do not include all ADL tasks (e.g., in Italy and England). Moreover, many programmes give equal weight to each ADL and IADL limitation (e.g., in Belgium, Czech Republic, England and Poland). However, existing theories in gerontology suggest that IADLs and ADLs can be interpreted within a hierarchical structure (Njegovan et al., 2001). In general, programmes that give more weight to prevention typically give a relatively higher weight to limitations in IADLs and mobility (e.g., Austria), as opposed to being focused mainly on ADL limitations (e.g., Poland), because IADLs and mobility represent more complex tasks, which tend to emerge earlier than the more basic ADL tasks.

Some assessments also take into account social activities and factors such as loneliness, cognitive status and mental wellbeing. For example, needs assessments in Belgium incorporate awareness of dangers and the ability to have a social life, while in Denmark, assessments consider the scope for rehabilitative treatment to restore functional abilities. Several countries have updated needs assessments to include not only functional limitations, like walking, but also mental and cognitive impairments. In Germany, for example, needs assessments recognise that dementia requires a different kind of support. While dementia patients may not exhibit physical impairments, they may face difficulties performing ADLs autonomously.

There is significant heterogeneity between countries in the way needs assessments aggregate different limitations to produce a single measure of overall severity of long-term care needs, which is used as a benchmark for determining someone's eligibility status. The reasons for these differences are not well understood, but are likely to involve a combination of: differences in the relative weight each system gives to concepts such as frailty and dependency; the relationship between the ministries of health and social affairs; available budgets; the supply of informal care; cultural factors (e.g., family as first line of support instead of the state); and the infrastructure and built environment, among other factors. In some countries, scores are calculated using different weights for different limitations, and needs assessments may require that the older person suffer from specific limitations to be eligible for any kind of public support. In Germany, a category called 'self-sufficiency', which is composed of thirteen indicators including eating and drinking, has the highest weight, while 'mobility' has the lowest weights. In Austria, no government support is possible if care needs amount to fewer than 65 hours of care per month. Some countries group scores into categories, which are then associated with levels of support and specific services. Categories with fewer limitations may be ineligible for public support. Countries differ in how many categories they set, how they combine scores into categories, and how categories are associated with specific care services. While some countries have three to five categories, Luxembourg sets fifteen categories based on the amount of time allocated for care per week. Moreover, the weight assigned to each ADL or IADL difficulty is typically different across programmes: some rules treat each ADL or IADL equally (e.g., in the Czech Republic), while others postulate that the impact of a loss of autonomy

differs depending on the specific limitations (e.g., in Austria). For example, difficulties in eating might be assumed to be more relevant than difficulties in dressing or in doing housework.

Not all countries have standardised long-term care needs assessments. Austria, Germany and Luxembourg have nationwide assessments using the same instruments, while Italy complements a national programme with regional ones whose criteria are different across territories. France uses a standardised assessment tool nationwide but there seems to be much variation across regions in the interpretation of the tool, generating differences in the number of beneficiaries. In Estonia, different agencies have different assessment scales and procedures. In Belgium, Canada and the United States, there are both federal and regional, state and municipal benefits and schemes, with their own specific rules and regulations. In Portugal, there is one needs assessment scale for cash benefits and another for in-kind care, the latter being left to the discretion of the private care provider. In Nordic countries (Denmark, Iceland, Finland, Norway, Sweden), municipalities are responsible for conducting needs assessments and setting eligibility criteria on a case-managed basis, although Finland is rolling out a nation-wide standardised needs assessment scale.

Countries and subnational areas differ as well in terms of the staff involved in long-term care needs assessments. A number of countries use multidisciplinary teams to perform assessments and the composition of the teams varies across countries. In Belgium and Finland, multidisciplinary teams conduct needs assessments. In Latvia, the teams include general practitioners (GPs) and social workers, while in Germany specialised doctors and nurses are involved. In Austria and England, assessments are based on a physician's evaluation. In California (United States), a social worker performs the assessment. In Japan, a computer-aided initial assessment (based on an 85-item questionnaire) is used to assign each applicant to one of seven levels of long-term care need. The Japanese Care Needs Certification Board, a committee composed of medical and other professionals, then reviews the results from the initial assessment.

In many countries, long-term care rules and benefits are decentralised. For example, the Austrian long-term care system consists of three pillars. The first pillar is a cash benefit, the second one consists of measures to support caregiving relatives, and the third pillar consists

of in-kind benefits. The first two pillars are the responsibility of the federal government, while the federal states are responsible for providing the third pillar. In Belgium, competencies are shared between the federal government, the communities (the Dutch-speaking or Flemish community, the French-speaking or Walloon community and the German-speaking community) and the Brussels Capital region. The Belgian long-term care system consists of ‘a mix of different services and measures, funded through different sources and organised at different levels’ (Pacolet & De Wispelaere, 2018:5). In Estonia, social welfare services are organised at both the state and municipality level, and personal care services are mostly organised by the local government (Paat-Ahi & Masso, 2018). In Italy, the public long-term care system is organised around two pillars (Matteo et al., 2018): first, the companion allowance, which is a cash benefit run centrally by the National Institute of Social Security; and second, home and residential care services provided by municipalities (personal care) and regions (health and nursing care).

Finally, eligibility for public long-term care support may also depend on social networks and external factors, such as the availability of an informal carer (this is the case in Croatia, Italy, the Netherlands and Ireland). We will discuss this in [section 3.5](#).

By the age of 65, most individuals will have accessed the health care system multiple times throughout their lives. They are likely to know enough about the health care system to be able to understand and anticipate what type of needs merits which type of care, where to access it, and whether they will be able to afford it. At the very least, they know where to find help navigating the system, typically through their local GP or family doctor. This is not necessarily true for the long-term care system, which most 65-year-olds may have never accessed before and, of which they may have a limited understanding (Bottery et al., 2018). Even identifying where to seek help may be challenging. Even more challenging is determining how much care will cost them out of pocket, given the very intricate rules and calculations that are used in many countries (see annex E in Hashiguchi & Llana-Nozal, 2020). While there is limited research into how well populations understand the eligibility requirements and OOP costs of long-term care, a cursory look at the rules in some countries suggests some older people might not be able to predict their eligibility and costs.

3.4 The challenge of defining and measuring long-term care need and eligibility for care

Measures of functioning are generally stronger predictors of outcomes in older age than single diseases. However, health surveillance systems are often developed around specific diseases such as cancer or cardiovascular disease, while there is no system focused on collecting information on functioning. This is partly due to disagreements on the definitions of long-term care need and instruments. Specific instruments do exist to measure specific dimensions of functioning, such as physical or cognitive function, but these instruments are often used for specific research or clinical purposes. Part of the challenge arises from the difficulty with defining key concepts, particularly *dependency* and *disability* in older age.

The International Classification of Functioning, Disability and Health (ICF) (WHO, 2007b) and the UN Convention on the Rights of Persons with Disabilities (UN, 2006) offer an ‘individualistic’ definition of dependency, ratified by the European Union (Becker, 2018). The UN definition states that ‘persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others’ (UN, 2006: Article 1). This definition emphasises impairments in individual function as the key element determining whether older individuals experience disability and dependency. In line with this concept, the assessment of dependency is often based on one of a number of scales that cover various dimensions of capacity or incapacity.

Many instruments are based on ADL scales. The rationale is that individuals unable to perform key everyday activities on their own (e.g., walking, getting out of bed, bathing) are considered to be dependent. These scales identify both whether individuals may be in need of care and the degree of dependency, by measuring and weighting the number of activities with which individuals experience difficulties, as well as the level of difficulty experienced. The expectation is that these scales provide a systematic assessment that allows comparisons across individuals and over time. Disability is primarily diagnosed based on self-reports of difficulties with tasks, but performance-based tests to measure function are increasingly available in clinical and research settings. The most common scales include assessment of disability in self-care

tasks (ADLs), household management (IADLs) and risk of mobility limitations (Chaves et al., 2000; Fried et al., 2004).

Although each country's framework applies a somewhat different definition (e.g., some systems emphasise deficiencies in performing common household chores, while other systems emphasise limitations with physical or psychological functioning), all systems imply a definition of dependency that hinges on the loss of *autonomy* to perform certain activities of daily life. The assessment of whether a person is dependent on long-term care is typically made by trained personnel, and it is used for decisions regarding the provision of long-term care and other social benefits. In some countries, such as the Nordic European countries, the assessment is made to measure the level of dependency and to establish the amount and specific type of care that individuals may require (Becker, 2018). In other countries, the assessment of dependency may be also be used for classifications of individuals based on a detailed point system, on the basis of which eligibility for cash benefits is established.

A critique of the focus of long-term systems on disability and dependency is that these concepts do not reflect the full spectrum and trajectories that characterise the process of ageing. In response, frailty is also often evoked as an important and distinct concept in understanding ageing and resilience in older age.

WHO defines frailty as 'a clinically recognisable state in older people who have increased vulnerability, resulting from age-associated declines in physiological reserve and function across multiple organ systems, such that the ability to cope with everyday or acute stressors is compromised' (WHO, 2017:VII). Ageing individuals move along a continuum that stretches from robustness to pre-frailty, frailty and care dependence. Frailty is thus a different concept than disability and may be critical to identifying opportunities for prevention and care.

Two major models to define frailty exist: the frailty phenotype, also referred to as Fried et al. (Fried et al., 2021; Fried et al., 2004), and the frailty index (WHO, 2017). The frailty phenotype is defined as a clinical syndrome and pathophysiology with validated clinical presentation (Bandein-Roche et al., 2006; Fried et al., 2001), often referred to as *physical frailty* (Fried et al., 2021). Based on a *deficit accumulation model*, the frailty index model emphasises the presence of multiple clinically identified diseases, their clinical manifestations and consequences, as well as various risk factors (Mitnitski et al., 2001; Rockwood &

Mitnitski, 2007). Both measures are strong predictors of mortality and institutionalisation, but they are based on different theories on underlying aetiologies, and use different measures to capture different processes. Other definitions integrate cognitive function and emotional or psychosocial dimensions, although a common critique is that these constructs are distinct from phenotypic frailty (Fried et al., 2021).

Physical frailty is a distinctive high-risk clinical state that signals a decrease in reserve and high vulnerability to stressors. Underlying the concept of frailty is the notion that a healthy organism is composed of systems with independent functions, each of which deteriorates with age (Fried et al., 2021). Physical frailty is typically diagnosed based on three or more of five key clinical signs and symptoms: physical weakness, slow walking speed, low physical activity, fatigue or exhaustion, and unintentional weight loss (Bandeem-Roche et al., 2006; Fried et al., 2021; Fried et al., 2001). Physical frailty emerges as a vulnerable state of dysregulation of a complex dynamic system. An important feature is that this is a non-linear process whereby a threshold of aggregate psychological dysfunction is reached, beyond which a state of lower functions of the entire organism occurs.

Implications for the assessment of need for long-term care

The above discussion aims to illustrate that disability, dependency, autonomy and frailty are distinct concepts that respond to different theoretical and clinical approaches to the process of ageing. However, these concepts are strongly interrelated; in particular, frailty predicts future disability and dependency (Bandeem-Roche et al., 2006; Fried et al., 2021; Fried et al., 2001). As a result, frailty and disability often co-exist, for instance, the prevalence of frailty is higher among persons with disability than among persons without disability (Bandeem-Roche et al., 2020; Fried et al., 2004; Walston et al., 2019).

In order to assess need for long-term care, is it important to distinguish frailty from disability? We argue that an appropriate identification of the type and level of need, as well as the type of care required, may be better achieved by distinguishing between these two states. Care for disability entails interventions to compensate for the loss of function, or rehabilitation to regain function or prevent further loss of function. By contrast, frail individuals may require care that focuses on increasing the ability to tolerate stressors, including medical procedures

or hospitalisations, and reducing the risk of future disability or dependency. Given that frailty is progressive and has a preclinical stage, early identification offers unique opportunities for prevention (Fried et al., 2004; Fried et al., 2001). Screening for frailty may thus be useful to identify early interventions to minimise risk from stressors and prevent a spiral of functional and physiological decline (Fried et al., 2004).

A second critique to current approaches to measuring need is that disability and dependency typically emphasise the negative dimensions of ageing. The concept of *independence* has therefore been increasingly emphasised, particularly in the context of an increasing role for home-based care. Independence has been the subject of academic debates across various disciplines from nursing and medicine to social work, social policy and sociology (Plath, 2007). Critics argue that disability assessments based on functional ability to perform tasks entail an individualistic interpretation of independence that does not consider social, emotional and practical functions (Plath, 2009). An alternative notion of independence therefore incorporates the concept of *social inclusion*. The argument is that exchanges with family, friends, communities, social institutions and government services may all contribute to meet the needs of older people and achieve social inclusion. This perspective advocates a broader focus of assessing need for long-term care beyond individualistic assessments of physical disability and dependency, to focus on social inclusion as a key element in the definition of independence in older age (Plath, 2007). Implicit in these concepts is the notion that dependency is multidimensional, incorporating economic, social and emotional dimensions (de Vries et al., 2011).

In conclusion, many countries use relatively narrow definitions of need for long-term care based primarily on the concepts of physical disability and dependency but a number have moved towards including assessment with a social dimension. A more multidimensional approach that considers independence and frailty is not yet available except in a few countries. A reason for this is that long-term care systems are often conceived with the key goal of compensating for the loss of function in an advanced stage of dependency. Yet this narrow approach does not capitalise on the opportunities to prevent further loss of function and future disability. In addition, narrow definitions of eligibility based on disability and dependence do not fully consider other dimensions of function and social inclusion that may also be important to the welfare of older people. Current approaches may

thus represent an efficiency loss, if interventions to compensate for the loss of function are less effective than interventions to prevent future decline; and if the focus is only on physical disability. In the context of an increasing focus on ageing in place and home-based care, a broader scope of assessments, that address frailty and independence and consider multiple dimensions of functioning beyond physical disability, may prove more effective in achieving overall welfare.

3.5 Should informal care matter for needs assessment?

In addition to functional impairments, several long-term care systems also consider the amount of informal care (e.g., from partner, adult children or other family members) which is available to the applicant. A general distinction is made between ‘carer-blind’ eligibility rules, where the availability of informal care does not affect eligibility for formal care, and ‘carer-sighted’ rules, where the availability of informal care plays a role (Eleftheriades & Wittenberg, 2013; Pickard, 2001). Furthermore, carer-sighted approaches can be ‘negative’ or ‘positive’: in a negative carer-sighted system an individual is less likely to be eligible for formal long-term care if informal care is available; in a positive carer-sighted system, the likelihood of being eligible is higher if the claimant receives informal care. The implications and justifications of these approaches are rarely discussed in the literature.

Carer-blind approaches are somewhat more frequent in systems adopting algorithm-based rules with clear-cut rules for eligibility determination, such as in France, Austria, Germany, Belgium and Japan. Conversely, carer-sighted approaches are more frequent in countries where the eligibility rules are more subjective, that is, they are determined under a case-managed approach (Brugiavini et al., 2017; Fernandez et al., 2011). However, carer-sighted rules are sometimes applied in countries with algorithm-based rules, such as in Italy. Although the Netherlands largely adopts a case-managed system, eligibility for intensive nursing care (the Wlz programme) is ‘carer-blind’, as it depends on the functioning level of the claimant, independent of the informal care they receive.¹ However, the Netherlands applies negative carer-sighted rules for some types of home-based formal care: individuals are eligible to receive home-based

¹ See the eligibility criteria listed by the CIZ, the institutional body which performs the eligibility tests: <https://ciz.nl/wlz-check>

formal care only when their social network is not capable of arranging sufficient support to fulfil their needs (Alders et al., 2015). England was traditionally classified as a case-managed system with a minimum safety net and a negative carer-sighted approach. However, since the Care Act 2014, the system is carer-blind (Brugiavini et al., 2017). Finally, some countries combine elements of a carer-blind and a carer-sighted approach. In France, for example, the availability of informal care does not influence whether someone is eligible for long-term care, but it does affect the amount and content of the care plan. In Italy on the other hand, either negative or positive carer-sighted approaches are employed, depending on the region.

Rationale

What is the rationale behind blind or sighted systems? The main difference between the two approaches lies in how they conceptualise needs. Building on the discussion in [section 2.1](#), we can refer to a well-known challenge in the health care literature (Asada, 2007): how to monitor a person's level of functionality (such as a person with paralysed legs and poor eyesight). Functionality could be measured as 'bare' functionality (mobility without wheelchair, eyesight without glasses), or it could take into account medical technologies (e.g., surgery or medication), non-human aids (e.g., wheelchair, glasses), human assistance (attendant), or environmental interventions (e.g., barrier-free physical environment, newspaper with large font). Carer-blind systems in long-term care define need as a level of vulnerability, determined by multiple dimensions and concepts of functioning such as frailty, disability, comorbidity or cognitive capacity. Conversely, carer-sighted systems define needs in terms of the level of care support required in order to achieve a certain level of welfare given existing informal support. This approach therefore includes a wider range of factors than health, such as the size of the informal network of support. *Negative* carer-sighted systems embed a perspective where informal carers are considered as *substitutes* for formal carers, so that government support is reduced or denied when informal support is available. In *positive* carer-sighted systems, informal carers are seen as *complements* to formal carers, so that the rule incentivises informal carers to provide support too. For example, some legislation in Italy prioritises older people who already benefit from informal care or who co-reside

with their family carers by giving them higher eligibility scores (Fernandez et al., 2011).

Equity considerations

Whether informal carers are considered in the evaluation of need is particularly important for equity objectives. Typically, the policy goal is to achieve equal access to publicly provided long-term care for individuals with the same level of need. This is called *horizontal equity*. A carer-blind system would maximise horizontal equity because it would provide equal access to public long-term care to individuals with the same level of need. By contrast, a carer-sighted (negative) system would prioritise access to public long-term care for people with lower informal support, and as such is less effective in ensuring equity in access to long-term care across the distribution of need: some individuals in need will not be eligible for long-term care because they have informal support available.

Another argument in favour of carer-blind eligibility rules is that they reduce the burden on informal carers (Twigg and Atkin, 1994; Pickard, 2001; Vellenoweth, 1999; Hu and Ma, 2018). The underlying idea is that better provision of formal care will replace support from informal carers (rather than simply adding to the total amount of care available). This means that provision of formal care will help alleviate the potential negative effects on informal carers' health, employment or quality of life, thus increasing total societal welfare (Hu & Ma, 2018; Rocard & Llana-Nozal, 2022). Given that women are more involved in providing informal care than men, carer-blind eligibility rules may also address gender equity concerns in informal care provision (Rocard & Llana-Nozal, 2022; Rodrigues, 2013). In terms of efficiency, a carer-blind system is likely to be easier to administer, as it is difficult to systematically establish the availability of informal support, as it is influenced by more intractable factors such as attitudes towards formal or informal care and willingness of family members to help members of their family network (Fernández et al., 2009).

On the other hand, a policy could prioritise maximising equity of welfare outcomes, rather than of access to care. From this perspective, a carer-sighted system would be more effective than a carer-blind system. In a carer-blind system, individuals with available informal support will ultimately receive more care in total than individuals receiving only

formal care. This would translate into unequal welfare outcomes, if we hypothesise that individuals with stronger informal care networks would receive more care overall, likely leading to higher welfare. Conversely, a carer-sighted approach would allocate relatively less public support to those with higher informal support than to those with little or no support, leading to a more equal distribution of total (formal + informal) care, and possibly welfare outcomes.

A carer-sighted (negative) system might be a tempting solution for countries which are at an early stage of public long-term care system development and funding. This is, for example, the suggestion of Hu and Ma (2018) in the context of China. They suggest that the long-term care system should be carer-sighted in the early development stage, and should only move to a carer-blind system once the backbone of formal long-term care provision has been established. The rationale is that those who do not have access to informal care will gain the most from formal care. There is early tentative evidence supporting this assumption (Forder et al., 2018), but overall this question is still debated. Moreover, the carer-sighted approach also assumes that informal care is comparable in its effectiveness and quality to formal care provision. While this might be true for low-skilled tasks, it might be a problematic assumption for more complex tasks such as nursing care support.

A rationale for a carer-sighted positive approach stems often from cost control considerations. Within some regional long-term care frameworks in Italy, it is specifically stated that the regulation acts as an incentive to the informal support network to provide care, so that the care receiver is eligible to receive formal care: 'This modification has been added to incentivise good practices and higher intensity by the informal caregivers, given that an adequate social networking has been introduced as a requisite for eligibility.' (Brugiavini et al., 2017: 75) Thus a key rationale seems to be to incentivise the provision of informal care (to meet needs as much as possible through informal care – if needs are still present, then top up with formal care), thereby potentially reducing total costs for formal care. Moreover, it is often argued that receiving informal care may enhance the *marginal utility* of an added unit of formal care. That is, formal care is more effective in improving outcomes if informal care is already available because, for example, formal carers can take advantage of existing care to do more or better

with the time available. However, existing evidence does not support this claim (Forder et al., 2018).

Ultimately, the difference between carer-blind and carer-sighted approaches brings us back to the core motivation of this chapter, that is, the challenge of defining *need*: should two individuals with the same level of loss of autonomy, but different levels of access to informal care, be considered as having an equal need for care? In other words, should ‘need’ be conceived either in terms of functional shortfall, or in terms of the amount of formal support required in order to achieve a certain level of welfare? Defining this is at the core of considering factors other than functioning as part of eligibility for long-term care.

3.6 How eligibility rules affect care coverage

Previous sections in this chapter have shown how the definition of eligibility for public long-term care differs between countries. We now ask a pragmatic question: how do these conceptual differences in needs assessment and eligibility rules affect the potential coverage of long-term care systems? Do different systems target different people, or does legislation mostly differ in language with little effect on the breadth of the different systems? We will show that different definitions of eligibility rules result in very different target populations, that is, the population with a potential access to long-term care support. In [section 3.9](#), we examine how eligibility rules affect long-term care coverage, public budgets and the wellbeing of older people.

Effect of eligibility rules on potential long-term care coverage: the case of European countries

The size and characteristics of the population potentially covered by at least the minimum public long-term care support depends on the definition of ‘need of care’ in the eligibility rules

We will use the term ‘potential coverage rate’ to refer to the share of the population aged 65 and older which fulfils the requirements defined by the rules for accessing public long-term care support. However, due to the complexity of long-term care rules, it is challenging to infer the potential coverage of different long-term care systems through a qualitative comparison of the rules described in [section 3.3](#). Nor would it be useful for our specific aim to compare the rate of actual long-term care

utilisation across countries (e.g., the percentage of long-term care users in Germany vs Spain), as countries differ not only in their eligibility rules, but most importantly also in the need for care in their population – a population in poor functional health will report higher rates of long-term care utilisation than a country whose population is in good functional health, even if their systems have the same eligibility rules. To understand potential coverage, therefore, we used individual-level data from the Survey of Health Ageing and Retirement in Europe (SHARE), a large survey conducted among people aged 50 years and over in Europe since 2004 (Börsch-Supan et al., 2013). SHARE includes detailed self-reported information on sociodemographic, income and health characteristics. We focused on a representative samples of individuals aged 65 and older in eight European countries, namely, Austria, Belgium, the Czech Republic, France, Germany, Italy (national programme), Poland and Spain. While our findings are informative for countries around the globe, we chose these countries because they have well-developed long-term care systems and they apply clear-cut long-term care eligibility rules (Brugiavini et al., 2017).

We estimated the potential coverage of long-term care rules through the method of direct adjustment standardisation (Brugiavini et al., 2017; Schokkaert & Van de Voorde, 2009), which enables us to compare the rate of coverage of long-term care for individuals while holding their demographic and health characteristics constant. Following Brugiavini et al. (2017) and Carrino et al. (2018), we built a binary index of long-term care eligibility for each person using information from both SHARE and the long-term care legislation. For example, an individual in SHARE (regardless of the country they lived in) would be classified as eligible for the long-term care rules of country A if their socio-medical profile fulfilled the requirements to obtain publicly funded long-term care in country A.

A qualitative analysis of the eligibility rules in the selected countries, briefly summarised in Table 3.5 in the appendix, and in more depth in Brugiavini et al. (2017), would highlight, for example, how some rules embed a stronger focus on prevention of the loss of autonomy, while others focus more on a cure (to support the individual after a major loss of autonomy occurred). Rules more focused on prevention typically give more weight to limitations in IADLs and/or mobility (e.g., the Austrian and German rules), as opposed to being focused mainly on ADLs limitations (e.g., Italy and Poland), because IADLs and mobility

represent more complex tasks, which tend to need help with earlier than ADL tasks. All the laws are carer-blind (as explained in [section 3.5](#), they do not consider whether informal care is already available). However, it is not fully clear whether some rules will lead to higher coverage than others. Our modelling below will help us to evaluate this.

We have computed the potential coverage rates through direct adjustment standardisation for the selected long-term care programmes and show the results in [Figure 3.1](#). This analysis addresses the following question: if we applied the eligibility rules of each country to all the SHARE respondents aged 65 and over living in the eight countries mentioned above, what proportion of them would be covered by long-term care services according to their different eligibility rules? A higher percentage tells us that a system is more comprehensive in its coverage by virtue of its eligibility rules, as we kept health constant by focusing on the sample underlying population. Coverage is expressed as a percentage of the sample aged 65 and over in the eight European countries. Notice that the denominator for these rates is the average European population, which includes many individuals who do not need care. However, the graph enables us to compare potential coverage rates across countries in a hypothetical scenario in which they would have the same level of health.

The results in [Figure 3.1](#) show that potential coverage for long-term care is highly heterogeneous between countries. Our estimates suggest that German rules (as reformed in 2017) cover around 20 per cent of the sample and are more inclusive than the rules in any other country, and more than the older German rules. The 2017 German reform lowered the minimum level of vulnerability that would give access to benefits, which explains why the potential coverage rate increased after 2017. The Austrian government has also reformed their eligibility rules in recent years. Unlike Germany, Austrian reforms aimed at tightening access to long-term care benefits by increasing the minimum number of hours of need required to become eligible. The results are visible in our analysis, which shows that the more recent definition of long-term care need in Austria would cover around 12 per cent of older Europeans, compared to 16 per cent under the old rules. The long-term care coverage rates in the European population would also be significantly lower under the rules in Belgium (Wallonia and Flanders), Spain, Italy and Poland.

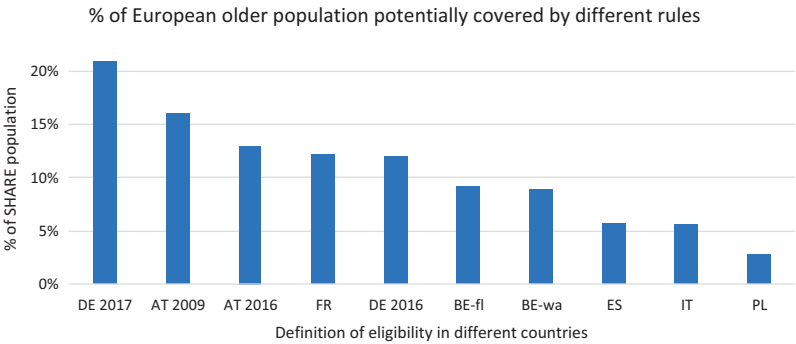


Figure 3.1. Potential coverage rate for an average of the European population aged 65+

Notes: We estimate the potential coverage embedded in different long-term care rules, defined as the percentage of older Europeans who would be eligible for long-term care benefits according to the definitions of need of various European countries. Each bar therefore does not represent the actual use of care in each specific country, but rather the share of older Europeans who would be eligible for long-term care according to the rules in each specific country. The European population consists of a sample of 19,880 respondents aged 65+, interviewed in the 6th wave of SHARE (2016) in Austria (AT), Belgium-Flanders (BE-fl), Belgium-Wallonia (BE-wa), Czech Republic (CZ), France (FR), Germany (DE), Italy (IT), Poland (PL) and Spain (ES). The graph reports more than one time point for the eligibility rules in Austria and Germany, to capture recent changes in legislation.

A possible interpretation, as suggested by Colombo and Mercier (2012), is that countries with a higher rate of potential coverage (e.g., Germany, Austria) have a more pronounced focus on prevention or at least early intervention, while countries with lower potential coverage place a stronger focus on those with already significant limitations (e.g., Italy, Poland, Belgium). However, not all countries with higher potential coverage necessarily focus on prevention. For example, France’s system is primarily focused on acute ADL difficulties and cognitive impairment, while Spain’s long-term care rules assess needs through a more encompassing approach which combines information on difficulties with IADLs, ADLs and cognitive impairment. Yet the French definition of need has a higher coverage than the Spanish one, which shows that the French system compensates its narrower assessment of

need with a much looser threshold of minimum dependence; the Spanish system has a broader assessment of need but stricter eligibility criteria, ultimately leading to lower potential coverage.

Effect of eligibility rules on unmet need for people with disabilities

We now show how the differences in the legislative definition of need translate into different coverage rates for older Europeans in poor functional health. We do this by estimating the probability of not being eligible for public support while having a functional health problem, which we will refer to as ‘unmet need’ risk. We considered five different hypothetical functional health profiles, from less to more severe limitations:

1. people with limitations in at least one IADL but no limitation in ADLs or cognition;
2. individuals with at least one limitation in ADLs;
3. individuals with at least 3 ADLs lost; and
4. those with severe cognitive impairment.

In [Figure 3.2](#), we computed the percentage of individuals in each of those groups who would be eligible to receive public long-term care support according to the definitions of needs in Germany (after 2017), France, Italy (national programme) and Poland. Unsurprisingly, the proportion eligible among the groups with only IADL limitations is much lower than that for the group with ADL limitations, illustrating the focus of current programmes on those with severe limitations. Among those with IADL limitations, around 15 per cent would be eligible to receive support in Germany, compared to only around 5 per cent in France or Italy, and none in Poland. This confirms that the German system is more inclusive of people with less severe limitations – potentially prioritising prevention – than the French, Italian or Polish systems. But even in Germany, the risk of unmet needs is very high among those with IADLs.

Unmet needs are also high for those with ADL limitations, despite their higher level of dependency. The German eligibility rules would cover 85 per cent of people with any ADL limitations, whereas the French rules would cover 57 per cent. In contrast, the Italian and Polish systems would cover 21 per cent and 14 per cent respectively, leaving the majority of people with ADLs without coverage. Among individuals with severe activity restrictions (3+ ADLs lost), both the French

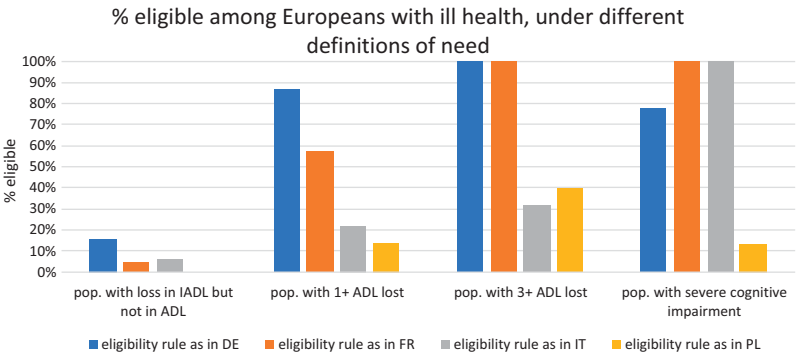


Figure 3.2. How alternative long-term care rules would cover older Europeans with ill health

Notes: Sample of 19,880 respondents aged 65+, interviewed in the 6th wave of SHARE (2016) in Austria, Belgium-Flanders, Belgium-Wallonia, Czech Republic, France, Germany, Italy, Poland and Spain.

and the German system would provide almost certain coverage (100 per cent). Conversely, the Italian and Polish system would provide coverage to less than 40 per cent of affected individuals. This again highlights how, except for Germany, these systems are focused on helping only those with very high levels of limitation.

Among individuals with severe cognitive impairment, coverage with the Italian definition reaches 100 per cent, as it does with the French definition. This is because both systems include cognition as a sufficient condition for obtaining eligibility status. The German system rules would cover 80 per cent of people with cognitive limitations, while the Polish system would only cover 10 per cent of this population.

In conclusion, our analysis suggests that eligibility rules have enormous implications for the level of coverage of long-term care systems. By targeting populations with different levels of need, eligibility rules are also a strategy through which countries operationalise a policy focus on early stages of limitations – potentially conferring importance to interventions in the early stages of functional decline, with the intention of preventing further decline or reversing limitations – as opposed to a policy focus on very advanced levels of functional decline, at which point prevention or reversal of functioning may no longer be possible (Colombo & Mercier, 2012).

3.7 How eligibility rules affect the intensity of potential coverage

In the [previous section](#) we examined how eligibility rules affect whether individuals are covered for public long-term care, but we ignored the fact that the amount of care for which individuals are eligible may also differ across countries. We will now consider the extent to which different systems vary in the intensity or amount of long-term care they provide. To address this question, we capture differences in the intensity of long-term care for which individuals are eligible, using information on the monetary costs of long-term care between countries. This gives us an indication not only of whether individuals receive care, but also how much they receive.

We have computed the share of total costs of long-term care for different severities and care settings that would be covered by public social protection systems in OECD and EU countries, depending on the claimant's level of need. As income and wealth can play a role in determining the intensity of government support, we have focused on individuals with a median income (among the income of people aged 65 or over) and no net wealth. Because of the level of detail required to perform this analysis, which includes legislation at the local level, it was not possible to include some countries, and only specific regions or cities where rich information was available were included in the analysis. Further details on the methodology are reported in Oliveira Hashiguchi and Llana-Nozal (2020).

The results are shown in [Figure 3.3](#). Panel A refers to the costs of home care for someone with low, moderate or severe needs. Panel B refers to the costs of home and institutional care for people with severe needs. Government support tends to be greater for older people with more severe needs. However, systems vary widely in their coverage of total long-term care costs, even for individuals with comparable levels of need. This is in line with the heterogeneous picture that emerged from the [previous section](#): most systems cover a greater share of total costs of home-based long-term care for severe needs than for moderate and low needs. On the other hand, older people with lower levels of need in some countries (for example, France, Italian South Tyrol and Latvia) receive more support than those with moderate needs, and those with moderate needs receive more support than those with severe needs. This is due to limits set on the number of

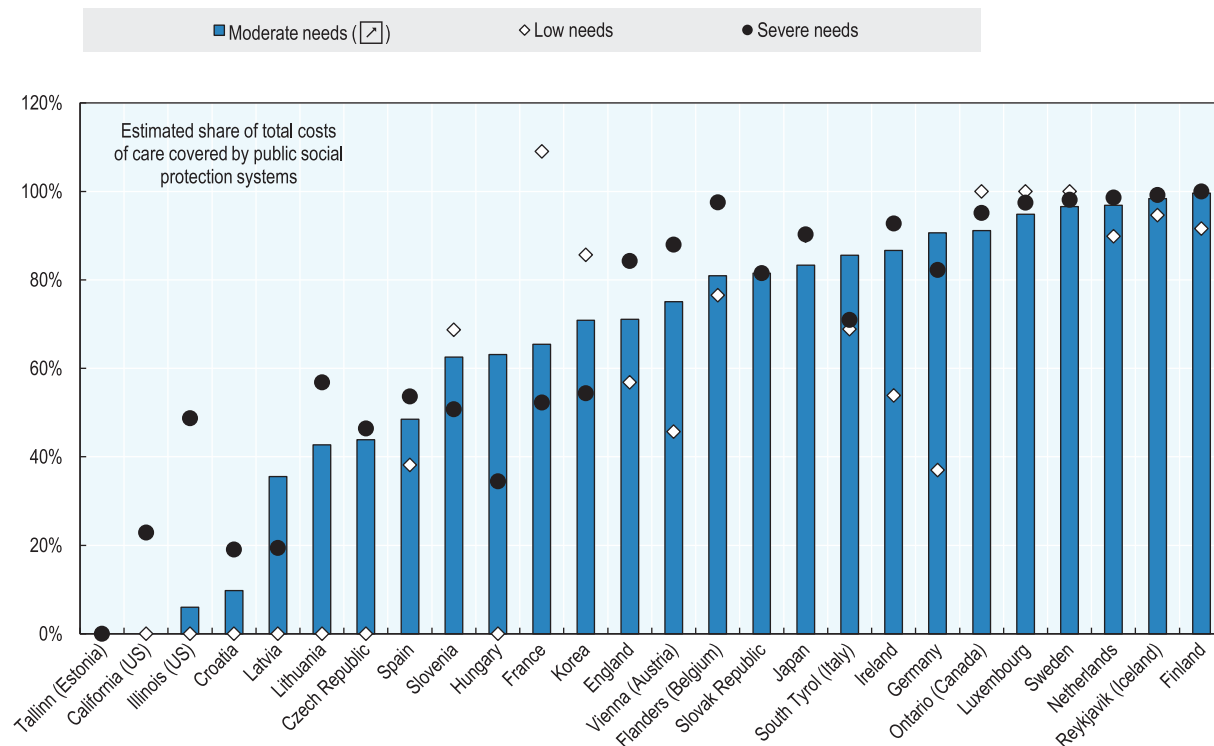


Figure 3.3. Share of total long-term care costs that would be covered by public social protection for care recipients earning a median income for older people and holding no net wealth, by severity and care setting.

Notes: Low, moderate and severe needs correspond to 6.5, 22.5 and 41.25 hours of care per week respectively. See methodological details in Oliveira Hashiguchi and Llana-Nozal (2020). Country abbreviations: Korea: Republic of Korea; Netherlands: Netherlands.

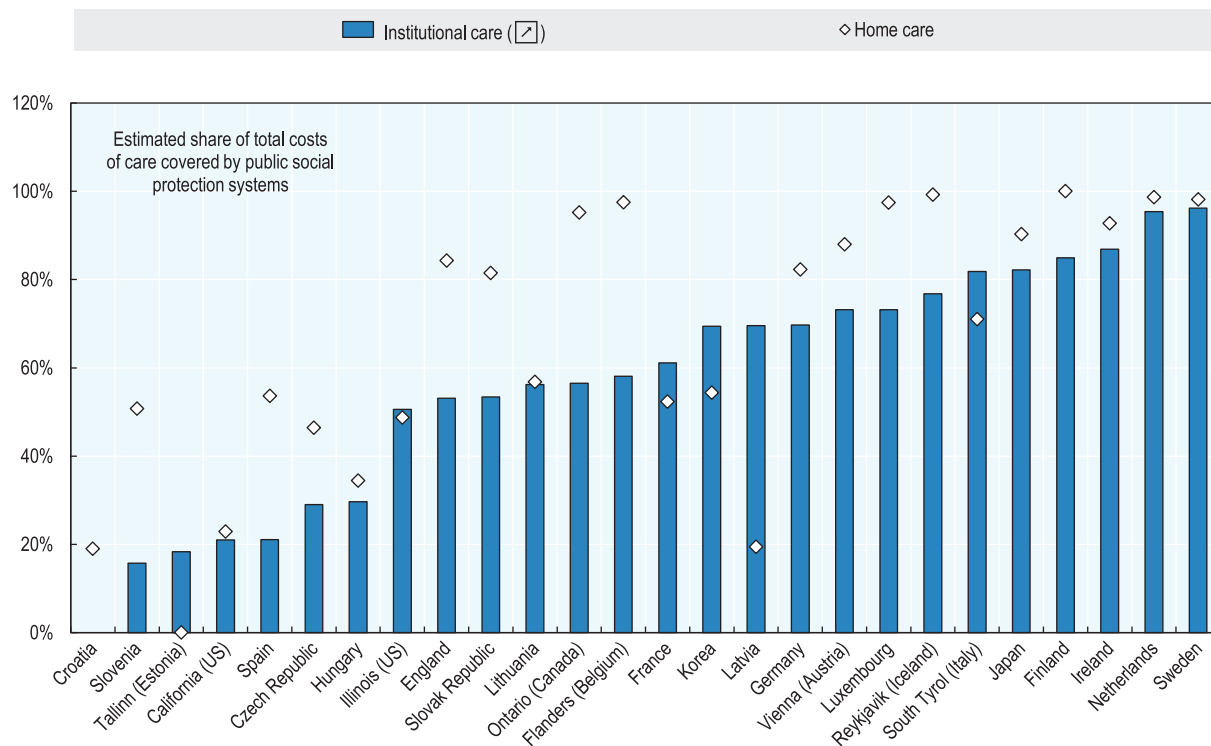


Figure 3.3. (cont.)

hours of care that can be covered through public long-term care benefits and schemes. Indeed, in some countries and subnational areas, there is no coverage for the costs of home care for older people with median income, nor for those with no net wealth and low care needs.

It is interesting to note that substantial differences in coverage appear even between countries which share similar stages of economic development and similar geographical locations, such as the Netherlands and Germany, or Ireland and England. Moreover, it is interesting to compare this ranking of countries against the widely used classification of welfare states by Esping-Andersen (1990), where countries' welfare systems are classified as liberal, social democratic or conservative-corporatist. We can broadly note that social democratic countries (Northern Europe) show the highest intensity of long-term care coverage, and that France, Germany and Austria (which are typically grouped together in the conservative group) show similar levels of coverage. However, many other countries which are typically grouped together in standard welfare classifications differ largely in this ranking, as shown, for example, by England, Ireland and California (liberal systems), the Netherlands and Belgium (conservative), Spain and Italy (conservative). This result is in line with emerging evidence that public policies in long-term care (and in social care more generally) tend not to follow the policy design of the broader welfare state in many countries (Bertin et al., 2021).

Our analysis suggests that the proportion of total costs of long-term care that public systems cover varies both between and within countries and subnational areas, and across levels of care recipient need. Overall, individuals with higher levels of need tend to receive higher coverage from the public long-term care system, yet there are several countries in which intensity does not increase with need of care. Moreover, international differences in long-term care coverage often do not match the general assumptions of welfare states classifications.

Finally, as we shall see in [section 3.9](#), the differences in eligibility rules we just outlined do not only impact coverage for long-term care, but they also have significant implications for the quality of life and wellbeing of older people with limitations and are therefore critical in achieving the goals of long-term care systems.

3.8 Consequences of means testing and eligibility rules

So far we have focused on analysing the impact of eligibility rules on coverage of long-term care. But a separate objective of long-term care systems is to achieve equity, which might potentially be more efficiently achieved by focusing on individuals with lower income or wealth who are unable to purchase long-term care in the market. In addition, while there may be good reasons to invest in more accessible and affordable long-term care, all countries and subnational areas have limited fiscal space. In order to protect older people from the risk of poverty and hardship associated with having long-term care needs, governments often target long-term care support to individuals with limited economic resources. As a result, many countries make eligibility for long-term care dependent not only on functional health needs but also on means testing, targeting government support to applicants with lower incomes and net wealth, while limiting – or even withholding – support from care recipients who can afford to pay more. Means tests can be used to determine both eligibility for long-term care and the level of support for those who are eligible. Different types and combinations of means – income, assets of various types – can be used. Put simply, if a long-term care benefit or scheme is means-tested, then the level of government support and thus the OOP user contributions are dependent on the means of the older person applying to receive care. Means tests can promote equity at the same time that they promote allocative efficiency. In some systems, means-tested benefits and schemes can be combined with non means-tested benefits and schemes (as seen in [Table 3.1](#)). However, it is known that this approach can also generate inefficiencies and drawbacks such as limited take-up, poverty traps (caused by high effective marginal tax rates), and stigmatisation (Cremer & Pestieau, 2018).

In England, Germany, South Tyrol (Italy), the Netherlands, Spain and Slovenia, public home care benefits and schemes mix both income and assets testing with non means-tested support. Vienna (Austria), Finland, Reykjavik (Iceland), Latvia and Lithuania combine non means-tested and income-tested only (not assets-tested) benefits and schemes. Ontario (Canada), the Czech Republic, Ireland,

Table 3.1. *The use of means testing to determine level of government support for long-term care*

	Assets-tested	Not assets-tested
Income-tested	Flanders (Belgium), Croatia, England, Tallinn (Estonia), France, Germany, Hungary, Ireland, South Tyrol (Italy), Japan, Lithuania, Netherlands, Slovenia, Spain, California (United States), Illinois (United States)	Vienna (Austria), Flanders (Belgium), Ontario (Canada), Tallinn (Estonia), Finland, France, Hungary, Reykjavik (Iceland), Republic of Korea, Latvia, Lithuania, Luxembourg, Slovak Republic, Sweden
Not income-tested	Croatia	Vienna (Austria), Flanders (Belgium), Ontario (Canada), Czech Republic, England, Finland, Germany, Reykjavik (Iceland), Ireland, South Tyrol (Italy), Latvia, Lithuania, Luxembourg, Slovak Republic, Slovenia, Spain

Note: Countries and subnational areas can belong to more than one category if they have more than one type of long-term care benefits and schemes

Source: Oliveira Hashiguchi and Llana-Nozal (2020)

Luxembourg and the Slovak Republic have only non means-tested benefits and schemes for home care, while Tallinn (Estonia), Hungary, Japan, the Rep. of Korea and Sweden provide only income-tested (not assets-tested) benefits and schemes. No system combines all four categories of means testing and non-means testing, either for home or institutional care. The most frequent combination

in institutional care is both income and assets-tested benefits and schemes, as in Hungary, Ireland, Japan, the Netherlands, Spain, and California and Illinois in the United States. Income testing is the most widely used option, often combined with assets tests, for institutional care in twenty-four countries and subnational areas, and in-home care in twenty-one countries and subnational areas.

The case of assets testing is particularly relevant from a life-course economics perspective. As with other types of means tests, the underlying assumption is that older people with higher net wealth are better able to afford the OOP costs of care; even if they might not be able to afford costs from their incomes alone, they are likely to be able to cover the shortfall from their assets. However, in order to qualify for greater government support, older people with care needs in countries and subnational areas with means tests may need or decide to deplete their assets to reach a threshold that qualifies them for increased public support (a process sometimes referred to as ‘strategic impoverishment’, see Cremer & Pestieau, 2018).

Assets-tested long-term care benefits and schemes are common in both home care and institutional care in OECD and EU countries and subnational areas. Assets tests tend to share certain features (see Table 3.2). Certain countries and subnational areas set wealth thresholds for greater government support, but these tend to be low compared to national mean net wealth among older people. Above these thresholds, some benefits and schemes take into account only a share of total assets when determining the level of government support. Different types of assets may be treated differently depending on the country, subnational area and even specific long-term care benefit or scheme. The primary residence is frequently excluded from assets tests, especially in the case of home care as it is expected that the person receiving care is still living in their home. Deferred payment agreements may be used, in which case older people receiving home care agree to use their assets (including their primary residence) to repay the public social protection system for OOP costs incurred while living in their home if they sell their house (e.g., when moving to institutional care) or when they die.

Assets testing might however incentivise distortionary behaviours in terms of saving decisions that people take. We discuss this in Box 3.1.

Box 3.1. The potential distortionary impact of assets tests on saving behaviour

A downside of assets tests is that they are a form of taxation on the wealth and savings of older people receiving care and, as such, have the potential to distort saving behaviour (OECD, 2018), influencing the allocation of savings across different types of assets and the allocation of savings over the lifecycle. In principle, assets tests can influence decisions to allocate savings both before and after retirement age. However, most people do not save for the possibility that they will have to pay for long-term care services, and so the distortionary potential in terms of allocation across different types of assets is likely to be more important than in terms of allocation over the lifecycle, although both are likely to be relevant. In other words, assets tests are more likely to lead people to distribute their wealth across different assets, rather than across time.

Assets tests may set certain conditions on asset transfers. For example, in Croatia, to qualify for greater public support, older people with care needs must not have sold any property in the year before they apply for public long-term care support. Those older people in England who have assets under GBP 23,250 are eligible for greater support from local authorities. However, if local authorities suspect that older people who apply for support have transferred or otherwise reduced their assets in order to be eligible for increased support (what is referred to as ‘deprivation of assets’), then they may charge the older person receiving care as if they still possessed the deprived assets, or even seek charges from the new asset holder. In Ireland, the nursing home support scheme also prohibits the deprivation of assets after applying for support or in the previous five years. All these conditions may impact the allocation of savings across different assets (i.e. portfolio composition).

The treatment of the primary residence in some forms of assets testing, a common practice as shown in Table 3.2, may also have a distortionary effect on the allocation of savings across different types of assets. Excluding the primary residence from assets tests introduces an incentive for older people with care needs to divert financial wealth into primary residence. This incentive is however weakened in most countries and subnational areas by the inclusion of primary residence in assets tests for institutional care.

There is limited real-world evidence or empirical analyses of the distortionary impact of assets tests on saving behaviour, even though their incentives are implicit in many types of assets tests. To prevent this, the English Institute and Faculty of Actuaries (IFoA) proposes changing the thresholds used in assets tests to incentivise savings among less wealthy older people, as well as introducing new financial products that allow savings to be exempt from assets tests, within certain limits.

Table 3.2. *Treatment of assets in long-term care benefits and schemes that apply assets tests (selected countries and/or regions with available information)*

Countries and subnational areas	Name of benefits and schemes	Setting (institution vs home)	Simplified description of rules	Types of assets	Deferred payment?
Flanders (Belgium)	Allowance for the assistance of older people	Both	6% of assets	Primary residence excluded	No
Croatia	Allowance for assistance and care	Institution	None	All	Yes
		Home	Not given out if care recipient has assets	All	No
England	Social care	Institution	No user contribution for assets below GBP 14,250, full contribution for assets above GBP 23,250	All	Yes
		Home		Primary residence excluded	Yes
Tallinn (Estonia)	Institutional care	Institution	Full user contribution if care recipient has assets	All	No
France	Allocation personnalisée d'autonomie Aide sociale à l'hébergement	Both	100% of assets can be used for contributions	Primary residence excluded	No
		Institution	None	All	Yes

Germany	Assistance for care (Hilfe zur Pflege)	Both	EUR 5,000 excluded	All	No
Hungary	Older people	Institution	Full user contribution if care recipient has assets; higher income allowance for care recipients with assets	All	No
Japan	Long-term care insurance	Institution	To qualify for reduced board and lodging fees, care recipients must have assets worth below JPY 10,000,000	Excludes life insurance, cars, watches	No
Lithuania	Institutional care	Institution	1% of assets over EUR 4,260 ¹	All	No
Luxembourg	Complément accueil g�rontologique	Institution	None	All	Yes
Netherlands	Wet langdurige zorg (Wlz) Wet Maatschappelijke Ondersteuning (Wmo)	Both	8% of assets over EUR 21,330	All	No
Slovenia	Municipality-subsidised care	Institution Home	100% of assets over EUR 2,500	All Primary residence excluded	No No

Table 3.2. *(cont.)*

Countries and subnational areas	Name of benefits and schemes	Setting (institution vs home)	Simplified description of rules	Types of assets	Deferred payment?
Spain	Ayuda al domicilio	Home	5% of assets	Primary residence	No
	Prestación económica vinculada al servicio	Home		excluded	No
	Antención Residencial	Institution		All	No
				All	
California (United States)	In-home support services	Home	Full user contribution if care recipient has assets worth over USD 2,000	Primary residence	No
		Institution		excluded	No
	Medi-Cal institutional care			Primary residence excluded only if worth less than USD 585,000	
Illinois (United States)	Home and Community-Based Services	Home	Full user contribution if care recipient has assets worth over USD 2,000	Primary residence	No
		Institution		excluded	No
	Medicaid institutional care			Primary residence excluded only if worth less than USD 585,000	

Notes: ¹Based on a value of EUR 355 per square meter for a property with 12 square meters. Countries and subnational areas are sorted top to bottom alphabetically by the name of the country.

Source: Oliveira Hashiguchi & Llana-Nozal, 2020

3.9 Do differences in eligibility rules affect care utilisation and wellbeing of older people?

Eligibility rules increase access to care, but their effect is unequal

Our discussion so far has highlighted that different eligibility rules can strongly affect the target population to whom public long-term care support is made accessible and the intensity of its potential coverage. We will now go a step further and ask: to what extent do policy decisions over eligibility rules impact actual long-term care coverage, that is, the actual access to long-term care services? Unlike potential coverage, the actual utilisation of care (sometimes referred to as *realised access*) is the result of an interaction between the supply and demand sides of the market for long-term care. In fact, use of care is determined by structural features of the long-term care system (e.g., availability of programmes, eligibility rules), features of individuals (predisposing and enabling factors) and process factors (the administrative process through which access is realised) (Andersen & Newman, 2005; Levesque et al., 2013). It is generally believed that care use is mostly driven by population needs; indeed, large microsimulation exercises predict the future utilisation of long-term care through careful estimations of trends in functional health (European Commission, 2021). We will show that such reasoning overlooks the role of institutions: through changes in the eligibility rules, long-term care legislation can incentivise or disincentivise access to care, with important consequences for realised access to long-term care.

The eligibility rules that we will consider are valid for both home care and institutional care. However, in what follows, we will focus on home-based care use only, as this focus allows us to use the SHARE dataset (introduced in an earlier section). This enables us to draw more robust and representative conclusions with respect to single-country analysis. Home-based care has become a very relevant dimension of long-term care systems in recent decades: the rising demand for long-term care has been met with an increasingly common policy response to encourage ageing in place, defined as ‘remaining living in the community with some level of independence’ (Davey et al., 2004: 133). In line with this approach, most European countries increasingly prioritise the provision of formal home-based care (WHO, 2015), with a focus on

subsidised services for vulnerable older people. However, the implications we draw from our analysis are also valid for institutional care, as has been shown by country-specific studies (see, for example, the study by Bakx et al., 2020).

Among older people aged 65 and over in the eight European countries we considered (respondents from Austria, Belgium, the Czech Republic, France, Germany, Italy, Poland and Spain, interviewed in SHARE between 2004 and 2018), around 7 per cent reported using some kind of formal home-based long-term care, defined as nursing or personal care, or meals on wheels, from either public or private providers. In Table 3.3, we split our sample based on their eligibility status according to the long-term care rules implemented in their region of residence and the year of interview. As expected, the eligible population is older (80.5 vs 74.2) and with worse functional health (ADL and IADL functioning, cognitive status, depression) than the non-eligible population. They are also much more likely to use formal home-based care (47 per cent vs 4 per cent). However, because eligible individuals have on average worse health than non-eligible people, we cannot infer that they use more care because of eligibility rules: it could be that they use more care because they have more functional problems. Hence we need to compare individuals with similar functional health but different eligibility status (Carrino et al., 2018). We can do this because, as discussed in section 3.3, long-term care rules differ greatly between countries (so that individuals with the same functional health living in different countries could have different eligibility status) and are operationalised through complex algorithms based on combinations of functional (including cognitive) health. As a result, individuals with similar functional health in the same country could have different eligibility status due to the specific combinations of their functional limitations). In Table 3.6 in the appendix we show how similar clinical profiles would result in different eligibility status in different countries, as a result of their different eligibility rules.

Eligibility for long-term care increases the probability of receiving care among older people

Figure 3.4 shows that, as we would expect, the probability of receiving home-based care increases as the number of functional limitations with ADLs increases. Most importantly, it shows that the probability of

Table 3.3. *Characteristics of populations eligible and non-eligible for home-based formal long-term care*

	TOTAL POPULATION	NON-ELIGIBLE for formal home- based long-term care	ELIGIBLE for formal home- based long-term care
Using formal home-based care	7%	4%	47%
Age (years)	74.6	74.2	80.5
Female	57%	57%	66%
Living with a spouse or partner	61%	62%	42%
Low wealth ^a	26%	25%	43%
Education levels			
Low (up to lower secondary)	51%	50%	61%
Intermediate (upper secondary)	32%	32%	30%
High (tertiary)	17%	17%	9%
At risk of clinical depression	34%	32%	62%
Low cognitive status	5%	3%	25%
Number of ADL difficulties	0.3	0.2	2.6
Number of IADL difficulties	0.6	0.4	4.1
With 2+ chronic diseases	60%	59%	84%
N	61,714	56237 (90.1%)	5477 (8.9%)

Notes: Sample of 61,714 respondents aged 65+, interviewed by the SHARE survey (2004-2018), in Austria, Belgium, Czech Republic, France, Germany, Italy, Poland and Spain. Risk of clinical depression corresponds to a score of 4 or higher on the EURO-D scale. Low cognitive status is proxied with inability to answer correctly at least two questions including current year, month, day and day of the week.

^aLow wealth corresponds to being in the first quartile (0-25%) of the country-specific wealth distribution.

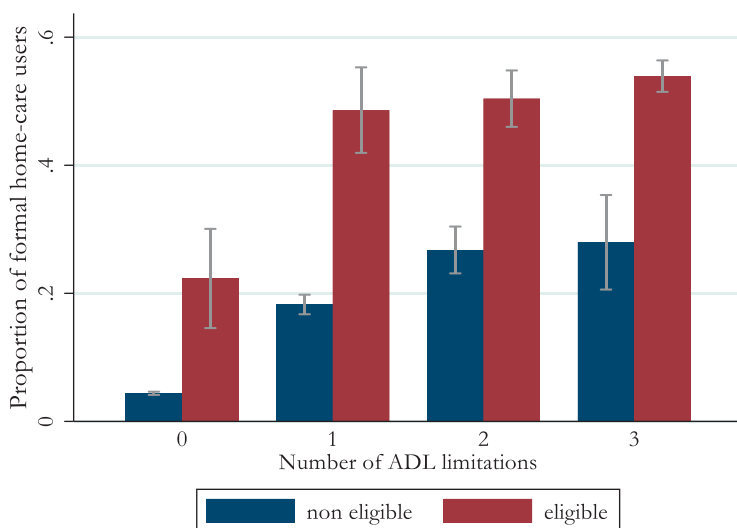


Figure 3.4. Proportion of respondents receiving formal home care, by number of ADL/IADL limitations and by long-term care eligibility status

Note: Sample consists of 19,880 respondents aged 65+, interviewed in the 6th wave of SHARE (2016) in Austria (AT), Belgium-Flanders (BE-fl), Belgium-Wallonia (BE-wa), Czech Republic (CZ), France (FR), Germany (DE), Italy (IT), Poland (PL) and Spain (ES). The graph reports more than one time point for the eligibility rules in Austria and Germany, to capture recent changes in legislation.

receiving home-based care is higher for individuals who are eligible for public long-term care support (the red bar) than for individuals who are not eligible (the blue bar). It is very important to stress that this is true even for individuals who have the same number of ADL limitations, e.g., among those with only one ADL limitation, the probability of receiving home-based care is just below 50 per cent for the eligible group, compared to less than 20 per cent for the non-eligible group.

We performed a full statistical exercise to estimate the effect of being eligible on the probability of receiving home-based long-term care, where we controlled for such confounding variables as socio-demographics, health and functioning status. Our results suggest that being eligible for public long-term care support increases the probability of receiving home-based care by twelve percentage points

(baseline level, 7 per cent): for an individual of average health, the probability of accessing long-term care is 19.7% if they are eligible, compared to 7.4% if they are not. This implies that a change to eligibility rules can substantially increase – or decrease – the likelihood that people will be covered for long-term care. This is particularly relevant for policy makers, as it shows that eligibility rules play an important role in reducing the risk of unmet needs among older people, above and beyond individual characteristics such as education, income wealth and health.

Are some groups more likely to gain access due to their eligibility status?

Eligibility for long-term care seems to act as a strong incentive to access formal long-term care. However, there might be some groups of individuals for whom the incentive is stronger. We are particularly concerned about individuals who might fail to access formal care despite being eligible for it (and therefore face a higher risk of unmet needs). Our analysis identified two groups at higher risk of unmet needs, who would particularly benefit from policy support:

1. Our evidence suggests that people with lower levels of education are less likely to access formal care even after they become eligible for it, and hence face a higher risk of unmet needs. In [Figure 3.5](#) (first panel) we show that, comparing people with similar health status, those with lower levels of education (up to lower secondary degree) have roughly the same probability of using care as higher educated groups, if they are not eligible for long-term care programmes. While all groups are more likely to use care if they are eligible for public long-term care, the increase in care use induced by eligibility status is significantly higher for those with higher education. This may suggest that people with higher education have a stronger preference for the use of formal care than their less educated counterparts. However, the fact that people with lower levels of education are less likely to take up formal care even when they become eligible for it, compared to people of higher education and with similar health, suggests that policy makers should be very conscious of differences in long-term care literacy, economic endowments, and individuals' ability to navigate the complex mechanisms or

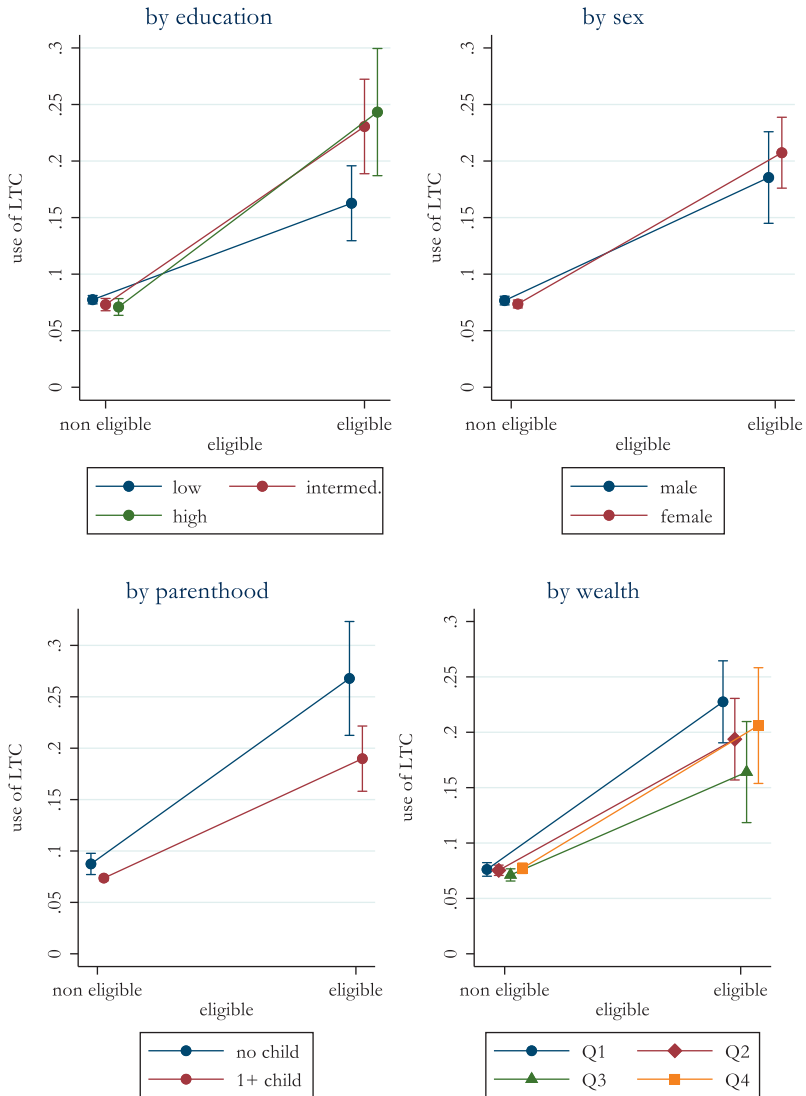


Figure 3.5. Differential impact of eligibility for long-term care on care use, by sociodemographic characteristics

Note: Sample consists of 19,880 respondents aged 65+, interviewed in the 6th wave of SHARE (2016) in Austria (AT), Belgium-Flanders (BE-fl), Belgium-Wallonia (BE-wa), Czech Republic (CZ), France (FR), Germany (DE), Italy (IT), Poland (PL) and Spain (ES). The graph reports more than one time point for the eligibility rules in Austria and Germany, to capture recent changes in legislation.

rules and points of access (García-Gómez et al, 2015; Rodrigues et al., 2017).

2. Our evidence also suggests that, among older people eligible for formal home-based care, those living alone are more likely to receive it than people living with their relatives. The impact of long-term care eligibility on care utilisation varies by parenthood status: compared to non-eligible respondents, people eligible for long-term care but with no children increase their likelihood of accessing care much more than people with children (Figure 3.5, third panel). This suggests that the availability of a family network, which is the main source of long-term care support worldwide, might constitute a partial disincentive to seek formal support, due to the preference of many older people to be cared for by family members rather than external professionals (Kalwij et al., 2014). While this could reflect the preference of older people, it might also highlight that such individuals are missing out on potential help from the state. There are at least two reasons why governments should be concerned by this result. First, the absence of formal support may deprive older people of access to higher-skilled care, often provided by formally trained caregivers in comparison to informal ones. Second, it highlights the risk of increasing the psychological and physical burden on caregivers (including work/family conflicts), who could have been partially relieved or helped by publicly subsidised care.

Finally, we show that eligibility for long-term care increases care use in a similar way for both sexes and for people with different levels of wealth (Figure 3.5, second and fourth panels).

3.10 Policy experiment: how would care utilisation among older populations change if governments adopted different eligibility rules?

How can policy changes in eligibility rules affect the demand for domiciliary long-term care? In Figure 3.6 we show how the current percentage of long-term care users in eight European countries would change if governments reformed their long-term care eligibility rules for home care support by shifting the focus from providing assistance

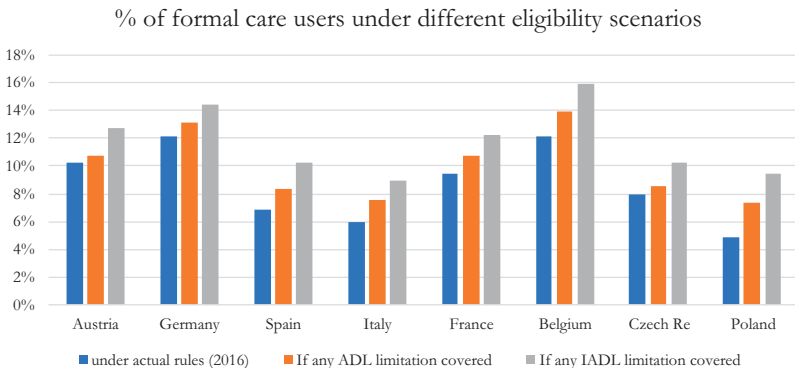


Figure 3.6. Eligibility rules more focused on prevention (IADL limitations) compared to current rules would expand population of care users

Note: Sample consists of 19,880 respondents aged 65+, interviewed in the 6th wave of SHARE (2016) in Austria (AT), Belgium-Flanders (BE-fl), Belgium-Wallonia (BE-wa), Czech Republic (CZ), France (FR), Germany (DE), Italy (IT), Poland (PL) and Spain (ES). The graph reports more than one time point for the eligibility rules in Austria and Germany, to capture recent changes in legislation.

for severely impaired people to prevention of loss of autonomy. We evaluated the impact on care utilisation of two scenarios in particular: (i) governments reform eligibility rules so that anyone with an ADL limitation is eligible; or (ii) governments reform eligibility rules so that anyone with limitations in either ADL or IADL tasks is eligible. These scenarios are compared to the current status quo, i.e. the share of older adults currently using formal home care under the current rules. Results show that, in general, such changes would significantly expand the population of formal home care users. The effects vary between countries, due to the different prevalence of functional limitations and the different extent to which current eligibility rules already cover ADL and IADL limitations. Allowing the eligibility rules to cover all ADL limitations would lead to an increase in actual access to care by around 2 percentage points in Italy, Spain, France, Belgium and Poland, whereas extending the eligibility rules to all IADL limitations (i.e. an approach more focused on prevention) would increase access to care by a minimum of 2.5 points and a maximum of 4.6 points.

The wellbeing implications of eligibility rules for home care

In this section, we explore a critical question: does access to public long-term care actually improve the wellbeing of older people? At first, the answer to this question may seem obvious – if people receive the care they need, they should be able to perform the activities that are important to them, and this should lead to an improvement in their wellbeing. Another common argument, particularly important for policies that promote long-term care at home, is that home-based care enables people to age in place – that is, to remain living at home and in their community, which should also improve their wellbeing (Hashiguchi & Llana-Nozal, 2020). The implication is that long-term care systems that have more inclusive coverage of care should in principle also be more successful in maintaining or preventing decline in overall wellbeing among older people. And yet, so far there is limited empirical evidence showing how home-based care influences the wellbeing of older people.

In this section, we study home-based long-term care is effective in helping maintain wellbeing among older people, by examining how eligibility for home-based long-term care across Europe impacts wellbeing. To illustrate this, we choose to focus on the case of mental health, and in particular on the case of depressive symptoms and psychological wellbeing, two key indicators of wellbeing in older age. Depression affects around 6 per cent of adults aged 65-74 years and 12 per cent of those aged ≥ 75 in Europe (Arias-de la Torre et al., 2021). Depressive symptoms are even more common among older adults with activity restrictions and functional limitations (Penninx et al., 1998; Williamson & Shaffer, 2002), and have been linked to declines in cognitive and physical functioning (Ormel, Rijdsdijk, Sullivan, Van Sonderen, & Kempen, 2002). Depression is also a major cause of disability (James et al., 2018; Purebl et al., 2015), with economic costs estimated at 1.5% of GDP in major economies such as the United States (Greenberg et al., 2021), while the overall cost of mental illness reaches 4% of GDP in OECD countries (OECD/EU, 2018). As in the [previous section](#), we will focus on home-based care settings, in particular in four countries where eligibility rules provide in-kind support for home-based care: Belgium, France, Germany and Spain. We measured psychological wellbeing using the EURO-D depression

scale, a validated measure of depressive symptoms, and complemented this with data on quality of life (CASP-19 scale).

To examine the causal impact of home-based care eligibility on depression, we followed the same method as in the [previous section](#), that is, we compared the psychological wellbeing of individuals with similar physical and cognitive functional status (and other socioeconomic characteristics), and yet with different eligibility status. In [Table 3.4](#) we have shown that otherwise similar individuals with different eligibility status face very different likelihoods of accessing care. If eligibility for home-based care has an impact on depressive symptoms, we would expect eligible individuals to have lower levels of depressive symptoms than non-eligible individuals.

Eligibility rules allow care users to receive long-term care and improve their psychological wellbeing

The results of this analysis are summarised in [Table 3.4](#), which shows the effect of being eligible for public home-based long-term care on our two outcomes of interest. The first column shows that being eligible for public long-term care lowers depression by a clinically significant amount – namely we estimate a reduction of 6 percentage points in the probability of having four or more depressive symptoms measured on the EURO-D scale (a validated cutoff for risk of clinical depression). Considering that the prevalence of depressive symptoms is around 30 per cent in our sample, the effect would seem clinically significant. Being eligible for public care also has a large positive effect on the CASP-19 score (column 2), a measure of quality of life. Specifically, being eligible improves the control component of the CASP-19 score (which captures individuals' perception of the extent to which they are able to shape life through their own behaviours) and the pleasure component, which captures the ability to pursue enjoyable activities.

These results show that the net effect of home-based long-term care on mental health and quality of life is positive and clinically meaningful: older people who are eligible for formal home care have better mental health and quality of life than those who are not eligible for formal home care services. Expanding eligibility for home-based care may impact depressive symptoms through several mechanisms. Home-based care may increase social connections and reduce feelings of loneliness (Berkman et al., 2000; Thomas et al., 2016; Wolff &

Table 3.4. *The impact of eligibility for long-term care on depressive symptoms and psychological wellbeing*

Columns	Depressive symptoms (EURO-D)	Psychological well-being (CASP-19)				
	1	2	3	4	5	6
	High depressive symptoms	CASP-19 score	CASP-19 Control	CASP-19 Autonomy	CASP-19 Self realisation	CASP-19 pleasure
Eligible for long-term care	-0.060*** (0.018)	0.678*** (0.215)	0.236** (0.091)	0.054 (0.082)	0.137 (0.099)	0.277*** (0.100)
N	24,878	21,955	21,955	21,955	21,955	21,955
Sample average	0.304	36.996	8.449	9.274	9.033	10.252

Notes. Standard errors in parentheses. Sample: individuals aged 65+, with children, in SHARE waves 1, 2, 5-7 in Belgium, France, Germany and Spain. Controls: age (quadratic), sex, living arrangements, education, living area, self-reported health, ADL limitations, IADL limitations, mobility limitations, cognitive health, fixed effects for household income (quintiles), waves and NUTS-1 regions. Standard errors are clustered by NUTS-1 regions (57). Full results available from the authors. Statistical significance: *** p<0.01, ** p<0.05, * p<0.1.

Agree, 2004). It may increase the capability to maintain participation in leisure activities, hobbies and social contacts, which may increase enjoyment, security, control, personal dignity and self-respect (Grewal *et al.*, 2006). Home-based care may also help prevent further functional decline and activity restriction (Forder & Caiels, 2011), for example, by helping older persons to dress, eat and go out (WHO, 2015; Williamson & Shaffer, 2002). Home care may also increase flexibility in leisure time allocation, consumption and living arrangement decisions, which may increase control and autonomy (Grewal *et al.*, 2006), thus leading to improved mental wellbeing.

In conclusion, these results provide evidence that a policy that increases eligibility for home-based care may improve the mental health and wellbeing outcomes of older people. This suggests that budget cuts to long-term care services should factor in possible welfare losses for older people, while investments in long-term care may bring wellbeing and mental health benefits that are often ignored.

3.11 Conclusions

All governments have limited fiscal space to provide long-term care support and services, and needs assessments are one mechanism to make sure those limited resources are used in ways that maximise access, affordability, equity (i.e. the most vulnerable are adequately protected) and efficiency (i.e. a given level of results is achieved at the lowest cost to the public purse). This chapter has focused on the lessons learned from OECD countries with advanced long-term care systems, many of which are European. Even though all countries explored in our analysis offer long-term care services and support, these programmes do not achieve comprehensive coverage due to the nature of their eligibility rules.

This chapter has explored the economic and wellbeing consequences of long-term care eligibility rules, with a particular focus on home-based care. Eligibility rules of public care can substantially affect access to home-based care among older people. Eligibility to receive care can also offer social protection from the financial risks associated with functional decline and the need for long-term care, contributing to reducing the risk of poverty. Long-term care coverage through public eligibility can also improve the mental wellbeing and life satisfaction of older people, thus delivering better outcomes. We have shown that, in

most countries with mature long-term care systems, eligibility for home-based care targets advanced levels of disability, with a focus on compensation or rehabilitation rather than prevention. Going beyond disability and incorporating measures of frailty may enable governments to intervene early and prevent a spiral of decline, which may improve long-term wellbeing outcomes and reduce costs of long-term care. Moreover, eligibility rules are sometimes complemented with means assessments, which prioritises groups with lower economic resources.

We outline here four major takeaways from our study.

1. Policy makers should carefully design eligibility rules that may use a range of criteria based on functional health-related needs, monetary and contextual characteristics of the applicants

In defining the procedures and mechanism that regulate access to care, governments must anticipate challenges in establishing homogeneous assessment procedures due to the lack of a universally agreed approach to measuring the need for care. Disability, dependency and frailty are contested concepts and the methods of assessing them represent particular theoretical perspectives on the physical and cognitive decline that occurs with ageing. Even among countries with well-established welfare systems, the operational definition of ‘need of care’ varies largely. As a result, individuals with very similar functional health can face different entitlements to long-term care by virtue of the eligibility rules they are subject to. This translates into important differences in care use and wellbeing, as eligibility for public long-term care is an important incentive for older people to use formal care. Our analysis has shown that potential coverage is generally lower for countries or regions where the minimum threshold for eligibility is triggered either by multiple limitations in ADLs or by severe cognitive deficit. These rules identify individuals in an advanced stage of disability and dependency, and therefore do not cover older people who are facing early signs of loss of autonomy (e.g., having lost the ability to perform one ADL and multiple IADL tasks). Conversely, eligibility rules focused on more complex dimensions of vulnerability such as IADLs, mobility and less severe cognitive impairment, tend to be more inclusive, leading to higher coverage. Likewise, using frailty rather than ADLs and IADLs

to define eligibility may enable earlier intervention and prevent a spiral of functional and physiological decline (Fried et al., 2004), although it might be challenging for countries to implement it in practice unless screening through the health system is in place.

Given the substantial heterogeneity between countries in the weight given to different limitations, we believe countries should put considerable effort into adopting a common framework for the evaluation of needs which links more consistently with the evidence in the literature. For example, many laws assign equal weight to all ADL or IADL limitations. However, countries could consider that a hierarchy exists within and between ADL and IADL limitations and assign a higher weight to limitations which are likely to represent more severe signs of loss of autonomy.

Further challenges exist in defining the best approach to means testing – based on income or various types of assets – for establishing eligibility. Means tests can promote both equity and efficiency. However, assets tests can act as a form of taxation on the wealth and savings of older people receiving care and, as such, have the potential to distort saving behaviour (OECD, 2018), influencing the allocation of savings across different types of assets and over the lifecycle.

2. Policy makers should balance transparency of rules with individual consideration of needs assessment and eligibility rules

This chapter has also discussed how eligibility rules can be designed to enhance transparency of the needs evaluation process (algorithm-based) at the cost of reducing consideration of individual circumstances. The algorithm-based approach provides clearer and more explicit information to the applicant, while a case-managed approach that focuses on each individual situation requires a more complex and often less transparent evaluation process. However, the algorithm-based approach is generally less able than the case-managed approach to account for the complexity of individuals' characteristics and contextual circumstances, and therefore less able to fully match entitlement to needs.

In choosing what approach (or mix of approaches) to adopt, governments should remember that older people who require long-term care

are often in a vulnerable situation. It is probably not optimal to have them navigate a complicated system to access support, with intricate definitions of needs, complex sets of rules and procedures to determine eligibility and OOP costs, and unpredictable consequences for their mental, physical and financial wellbeing. Policy makers seeking to introduce a long-term care system or reform an existing system should take inspiration from recent health care reforms, which increasingly favour person-centred, responsive, accessible and affordable high-quality services. Older people should be able to navigate the system, starting with clear entry points (e.g., a referral from their local GP or family doctor, or a reference from their local government office). Once in the system, they should be able to understand how their needs relate to the services that are available to them, and how their means (income and assets) determine how much financial support they will receive. We suggest that eligibility rules should be designed so that older people and their families can clearly anticipate how their social context and living arrangements may affect their eligibility for public support, and what responsibilities each stakeholder has. If there are means tests, these should be easy to understand and give predictable results: the older person and their relatives should be able to predict the OOP costs and the potential impact on their disposable income and net wealth before deciding. If multiple services are available, some degree of choice for the older person and their relatives should be allowed.

3. Policy makers should consider expanding eligibility rules to increase access to care and improve wellbeing

Policy makers should consider expanding eligibility for home-based long-term care for older adults in need, as they can directly impact older people's care arrangement choices and improve wellbeing. There are three arguments to support this recommendation. First, softening eligibility rules raises incentives to access long-term care. Among people with loss of autonomy, being eligible for long-term care implies higher rates of care utilisation. This suggests that on average, older people with limitations react to the availability of public support (in cash or in kind) and use it to improve the amount of care they receive. This is important for reducing the risk of unmet need, which can in turn reduce the burden of ill health and disability on families and government. In addition, studies show that if given the opportunity to receive more

government support, older people tend to also receive more support from their informal network, which acts as a complement to the formal pillar of care provision (Carrino et al., 2018). This effect would further enhance the aforementioned positive effects of long-term care eligibility in reducing the risk of unmet needs among vulnerable people.

Second, although government support might be available, its intensity is often limited. Differences in eligibility rules imply a different intensity of social protection across countries. In most OECD countries, including those with the most mature long-term care systems, the majority of older people would not be able to afford long-term care services unless they had savings to draw on, even when they were entitled to public support. Lower-income groups face a particularly high risk of being unable to afford the costs of long-term care services from their incomes alone. Even with social protection, the risk of poverty is still higher for those with long-term care needs than for the population in general. Government support for home care for severe needs is often not sufficient to reduce poverty risks to the levels of people who do not need long-term care (Angrisani et al., 2022).

Third, we show that by expanding eligibility governments can improve the mental health and quality of life of older people. Expanding eligibility rules is likely to allow individuals to increase social connections, reduce feelings of loneliness, enhance their capability to sustain active ageing, and face a lower functional decline. All these positive effects may contribute to an enhanced feeling of control and autonomy, leading to improvements in wellbeing. This effect is socially and economically relevant, as mental health problems such as depression are an increasingly common among older people and are a major cause of disability, with large economic costs. This suggests that a policy shift towards coverage of publicly funded home-based care may be justified in terms of increased societal welfare. In turn, cuts in public funding for long-term care services might entail welfare losses that are often ignored.

4. Policy makers should consider the equity impacts of eligibility rules for long-term care

Our analysis highlights that inequalities in access to long-term care may be increased as a result of eligibility rules. For example, older people with lower levels of education are less well versed in how to accrue the

benefits of eligibility than those with higher education. The literature indeed suggests that older people of lower socioeconomic status find it harder to cope with a long-term care system that is often complex and intricate (Bottery, 2018; Carrino & Orso, 2015). This reinforces the previous discussion about the need for clear and simple eligibility rules that can be communicated and understood by older adults, or for the implementation of tools that can compensate for the difficulties in navigating complex bureaucratic procedures which may limit access to care.

3.12 Appendix to **Chapter 3**: Needs assessments and eligibility rules review

Table 3.5. *Needs assessments in use in EU member states and OECD countries*

Country	Standardised assessment	Evaluation	ADL, IADL, cognitive	Weights/points threshold	Categories or levels
Australia	National standardised assessment ACAT	Multidisciplinary Aged Care Assessment Teams (ACATs)	Yes to all. Use 5 domains, Social, Physical, Medical, Psychological, and Complexity / Vulnerability.	Under each of the 5 domains there is a classification of ability with 4 levels	4 levels
Austria	Based on care needs comprising a scale with 21 elements	Doctor's 'expert opinion', representatives of other fields (e.g., nursing) are also brought in for an extensive assessment of the situation	ADLs and IADLs as well as cognitive impairment	Eligibility set a 65h/month and that lasts presumably for at least 6 months	7 categories of long-term care based on care hours per month
Belgium	KATZ and Resident Assessment Instrument (RAI). For its financial benefits, Belgium uses the KATZ instrument at a national level.	Professionals involved in the assessments are part of a multidisciplinary team	ADL, IADL, and cognitive. Includes the need for supervision, to have a social life and to be aware of dangers	For cash benefit, points attributed for each function are added up and the person is assigned to a category	5 categories

Bulgaria	No nationwide system	Permanent assistance of a carer is defined by medical specialists while for long-term care social services it is by social workers	ADL	Minimum 50% disability	3 degrees
Croatia	No nationwide assessment	A body of experts composed of specialist doctors and other professionals	Type and degree of severity of physical, mental, intellectual or sensory impairments	Full amount for persons with severe disabilities	2 levels: full or partial
Czech Republic	National, differentiated on a four level scale according to the recipient's care needs using the International Classification of Functioning, Disability and Health (ICF)	Care Allowance (Příspěvek na péči) is assessed by a social worker from the Labour Office and by a medical doctor of the Medical Assessment Service	Uses ADLs and IADLs as well as cognitive impairment Indicators are based on the 10 basic living needs in ICF	Eligibility based on points Needs at least 3 out of 10 testing basic needs	4 levels
Denmark	No specific international scale is used. The decision on the assistance is taken on the basis of a questionnaire established by the local authorities.	Evaluators hired by the municipality and have experience in the social sector	Include functional ability based on Barthel index, IADL, cognitive but also home conditions and possibilities of self-determination, and an indication of rehabilitative support	No minimum level	

Table 3.5. (cont.)

Country	Standardised assessment	Evaluation	ADL, IADL, cognitive	Weights/points threshold	Categories or levels
England	No nationwide but use the Fair Access to Care initiative	Social care professionals are involved in the assessment and care management of social care needs. Cash benefits: A non-medical person is responsible for making a decision on a claim for personal care benefits	Feeding, personal hygiene, toileting, dressing, safety, household tasks, social relations, use of services		
Estonia	The State has developed an instrument for the local governments' social workers to assess the need for care based on the RAI – Resident Assessment Instrument	The assessment of the need for welfare services is undertaken by local social workers. The need for nursing care is undertaken by medical doctors and nurses and for more	ADL, IADL, psychological (mental health) and social (ability to work, communicate, etc.) capability is considered	Minimum 20 points	3 categories

	Local authorities have their own standards for assessing and reviewing the state of health, need for personal assistance, guidance or supervision	difficult cases by a multidisciplinary rehabilitation team			
Finland	No national assessment. Not standardised, the municipality grants services on the basis of an assessment of individual needs. Some use RAI.	The needs must be assessed in a versatile manner, using reliable evaluation methods, and in cooperation with various actors.	Assessment of the various dimensions of functional capacity, i.e. physical, cognitive, mental, social and environmental factors.	Thresholds vary across municipalities	
France	National grid AGGIR (<i>autonomie g�rontologique groupes iso-ressources</i>), aimed at assessing the degree of loss of autonomy or the degree of physical and mental dependency.	A medical-social team is responsible for evaluating the degree of loss of autonomy and elaborating an assistance plan	ADL, IADL, cognitive	10 variables with 4 degrees (spontaneously, totally, correctly, normally)	6 levels but only levels 1 to 4 give entitlement to APA

Table 3.5. (cont.)

Country	Standardised assessment	Evaluation	ADL, IADL, cognitive	Weights/points threshold	Categories or levels
Germany	Nationwide assessment in 6 areas of life	Specialist nurses and doctors	ADL, IADL, cognitive and communicative skills, behaviour and psychological problems, autonomy, but also coping with disease, organisation of everyday life and social contacts	For each criterion in the 6 areas the degree of autonomy is measured between 0 and 3. There are also different weightings which are combined to form a total value. Minimum of 12.5 points	5 grades or care levels
Greece	No specific nationwide indicators	Centres for Certifying Incapacity comprised of specialist doctors	No specific indicators. Invalidity levels of 50%, 67% or 80% on account of certain illnesses result in different levels of care provision	Minimum 50% invalidity	
Hungary	National assessment. A care needs assessment scale takes into account the person's need for social and health care as well as daily activities.	The evaluation of the dependency level is undertaken by the service provider	ADL, IADL, orientation in time and space, behaviour, communication	Points. Determines the level.	3 levels

Iceland	No nationwide standardised, although RAI often used for nursing homes	A specially appointed group of professionals in each health care district	Special assessment tool which describes ADL.	
Ireland	The Single Assessment Tool (SAT) is being implemented	For home care, a health care professional, usually a Public Health Nurse. For nursing home, a multidisciplinary assessment, involving a consultant geriatrician or psychiatrist of old age	ADL, IADL and cognitive, includes risks within the home environment and informal care availability	5 factors. The assessment of likelihood of a risk occurring is assigned a number from 1-5 and each factor has 0- 25 risk rating, with an overall priority ranking to a score of between 0-100
Italy	Non-standardised, depend on the regions	Ad hoc commissions within both the local health authorities and the legal medical department at the INPS	The method used is based on the KATZ scale (ADL), which uses bathing, feeding, dressing, continence, transferring and toileting. The criteria taken into account refer to the ability to take care of oneself.	

Table 3.5. (cont.)

Country	Standardised assessment	Evaluation	ADL, IADL, cognitive	Weights/points threshold	Categories or levels
Japan	Standardised and uniform across the country using a standardised national questionnaire	Needs assessment is entered into the computer for an initial care level. Computer generated decision is then reviewed by a nursing care needs certification board consisting of physicians, nurses and other experts in health and social care services	ADL, IADL, BPSD related care	74 items are used to estimate caring time for 8 categories	7 possible categories: two support levels and care levels graded from 1-5
Latvia	Nationwide	Multidisciplinary team composed of a general practitioner and a specialist social worker. If the person claims long-term institutional care, financed from the State budget, an additional check is provided by the State Social Integration Agency	ADL, IADL, communication, behaviour, settlement of conflicts.	Minimum level (level I of care): 75% ability for self-care and independency	4 levels

Lithuania		By social workers. It may also be assessed by a team of specialists, consisting of a social worker, their assistant, a community caregiver and a mental health caregiver	The need for social services is assessed on the basis of the relations of the person concerned with the community, communicativeness, and ability to accept the help of others, nutrition, housework, financial situation, cognitive and emotional, perceptions and other functions.		3 levels
Luxembourg	Nationwide	Doctor or a health professional (nurse, psychiatric nurse, occupational therapist, psychologist or social worker)	Focus on ADL, IADL	at least 3.5 hours per week and if his/her dependency condition is likely to last longer than 6 months or to be irreversible	15 levels based on minutes of care per week
Netherlands	Nationwide for Wlz, non-standardised for the municipal home care services	Care Needs Assessment Centre (Centrum Indicatiestelling Zorg, CIZ) for Wlz ZvW insurance Municipal social workers for home care	Health problems, physical and cognitive limitations, social and home environment, quality of life and service use, takes into account informal support		No specific care levels but based on the assessment, profiles are created

Table 3.5. (*cont.*)

Country	Standardised assessment	Evaluation	ADL, IADL, cognitive	Weights/points threshold	Categories or levels
Norway	Assessment depends on the municipality	Assessment by doctors and/or other qualified personnel (e.g., physiotherapists) about the need for services			
Poland	Nationwide	The authorised physician (doctors)	ADL, IADL	People with 0 to 40 points on the Barthel scale receive long-term care	
Portugal	Integrated Bio-psychosocial Assessment Instrument	Medical boards operating in the framework of the system for determining incapacity in terms of social security.	ADL		4 levels
Romania		Medical doctors and social workers	Integrated system of indicators: functional, sensory and psycho-emotional		

Slovak Republic		The medical examiner in cooperation with specialised doctors and with a social worker (social assessment activity)	ADL, IADL	Determined by the number of hours and activities – minimum requires at least 2h/day of assistance 12 criteria where activity is assessed by points 0-10.	5 levels of care based on the degree of reliance
Slovenia	No unified assessment	For home, it is done by individual experts while the need for institutional long-term care services is assessed by special teams (medical doctor, social worker, nurse)	ADL and IADL		For nursing homes there are 3 categories
Spain	Nationwide but instruments could be different across the regions	Evaluation board of the Autonomous Communities (Comunidades Autónomas). The board is composed of health and social professionals	A scale considers 47 tasks grouped into ten activities (eating and drinking, control of physical needs, bathing and hygiene, other physical care, dressing and undressing, maintaining one's health, mobility,	Score is the sum of the weights of the tasks for which the individual has difficulty, multiplied by the degree of supervision required and the weight assigned to that activity Minimum 25 points (highest is 100)	3 levels

Table 3.5. (cont.)

Country	Standardised assessment	Evaluation	ADL, IADL, cognitive	Weights/points threshold	Categories or levels
Sweden	Not standardised nationwide	Social workers employed by the municipalities	moving inside the home, moving outside the home, housework and making decisions). Some municipalities use the KATZ ADL or any other type of scale. Others use an administrative application form.		

Source: Hashiguchi and Llana-Nozal (2020)

Table 3.6. *Clinical profiles evaluated under the eligibility rules of Belgium and Germany*

Profile A	Profile B	Profile C	Profile D
Limited in 2 ADL, 3 IADL	Limited in 2 ADL, 3 IADL	Limited in 2 ADL, 3 IADL	Limited in 3 ADL, 3 IADL
Age: 74	Age: 85	Age: 74	Age: 84
Limitations in ADL: dressing, bathing	Limitations in ADL: dressing, bathing, transferring	Limitations in ADL: incontinence, bathing	Limitations in ADL: bathing, eating, using WC
Limitations in IADL: outdoor mobility, using the telephone, managing money	Limitations in IADL: shopping for groceries, meal preparation, housework	Limitations in IADL: outdoor mobility, shopping for groceries, housework	Limitations in IADL: shopping for groceries, housework, managing money
Cognitive limitations: yes	Cognitive limitations: no	Cognitive limitations: no	Cognitive limitations: no
Eligibility status: ELIGIBLE ONLY IN BELGIUM	Eligibility status: ELIGIBLE ONLY IN BELGIUM	Eligibility status: ELIGIBLE ONLY IN GERMANY	Eligibility status: ELIGIBLE ONLY IN GERMANY

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4 *How have countries configured long-term care service delivery to improve efficiency and access to needed services?*

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4.1 Introduction

As people grow older and their functional status declines, they are generally more likely to need help and support for everyday activities (Costa-Font & Raut, 2022). With ageing populations and increasing demands for long-term care worldwide (Costa-Font & Raut, 2022), questions related to access, affordability and quality of long-term care have become increasingly relevant. In Europe, for example, the European Pillar of Social Rights recognises the right to affordable long-term care services of good quality for all European citizens who need them (European Commission, 2017). In Asia, there is an acute awareness ‘of the increasing need to establish and finance long-term care services in response to demographic, economic, and social trends’ (UNESCAP, 2022; Asian Development Bank, 2022:v). To achieve these goals amid demographic and socioeconomic changes, governments are prioritising the re-design of care delivery, putting

people at the centre, and promoting coordination of services between health and social care systems.

As outlined in the introduction to this volume, the structure and scope of coverage of long-term care systems vary greatly between countries, reflecting widely diverging local contexts, social norms, demographic trends (ageing first and foremost), economic development and availability of resources. Although providing adequate long-term care is a huge challenge in rapidly ageing developed welfare states, LMICs are facing declining fertility rates and increasing life expectancy and consequently a growing need for long-term care as well as discussed in detail by Hu and Wittenberg in [chapter 2](#). Long-term care has historically been considered a family and close-community responsibility in many countries, with some actions covered by health and/or social protection systems. Recently, long-term care has begun to be provided through stand-alone, separate systems. In many Asian countries, for example, there has been a growing awareness of the need to develop facilitating environments to support older people to age well, and to ensure that families and communities are enabled to care for their older citizens (Asian Development Bank, [2022](#)).

Long-term care systems have been undergoing reform processes for as long as they have existed, and no gold standard model exists. Instead, the growth of formal long-term care in countries at all income levels in the mid-twentieth century presented a wide range of opportunities, closely linked to other elements of the welfare system and a product of historical, political and social factors (Zimmerman, et al., [2022](#)). The Covid-19 pandemic had and continues to have significant implications for the provision of long-term care especially for vulnerable groups. The pandemic accentuated already existing structural challenges, including access, affordability, quality of services, staff shortages and the costs of fragmentation across health and long-term care. It also unveiled new ones, such as insufficient infection prevention and control standards and practices, shortages of personal protective equipment and inadequate testing (European Commission, [2021a](#); Asian Development Bank, [2022](#)).

The purpose of this chapter is to provide an understanding of different long-term care service delivery models and how these enable access while securing efficient use of resources. The chapter starts with an overview of the key challenges facing international long-term care

systems before discussing how countries have been responding to these challenges by looking at emerging trends in long-term care service delivery. To dive in deeper, the [next section](#) reviews the evolution of long-term care service delivery in selected countries, focusing on recent and ongoing developments. It concludes with cross cutting lessons for policy makers looking to improve accessibility and efficiency of long-term care in their countries before finishing with a short conclusion.

4.2 Challenges and trends in the delivery of long-term care services

Challenges

Despite pronounced differences between national systems and contexts, countries across the globe face common challenges regarding delivering long-term care.

The first challenge is that countries are undergoing demographic and epidemiological changes, including accelerated population ageing and the growing prevalence of chronic conditions, multimorbidity and functional limitations that increase considerably with age. This can translate into an ever-growing share of the population that now and in the future requires support and care to maintain functionality and a high quality of life, with limited evidence that morbidity is compressed at the end of life as life expectancy increases. The proportion of older individuals needing long-term care has continued to grow in the last two decades (Costa-Font & Raut, 2022). Almost all Western European countries as well as India, Ghana and the Russian Federation amongst others showed an increasing trend in terms of long-term care needs measured in numbers of people requiring assistance for IADLs that facilitate their independent living. To meet these demands, countries are working towards strengthening their long-term care systems across all delivery settings, both in care facilities, at home and in communities, ensuring service design and people-centredness, and boosting capacities to respond to evolving care needs (European Commission, 2019; UNESCAP, 2022).

The second challenge is that the ageing trend in both developed and developing countries is expected to increase the demand for both formal and informal care. Long-term care relies heavily on informal carers and while their numbers are declining, informal carers still provide the largest portion of long-term care (Costa-Font & Raut, 2022). Formal care is

often provided by a range of paid health professionals as either residential care (nursing homes, special housing, assisted living communities, day centres, etc.) or as home care. Informal care, on the other hand, is often provided within the context of a social relationship (close relatives or neighbours) and generally without pay (WHO, 2022a). Informal care can be provided in the user's home and, in many cases, in residential care settings. In many contexts, long-term care is provided as a mix of informal and formal care, and not only one or the other. Even in countries where long-term care systems are well-developed and the service packages are rather generous (e.g., Denmark, Netherlands, Sweden), informal care always has and still accounts for the majority of care provided (European Commission, 2021b; European Commission, 2021a). In addition, changes in family patterns, such as a growing number of single households, increasing participation of women in the labour market and generally more labour mobility, will likely result in declining availability of informal carers and increase the demand for available formal long-term care providers (Spasova, et al., 2018). Adding to this, the attractiveness of the formal care sector for potential workers is undermined by several negative perceptions linked to poor and strenuous working conditions (both physical and mental) and inadequate pay (Eurofound, 2020; European Commission, 2021a; European Commission, 2021b).

A third major challenge, also addressed in chapter 2, is the persistent shortage of health professionals and a workforce with the proper skill mix. WHO has estimated that there will be a global shortfall of ten million health workers by 2030, with more profound decreases in low- and lower middle-income countries and across all health professions (WHO, 2022b). This can severely impact the successful implementation of long-term care policies and the provision and quality of care. As countries are looking for ways to reconfigure the delivery of formal long-term care services, they need to address how to: 1) increase the numbers of formal health professionals and informal caregivers, 2) retain the existing workforce, 3) improve working conditions, and 4) ensure the proper support for informal caregivers. Furthermore, having a long-term care workforce with the size and skills needed to meet the increasing demand for long-term care is a challenging task because of the many and often interrelated factors at play. Such factors include the population's demographic characteristics, economic growth, technology, migration of long-term care professionals, education/training, and retirement policies (Grubanov-Boskovic, et al., 2021). This implies a need for a holistic approach to

workforce planning that integrates and coordinates different policy areas at local, national and international levels (Grubanov-Boskovic, et al., 2021). These complex and often interrelated demand and supply-side factors translate into rising numbers of people requiring and looking for long-term care services, while the number of people providing these services is not rising commensurately but is rather stagnating or even declining. This leads to a growing imbalance between the supply and demand for long-term care services.

Trends

Countries around the globe are grappling with the challenges of ageing, increased demand and workforce shortages to varying degrees. Consequently, countries have been promoting new care delivery models to tackle these, and specific trends have emerged. The most prevalent are presented below.

Enhancing the integration of long-term care services is a widely used approach to improve their access, affordability and quality

The provision of long-term care services involves a wide range of service providers including medical and nursing care, personal care services, assistance services, social services and informal carers. Furthermore, different funding schemes are often used, e.g., for social care, health care and long-term care. While collaboration between formal long-term care workers with other professionals and informal caregivers is widespread, the division and coordination of tasks are not always clear-cut and responsibilities sometimes overlap. Due to this fragmentation in provision and funding, long-term care is often poorly coordinated and not delivered in a patient-centred way. One solution is to better integrate services within the spectrum of long-term care and within the wider health system so that people in need of long-term care, who often have complex health needs, have a more seamless, effective and positive care experience. Such care could consist of:

- 1) a targeted, community-based and proactive approach to care for people who have complex health needs (case management),
- 2) the collaboration of different professionals in multi- or interdisciplinary teams, working interdependently under a common care plan to address people's long-term care needs, and

- 3) proactive patient care coordination by a case manager throughout the entire continuum of care, bringing together care professionals and providers around the patient's needs across various settings (WHO, 2021).

Enhancing integrated care has been a widely followed approach, aiming to improve access to long-term care as well as affordability and quality of services (Asian Development Bank, 2022; Costa-Font & Raut, 2022). The successful implementation of policies that aim at strengthening the integration of care is highly dependent on having an adequate workforce in place that has the right training and skill set.

The most commonly applied measures to reinforce the integrated delivery of care tackle sectoral disparities between health care and social care by setting up coordination structures. These aim to improve care management and hence population health and well-being through enhancing communication and cooperation between formal long-term care providers to improve the effectiveness and efficiency of care delivery (see Box 4.1 for examples) (Costa-Font & Raut, 2022).

Box 4.1. Several countries have been reforming long-term care to become better coordinated and integrated

In Bulgaria, attempts have been made to establish a revised model of integrated, high-quality social services. An integrated network of home care services for people with disabilities and older people is expected to increase access to long-term care, supporting more than 30,000 people (European Commission, 2021a). In Greece, a government programme established 150 integrated care centres for older people in 2018, which provide them with information and support on home care services and coordinate care services (European Commission, 2021a). In Belgium, twelve projects have been set up at the local level since 2018 to test a range of measures to increase the integration of care and support to improve the care of people with chronic diseases, including older people (European Commission, 2021a). Finland took steps in 2018 to improve the sharing of individual's social welfare information in the national archive with care institutions at the county level, aiming to improve care management through better and more efficient communication (European

Box 4.1. (cont.)

Commission and Social Protection Committee, 2021). Despite these developments, it must be noted that throughout the Covid-19 pandemic, many national strategies and emergency response plans across Europe did not explicitly prioritise integrated perspectives on long-term care provision, often leaving long-term care systems under capacity (WHO, 2022a).

In Thailand, a government-led pilot project was launched in 2016, with the aim of establishing a care management system for community-based long-term care. A key aspect of the programme is a care manager who is assigned to older people eligible for long-term care. The care manager is typically a nurse from a community health promotion hospital or primary health centre, who is responsible for assessing the care needs of the older person. Based on this, an individual care plan is developed jointly with a multidisciplinary team. Also, the care manager assigns and supervises the community caregivers who provide social care services based on the older person's care plan; health professionals provide further health and medical services, including preventive services, rehabilitation and assistive devices. The initial target was set at 100,000 beneficiaries in 1,000 out of 7,255 subdistricts. In 2018, the programme budget was increased to B1.159 billion (USD 35.4 million), to enable the project to reach 193,200 people. In that year, 72,000 trained caregivers participated in this project (Asian Development Bank, 2022).

In Canada, there have been several initiatives, such as the Comprehensive Home Option for Integrated Care of the Elderly (CHOICE) programme in Alberta implemented in 1996, to integrate medical and social care through the provision of transportation, day centres, social and health services, and the SIPA programme (Integrated Services for Frail Older Persons), which combines the provision of community services, a multidisciplinary team and case management in Quebec.

The PRISMA (Program of Research to Integrate the Services for the Maintenance of Autonomy) programme also exists in Quebec and uses community primary care services to integrate health and social services, acute and long-term care, and community and residential services such as hospitals and nursing homes. These projects follow the principal objectives of improving the integration of care for frail and older people while pursuing cost savings and efficiency gains for providers, higher quality for clients and better health outcomes (Costa-Font & Raut, 2022).

Several countries have shifted their long-term care delivery model towards home and community-based care

There have been developments in most European countries to improve the delivery of long-term care in residential settings and at the same time expand community-based solutions. The aim is to achieve better outcomes for users and their families at lower or comparable costs. On the downside, it potentially puts many long-term care service delivery structures under constant pressure for reform (Ilinca, *et al.*, 2015). In some countries, this has led to a decrease of residential care capacity while simultaneously increasing home care and community-based care (e.g., in the Nordic countries and Netherlands). However, in countries with traditionally low levels of residential care provision for older people and where the family support structure has generally been the main provider of long-term care, there has been an increase in residential care capacity (e.g. Southern and Eastern Europe or the Republic of Korea) (Spasova, *et al.*, 2018; Alders & Schut, 2019), while community-based care has not developed at the same pace or has even been reduced. Although a majority of countries have recognised the importance of de-institutionalisation and many are strategically shifting towards it, progress towards this goal has been mixed.

Older people prefer receiving home care instead of residential care, although many expect such services will not be available when needed (Ilinca & Simmons, 2022). Attempts to de-institutionalise long-term care have often been accompanied by a greater focus on home and community-based care solutions (Spasova, *et al.*, 2018). For example, in some countries home and community-based care solutions have been expanded to enable long-term care users to continue living in their own homes (e.g., Belgium, Canada, Denmark, Japan, Ireland, Netherlands, New Zealand, Norway, Sweden, Poland and Switzerland). This trend, which is often labelled ‘ageing in place’, is defined as ‘remaining living in the community, with some level of independence, rather than in residential care’ (Davey *et al.*, 2004: 133; Alders & Schut, 2019). In the Netherlands, for example, since a large-scale reform of long-term care in 2015, the number of beds in residential facilities has been reduced while capacity for ageing in place has been built up (Janssen *et al.*, 2016). Another approach has been to introduce regulatory measures to promote home care by making the eligibility criteria for residential care stricter (Finland, Czech Republic and Hungary). To enable these changes, countries are increasing public funding and

insurance coverage of home and community care. Furthermore, in some countries cash benefits, directed either at service users or providers, aim to incentivise the use of home and community-based care solutions (e.g., Austria, Germany, Netherlands, Sweden, United States and United Kingdom) (Feng, et al., 2020). Additionally, there has been a trend towards protective housing and co-housing/co-living in the Netherlands, neighbourhood developments in Germany, and empowerment-oriented community development in Japan (Inaba, 2016; Johansen & van den Bosch, 2017; WHO, 2020; Rusinovic, et al., 2019).

While most older people prefer to stay in their own homes and receive community-based care (Ilinca & Simmons, 2022), this option does not always exist for all groups of the population. For some people, the informal care resources that are often needed to complement professional care delivery are not available for a range of reasons, for instance, lacking a supportive social network and environment. Furthermore, people with severe limitations in everyday activities may require more intensive support than their social network and home-based services can offer (Oliveira Hashiguchi & Llana-Nozal, 2020). Lastly, the affordability or availability of care services in the community often severely limits the options that older people have. Residential care is the final public safety net in many countries, as community-based care is often subject to high cost sharing.

Digital technologies are changing the delivery of long-term care, requiring new professional skills

Since the outbreak of the Covid-19 pandemic, many countries have seen a shift towards accelerating the use of digital technologies in the provision of long-term care. Digital technologies can be enablers in providing long-term care in residential settings, as well as home care and community-based settings. With adequate support for users (e.g., training and capacity building) these technologies can help improve the daily activities and overall quality of life of older people receiving long-term care, their relatives and their professional caregivers (Gallistl, et al., 2021).

Having a robust digital infrastructure in place can facilitate communication between health workers, people receiving long-term care and their families and local communities. Furthermore, digital technologies can improve access to and the delivery of care, for example by enabling remote monitoring by providers, ‘smart home’ technology to ensure the

safety of users at home, and telecare and telehealth to facilitate exchanges between care users, formal providers and informal caregivers. This plays a key role in improving integration between different long-term care and health care services, resulting in more efficient joint provision of care across levels and care types. Lastly, digital solutions may allow people with long-term care needs to stay in their homes or communities instead of receiving more expensive care in residential facilities.

The shifts towards greater use of digital technologies in the delivery of long-term care is generating a need for new professional roles and skills, affecting both the demand for and the supply of health and care workers. The effect of increased use of these technologies on the health and care workforce remains closely related to a range of ethical (relating to issues such as data privacy, fairness and human oversight of digital and automatised solutions), social (higher ability and acceptance of working with IT devices than working with people) and labour market aspects (i.e. when IT could replace labour or could expand productivity in long-term care occupations, adding to labour-enhancing effects) (Grubanov-Boskovic et al., 2021).

While overall use of digital technologies by healthy older people across the European region has increased significantly in recent years (Seifert, et al., 2020), implementing and using digital tools can be challenging, especially when older people and their caregivers (both formal and informal) lack access to these tools or do not have sufficient digital skills to operate and benefit from them. Hence, a precondition for mainstreaming digital technology use in long-term care is continued investment in digital literacy for care users, their families and the care workforce (Grubanov-Boskovic et al., 2021). It should also be noted that vast differences persist across countries in the European region in terms of connectivity, internet service use, and uptake of digital products and their integration in long-term care, underlining that implementation of information and communication technology (ICT) use in long-term care is strongly context dependent.

Private providers have been emerging to fill gaps in the public provision of care

Several countries are experiencing an increasing demand for residential care facilities and a correspondingly insufficient supply of publicly provided formal long-term care. Consequently, private organisations

have been emerging to fill these gaps in the public provision of care for those who can afford it (European Commission, 2021a) (Spasova, et al., 2018). Strategies that countries have been deliberately choosing include: increasingly allowing the private provision of services and the development of private for-profit and not-for-profit institutions (Germany, Sweden, United Kingdom, Netherlands); allowing private for-profit care institutions to qualify for public funding (Belgium, Germany) and public authorities to contract beds in private residential facilities (Malta, Türkiye); and introducing more market mechanisms through cash benefit schemes and personal care budgets, and allowing patients to purchase care from private providers (Malta, Spain, Finland) (Spasova, et al., 2018; European Commission, 2021a). Also, in Ireland, the supply of long-term care services was stimulated by fostering private sector participation through changes in the regulatory framework (European Commission, 2021a).

However, it is important to note that there are disadvantages: an increased risk of difficulties in monitoring and promoting quality, problems of equity (both in terms of service quality and distribution of services), perverse incentives to accept users whose care is expected to be less expensive and reject those whose care is expected to be more costly, and lack of incentives to invest in prevention and rehabilitation. For example, the introduction of a long-term care insurance programme in the Republic of Korea in 2008 rapidly increased the number of private providers, but without an adequate quality management programme (Walker & Wyse, 2021). Another concern is that it may contribute to further fragmentation of service delivery, which creates new challenges for users in navigating a complex system of different providers (Leichsenring, et al., 2015).

4.3 Country case studies

In the following section, five country case studies will illustrate the four major trends in long-term care outlined above and place them in the context of the development of long-term care in these countries. The case studies will show that these trends are often overlapping and linked but also that there are notable differences in how these manifest in different countries and contexts. We will focus on Germany, Japan, Norway, Romania and Sweden, which differ in how their long-term care systems are organised, demographic trends, levels of spending on long-term care as well as level of institutionalisation (see Table 4.1).

Table 4.1. *Type of long-term care system and key country characteristics*

Country	Type of long-term care system (year of inception)	Population ages 65+ (% of total population) in 2023*	Long-term care health spending (in current USD per capita) in 2021**	% of long-term care recipients in institutions (65+, % of 65+ population) in 2020***	% of long-term care recipients at home (65+, % of total population 65+) in 2020***	Beds in residential long-term care facilities (per 1000 population aged 65+) in 2020***
Germany	Federally organised long-term care insurance (1995)	23	1,273	4.0	15.6	54.2 (2019)
Japan	National long-term care insurance provided by municipalities (2020)	30	880 (2020)	2.6	na	26.4
Norway	National tax-funded long-term care system provided by municipalities (2012)	19	2,644	3.8	10.8	42.1

Romania	National tax- and contribution-funded long-term care system (2000)	18	49	na	na	na
Sweden	National tax-funded long-term care system divided between national, regional and local levels of government (1982)	20	1,736	4.0	12.8	64.8

Notes: * World Bank (2024)** WHO (2024)*** OECD (2023)

Germany: The introduction of long-term care insurance paved the way for privatisation of services and more recent strengthening of long-term care services integration

Long-term care in Germany is provided within the institutional framework of long-term care insurance. This form of insurance was introduced as the fifth pillar of the social security system in Germany in 1994–5 and runs parallel to the health care system, following the same principles in terms of population coverage, access and choice but with substantially higher cost sharing. Long-term care insurance in Germany is funded by mandatory contributions deducted from the salaries of all employees in the country (currently 3.05–3.4% of annual salary). In 2018, 72.8 million (87.7%) of Germany's population was covered by mandatory social long-term care insurance and about 9.2 million (11.1%) by mandatory private insurance (Blümel, et al., 2020). Statutory and private insurance do not differ in coverage, which under both schemes is limited to a portion of long-term costs, with the rest being paid OOP by beneficiaries and families (WHO, 2020a).

The Federal Ministry of Health, specifically the Department of Long-Term Care, bears the main responsibility for governance of long-term care. Local authorities also contribute to long-term care financing in their role of funders providing social assistance by covering high cost sharing (in particular co-payment for board and lodging in residential care) for families that cannot afford these payments. The role of local authorities is being reinforced through the promotion of neighbourhood development (*Quartiersentwicklung*) and the allocation of care counselling to municipalities. Overall, there is growing interest in improving counselling for people in need of care and their caregivers, in particular by enhancing the coordination of health services and long-term care and by strengthening the role of local authorities (WHO, 2020a).

Eligibility for long-term care in Germany had been traditionally limited to people with 'restricted competencies in daily life'. Following the advice of an expert committee in 2013 to expand this definition to better reflect the needs of an increasingly ageing population, this was modified to those 'with health-related impairments of their independence or abilities and therefore requiring help from others' (WHO, 2020a:23). As a result of new legislation following this, the three previously defined levels of care needs were replaced by

five care grades based on physical, mental and physiological disabilities, paying more attention to retaining autonomy while considering mental disabilities (WHO, 2020a). Following a long-term care needs assessment, beneficiaries can choose among cash benefits, benefits in kind and residential care. They can also choose providers. Needs are generally assessed after an acute episode requiring hospitalisation, and often hospitals include the needs assessment within the management of the patient discharge.

In principle, home care is given priority over residential care, i.e. people are cared for at home as much as possible, notwithstanding their individual right to choose between home care and residential care. Eligible beneficiaries can apply to receive care in a nursing home, which often also offer short-term care, day or night care, as well as respite services for informal caregivers. Beneficiaries who forgo cash benefits and opt for in-kind benefits at their home can receive care provided by ambulatory care providers. Services include nursing and social services, ranging from assistance with household activities to curative care services prescribed by physicians (Federal Ministry of Health, 2020). Beneficiaries may also request additional services such as day care or short-term care. In order to be eligible for service provision, providers have to obtain a utility supply contract with the long-term care insurance fund, based on compliance with staffing, training and various other regulations. Some support is available for caregivers as well (see [Box 4.2](#)).

Through the introduction of long-term care insurance in 1994–5, the infrastructure for long-term care delivery changed notably. The previously prevailing provider structure of large not-for-profit organisations was reorganised through a deliberate reliance on private investments in long-term care, which was considered essential to extend supply structures in Germany. This reorganisation led to a marketisation trend and the emergence of new for-profit and not-for-profit providers on the long-term care market, while the number of public service providers decreased considerably, affecting competition, coordination of long-term care services and users' choice (Glendinning & Moran, 2009; WHO, 2020a; Leichsenring et al., 2015). Several small providers of home care have been founded in urban areas; both family businesses and large investors boosted the share of private for-profit providers in residential care from 50.9% in 1999 to 65.4% in 2015 (WHO, 2020a).

Box 4.2. Services for unpaid caregivers in Germany providing long-term care services at home

Different services are available to unpaid caregivers providing care for older people at home. First and foremost, unpaid caregivers are covered by statutory pension insurance while providing services to a beneficiary, as long as the care amounts to at least 14 hours per week at the beneficiary's home and the caregiver works less than 30 hours per week or not at all. Employed caregivers who leave their job to care for a family member are also covered by unemployment and accident insurance, with contributions paid by long-term care insurance.

Also, starting in 2012, new schemes have been put in place for those taking care of a family member to be able to reduce their working hours, take a loan to cover forgone salary as well as take up to six months care leave.

For beneficiaries who choose long-term care services in the form of cash benefits, funds can be used to cover a small compensation for informal care work. An increasing number of households are employing live-in caregivers, often immigrants. Respite care is also available to unpaid caregivers who get sick or take holidays (WHO, 2020a).

The Long-Term Care Further Development Act in 2008 gave room for long-term care insurance to establish integrated care arrangements with care providers and other contracting partners, such as family doctors. These integrated care contracts are aligned between health insurers and care providers, as regards service provision and reimbursement for providers (Leichsenring et al., 2015). The financial incentives built into the long-term care insurance model are one of the most powerful tools promoting integration and innovation (WHO, 2022a). Disease management and integrated care initiatives were established at the local level from 2002 onward to improve the quality of care, contain costs and promote coordination and self-management, with considerable uptake.

Multidisciplinary practices with family doctors and specialists aimed at facilitating care integration have also become increasingly common, especially in rural settings. Arrangements often either take the form of family doctors as care providers, referring beneficiaries to specialists within the network, or family doctors facilitating communication with ambulatory care after a patient is discharged from hospital (WHO, 2020). In another example, local advisory centres for long-term care

(*Pflegestützpunkte*) funded by long-term care insurance exist to facilitate coordination across local service providers and services and to provide counselling for people with care needs (WHO, 2022a).

There are important challenges, however. First, the delivery of health and social services is still considered fragmented and poorly coordinated in Germany (WHO, 2020). Major weaknesses include limited information exchange and communication among providers, poor collaboration with other sectors, as well as family doctors not being informed adequately or in a timely fashion about their patients' discharge from hospital care. There are no care pathways or discharge plans for people in need of long-term care. To fill the gap of fragmented service delivery, unpaid caregivers often take on an additional and burdensome role as care coordinators for which they may be ill-equipped. In addition, care integration is often hampered by provider payment mechanisms that result in competition to attract patients. Also, the fact that health care insurance covers the total costs of interventions, while long-term care insurance provides only partial financial coverage, adds to a set-up where insurers and providers have limited incentives to better align delivery services (WHO, 2020).

Second, Germany's long-term care system is faced with an inadequate supply of trained workers. While most long-term care is still provided at home by unpaid caregivers such as spouses, partners or adult children, a professionalisation process has taken place with 355,000 people working in home care and 730,100 practitioners in residential care in 2015 (WHO, 2020). Nevertheless, the increased demand for qualified personnel is becoming noticeable, especially in rural regions. In recent years, various training, qualification and compensation interventions at both the federal and regional levels have been implemented to attempt to improve the situation. However, despite these endeavours, there are concerns related to quantity and quality of the future workforce in long-term care in Germany (WHO, 2020).

Japan: A strong focus on community-based integrated long-term care services while building up disability prevention and home care capacity

Japan is the country with the oldest population in the world. People aged 65 years or older accounted for 30 per cent of the total population in 2023 depending on whether the updated data in [Table 4.1](#) is

incorporated (see [Table 4.1](#)). A long-term care insurance system was launched in 2000 to address the needs of growing numbers of older people with impairments and support their independence. The system was established to shift the burden of family caregiving to social solidarity, shifting cost sharing through insurance payments and integrating long-term medical care and welfare programs (Yamada & Arai, 2020). The system is highly decentralised, with the municipalities operating as insurers that collect long-term care insurance contributions, provide insurance benefits and manage the long-term care insurance finances. They are also responsible for assessing eligibility using a 74-item questionnaire based on ADLs (Jin et al., 2022). (A detailed discussion of systems for determining eligibility for long-term care is provided by Carrino et al. in [chapter 3](#) of this volume.)

The long-term care insurance covers in-home services (e.g., home visits/day services and short-stay services/care) and services at facilities, including long-term care welfare facilities (also called special nursing homes), long-term care health facilities (also called geriatric health services facilities), and long-term care medical facilities (also called medical long-term care sanatoriums). There are no cash benefits or other direct benefits for family caregivers. Health care managers are actively involved in care plans and service arrangements. Individuals deemed not eligible for long-term care or support may still use preventive care services (Yamada & Arai, 2020).

Following the adoption of the long-term care insurance system, there was a significant growth in the number of people eligible for long-term care, leading to substantial increases in the government's financial burden. As a result, the Japanese government launched a disability prevention programme in which older persons were assessed for frailty using the so-called 'Kihon' checklist and a strategy with community-specific preventive activities aimed at high-risk individuals. The Kihon checklist, however, proved insufficient to identify individuals at high risk of disability; additionally, engagement in local intervention programs was relatively low (Yamada & Arai, 2020).

Following the unsatisfactory outcomes of the high-risk approach to disability prevention, the government shifted to a community-based strategy. This strategy aims to set up a community-based integrated care system by 2025 that can provide seamless preventive, medical and long-term care, as well as welfare and housing services to all individuals (Yamada & Arai, 2020). Home care will play a key role in this

community-based integrated system, but this will need the development of home medical care, home visit services and nursing care. In terms of disability prevention, central and local governments have been promoting community activities, such as salons, to facilitate group participation and encourage social activities among older people (Yamada & Arai, 2020), which have had positive results in reducing disability incidence and cost (Yamada & Arai, 2017; Saito et al., 2019).

Important challenges remain. First, the long-term care insurance system's capacity to prevent disability is still insufficient and needs further attention. Second, there are not enough geriatricians and physicians who practice geriatrics. A strategy is needed to stimulate and motivate physicians to provide frailty prevention in their daily practice. Third, most physicians still employ a disease-oriented rather than a function-oriented approach for older persons, which needs to be addressed in training and continued professional development (Yamada & Arai, 2020).

Norway: A strong focus on de-institutionalisation and integration has resulted in a large proportion of older people receiving care at home

In Norway, the government formulates the overall care policy for long-term care, while the municipalities are responsible for planning and providing long-term care services (Sogstad et al., 2020). They are financed through general tax revenue, block grants from the government and user charges (Grødem, 2018; Theisen, 2020). Services are provided in nursing homes, sheltered housing and in people's homes (Sogstad et al., 2020). The guiding principle for providing long-term care, no matter the setting, is enabling people to stay in their homes for as long as possible (Sperre Saunes et al., 2020).

The role of Norwegian municipalities in long-term care services has gradually changed since the 1970s (Hagen & Tingvold, 2018; Sogstad et al., 2020), which has led to increasing decentralisation, integration, and de-institutionalisation (Hagen & Tingvold, 2018). In 1988, the responsibility for nursing homes was transferred from regional to municipal authorities (Otnes, 2015). Between 1991 and 1995 the responsibility for the care of persons with developmental disabilities was placed with the municipalities. The aim of the reform, known as the HVPU reform, was to shift care from institutions to home care. As a result, people younger

than 67 years now account for 42 per cent of recipients of home-based care in Norway (Helgheim & Sandbaek, 2021). In 2008, the government introduced 'Care Plan 2015', aiming to gradually expand municipal care services (Helse- og Omsorgsdepartementet, 2008). As part of the plan, an investment grant scheme for nursing facilities and residential care homes was established, administered by the Norwegian State Housing Bank (Helse- og Omsorgsdepartementet, 2008; Hagen & Tingvold, 2018). The aim was to encourage the municipalities to increase and improve their existing nursing and care homes, aiming to increase the quality of care (Westberg *et al.*, 2019).

In 2012, the Coordination Reform was implemented, aiming to improve the coordination of care between municipalities and hospitals (Sperre Saunes *et al.*, 2020). Following the reform, the care services landscape evolved, with municipalities increasingly establishing specialised care services for different user groups and their care needs (Sogstad *et al.*, 2020). Examples include municipal acute inpatient units with 24-hour admissions, larger and more specialised short-term care units in nursing homes, and home care teams with particular expertise in dealing with specific patient groups (e.g., people with dementia) or providing specific services (e.g., palliative care and rehabilitation) (Sogstad *et al.*, 2020). With the Coordination Reform, the municipal level was tasked to create more comprehensive and coherent services, which created new demand and required municipalities to build health services to a larger extent than before (Spasova, *et al.*, 2018). Therefore, the transition from hospitals to municipalities has remained burdensome. The reform may have solved some problems but also created new challenges. For example, the ombudsman for users and patients has expressed concern that the reform requires hospitals to discharge patients after treatment when hospital care is concluded and transfer responsibility to the municipality. At the same time, the municipalities may not have the necessary services in place. The transition phase has proven complex, and there have been instances where it resulted in lower quality of care (Spasova, *et al.*, 2018). Evaluations of the effects of the Coordination Reform have shown mixed results. However, the reform has generally supported care delivery at the lowest, most effective level of care and it paved the way for primary care and public health reforms in 2015 (Sperre Saunes *et al.*, 2020).

As a result of the Coordination Reform, there was a shift in tasks between specialised and municipal health services, resulting in shorter

hospital stays and more patients discharged to municipal health services (Utviklingssenter for sykehjem og hjemmetjenester, 2021). Consequently, there is a need for professional restructuring with a higher level and different kinds of expertise, new work methods and new professional approaches (Ministry of Health and Care Services, 2013; Ministry of Health and Care Services, 2020). For example, between September 2014 and January 2015, the municipality of Eidsberg piloted a project on virtual wards, which is not an actual department but a way of organising resources (Eidsberg Municipality, 2015). The virtual wards followed a patient directly to their home after discharge from hospital and consisted of a team of doctors and physiotherapists headed by a nurse with advanced training in geriatric nursing (Ministry of Health and Care Services, 2020).

The government's Care Plan 2015–2020 introduced reablement as a key priority area (Ambugo, et al., 2022; Vabø, et al., 2022), which is also referred to as everyday rehabilitation or rehabilitation for people living at home (Ministry of Health and Care Services, 2020). A broadly used definition of reablement is 'a person-centred, holistic approach that aims to enhance an individual's physical and/or other functioning, to increase or maintain their independence in meaningful activities of daily living at their place of residence and to reduce their need for long-term services' (Ambugo et al., 2022:2).

Another key policy area highlighted in the Care Plan 2015–2020 is the need for new architecture and (digital) technology to strengthen current services and prepare for the future care needs of the population. One element of this policy area is the continuation of the Norwegian State Housing Bank's investment grant scheme for nursing facilities and residential care homes. One example of a project for residential care homes and nursing homes is a shared housing facility for people who need 24-hour nursing and care in Trondheim (Ministry of Health and Care Services, 2020). Another element of the policy area is the national programme for the development and implementation of welfare technology. Welfare technology can help people cope with their daily lives and health issues, allow more people to live longer in their own homes despite reduced functionality, and help prevent or postpone admission to an institution (Ministry of Health and Care Services, 2020). Some of the more common technologies are safety alarms, GPS, cooker monitors, electronic calendars, electronic medicine dispensers and various sensors (Tjerbo et al., 2022).

Romania: National policy aims to increase community-based provision of long-term care services but lack of resources limits progress and private providers are filling the gap

Rooted in legislation adopted in 2000 (Law 17/2000 on Social Assistance for Older People), the current structure of the Romanian long-term care system, eligibility criteria, care services and the settings in which they can be provided were established by Law 292/2011 on the Social Assistance Framework (*Legea-cadru a asistenței sociale*). Important service capacity and development progress has been achieved since then. The legislative framework has been completed to include quality and cost standards for long-term care services (European Commission, 2021b). At the same time, the Romanian long-term care system remains severely underfinanced and underdeveloped, both concerning the estimated care needs it aims to respond to and in comparison to other EU countries (European Commission, 2021a). Accessibility, affordability and quality of care services are pressing concerns, while the sustainability of a system facing marked workforce shortages and heavily reliant on informally provided care is threatened by prevalent sociodemographic and population migration trends, as well as by the lack of meaningful support for informal caregivers (Ministry of Labour and Social Justice, 2018). High levels of fragmentation pose an additional challenge, leaving care users and their families to navigate a complex system with very little support.

Long-term care benefits and services are distributed between the health care systems (home health care), the national system for the support of people living with disabilities (51 per cent of beneficiaries are aged 65 and above), and the social assistance for older persons system. Following the adoption of the Framework Law of Decentralisation 195 (*Legea-cadru a descentralizării*) in 2006, local councils hold responsibility for planning, financing and organising public service provision in their territorial areas. As many local councils lack both the financial resources and the residential capacity to develop care services, chronic underfinancing in long-term care is the norm rather than the exception across Romanian municipalities (WHO, 2020b). In the absence of meaningful accountability and enforcement mechanisms, paralleled by limited and sporadic allocation of central budget financial resources, national authorities have little scope to support a more equitable and coordinated development of care

services. Noteworthy is the launch and progressive expansion of the national community care programme (*Asistență medicală comunitară*), pooling financial resources from national health, social and education budgets and coordinated across all three relevant ministries. In 2021, the community care programme supported 1,800 community care workers and 500 health mediators operating in the most deprived communities, where they often represent the only access to health or long-term care support (WHO, 2022a; Ciurea et al., 2021).

The National Strategy for Promoting Active Ageing 2015–2020 also recognised the development of the national long-term care system as one of its strategic objectives. It emphasised the need to strengthen the community-based provision of long-term care services and accelerate progress on de-institutionalisation. During the implementation period, three national programmes were launched, pooling European financing and national funding from the central budget. They represent the most ambitious investment to date in the development of the delivery network for community-based long-term care services, targeting primarily underserved and deprived communities.

Despite a political commitment to promoting community-based care and these recent positive developments, it is apparent that the pace of progress is insufficient to meet and keep up with expected increases in population care needs. Data collected in 2019 across Europe indicate Romania has the highest share of older individuals in need of long-term care (more than 55 per cent) but the lowest share of older people who are able to access home-based care services – 4.7%, in comparison to over 50 per cent in Denmark and an EU average of over 20 per cent (European Commission, 2021a). Moreover, there is no indication that current policies can put Romania on a pathway toward closing the vast gap between needed and available care, especially in community-based settings. Increases in care service capacity in recent years, while considerable in relative terms, have been largely concentrated among residential care providers. Between 2017 and 2020 the number of residential care facilities for older people virtually doubled, while the number of day care centres grew by one-third and that of home-based care providers by only one-fifth (National Institute of Statistics Romania, 2022). These data highlight the necessity of dramatic increases in formal care services investment in Romania to ensure service capacity grows rapidly; but importantly, such policies must be paired with

targeted legislation and earmarked funding for the specific development of community-based care options.

At the same time, the data point to another complementary and significant marketisation trend in the development of the Romanian long-term care system: highly differentiated growth patterns in terms of type, speed and concentration between privately and publicly owned care services. A decade ago (2012), a comparable number of private and public residential care providers were licensed to operate in Romania, with the bulk of residential care capacity accounted for by publicly owned facilities. In the intervening years, the private residential care market grew at an accelerated pace while public provision remained sluggish in its development. The most recent data at the time of writing (April 2022) indicate a profound restructuring of the residential care sector: 83 per cent of all residential care providers in Romania are privately owned entities, which account for 76 per cent of the total residential care capacity (number of beds/places) (Ministerul Muncii si Solidaritatii Sociale, 2022). In contrast, increases in the number of home-based care providers have been more rapid for publicly owned providers, supported by national investment programs, and comparatively slower for privately owned providers in the face of high operational costs, difficulties in attracting and retaining workers and smaller profit margins. As a result, Romania has failed to meet its goal of de-institutionalising care provision for older people with care needs. It is unclear whether this goal can be achieved without redesigning financing models and incentive structures for private long-term care providers.

Rapid growth in private provision has no doubt helped to alleviate unmet care needs, but it has also led to deepening inequalities in access to care as these options are not uniformly distributed across the country or covered by public insurance. Private provision is highly concentrated in those localities where both the demand for care and the willingness to pay for care services are high and stable. More urbanised and more economically developed counties benefit from this capacity increase, while rural and lower-income counties and communities remain severely underserved. In addition, a highly privatised long-term care provision with an overwhelming representation of for-profit private providers raises significant quality concerns. Despite having revised quality standards and assurance mechanism, Romanian authorities have been struggling to inspect and enforce these standards with regularity, as reflected in a series of scandals about severe abuse and improper conditions,

particularly in residential care centres. Romania's case highlights the crucial role of public authorities in regulating, monitoring and providing adequate incentives for high-quality long-term care delivery, even when provision of care services is primarily delegated to the private sector.

Sweden: National policies focus on de-institutionalising and better coordination of long-term care services, while allowing the private sector to offer such services

The long-term care system for older people in Sweden is a public, tax-financed and comprehensive system regulated through the Swedish Social Services Acts from 1982. The responsibility for long-term care for older people is divided between the national, regional and local levels of governance. The parliament and government set the overall policy targets and directives at the national level, while service provision is split between the regions and municipalities. The regions provide health care and medical treatment. The municipalities provide social care as either residential care (i.e. nursing homes, residential care facilities and group homes for persons with dementia) or home help care and services (Schön & Heap, 2018).

Previously, the county councils were responsible for providing care for older people. However, a community care reform (the Adel reform) in 1992 shifted the responsibility to the municipalities. The aim of the reform was to increase productivity at the hospital level and build a long-term care system based mainly on home care (Stolt & Winblad, 2008). Consequently there has been a reduction in the number of hospital beds, closure of residential facilities, and an increasing number of people being helped at home rather than in institutions (Schön & Heap, 2018). This is in line with the 'ageing in place' policy, which has dominated Swedish long-term care policy in recent years (Schön & Heap, 2018). In the years since the community care reform, Sweden has constantly expanded and strengthened the provision of home-based services, and today Sweden is held up as an example of successful home care for older people (Šiška & Beadle-Brown, 2020). However, home-based services have not increased at such a rate that it has outweighed the reduction in residential care capacity.

The reform also addressed the fragmentation between health and social care by introducing a reimbursement system for delayed hospital discharges and making joint care plans mandatory. Consequently,

collaboration between health professionals and social workers has increased, ensuring appropriate care and smoother transitions for users between different levels of care (Ilinca, et al., 2015).

Two long-term care policy trends that have co-existed in Sweden are marketisation and integration (Bihan & Sopadzhian, 2017). Various laws have been particularly important for the marketisation of social services. In 1992, a local government act enabled municipalities to introduce a purchaser-provider split and outsource the provision of care for older people to both for-profit and not-for-profit providers (Erlandsson et al., 2013; Moberg, 2021). Another key piece of legislation is the Act on System Choice in the Public Sector from 2009, which facilitated the introduction of consumer choice models without a process of competitive tendering and procurement (Meagher & Szebehely, 2010; Erlandsson et al., 2013). By 2019, about 159 of 290 municipalities offered a user choice in their home-based care, and 21 offered a choice in their residential care (Moberg, 2021). The Act on Tax Deductions on Household Services and Personal Care, which came into force in 2007, is another example of market policies (Szebehely & Trydegaard, 2012; Erlandsson et al., 2013).

The division of responsibilities between regions and municipalities in Sweden has not proved favourable for good coordination between the different care levels. Therefore, in recent years policies to improve care coordination, especially for older people with complex health problems and severe needs, have been high on the social policy agenda. The TioHundra organisation in Norrtälje municipality is one example of an integrated care model attempting to manage these problems (Agerholm et al., 2021). Founded in 2006 and owned, financed and managed jointly by the Norrtälje municipality (responsible for social care) and Region Stockholm (responsible for health care), TioHundra operates as a single comprehensive health and social care organisation (Agerholm et al., 2021).

Despite these important developments, the interface between health care and municipality care continues to be a problem area (Myndigheten för vård- och omsorgsanalys, 2021). Furthermore, a government investigation recently concluded that people in long-term care do not have access to health care to the same extent as the general population (SOU, 2022). There are thus structural deficiencies in

long-term medical care of older people, such as the shared responsibility between regions and municipalities, which may result in insufficient access to medical competence and equipment, staffing shortages and a lack of trained or licensed staff as well as deficient working conditions for staff (SOU, 2020).

4.4 Main lessons

In this section, we distil four overarching lessons that emerge from the review of trends and case studies, shedding light on the dynamic and context-dependent nature of long-term care systems.

1. De-institutionalising the care system requires building up community-based care solutions and investing in support services for informal caregivers

Most older people prefer to stay in their own homes and receive community-based care. This has a dual benefit, in that it can improve access to services while reducing the need for more expensive residential care and therefore contribute to a more efficient system. Indeed, shifting from residential care to home care services has been high on the reform agenda in many European countries, but often fails because home-based care services have been underdeveloped. De-institutionalisation should therefore be accompanied by policies that promote and facilitate community-based care solutions. This implies policies that help build up home care services and local support networks. For instance, in Sweden and Norway, community-based care solutions include policies that promote home care while at the same time making the eligibility criteria for residential care stricter. This requires reallocating public funding and insurance coverage towards home and community care – sometimes with the help of financial incentives as seen for example in Germany. Furthermore, de-institutionalisation should go hand in hand with the development of support services for informal caregivers. For example, in Sweden, the lack of support for informal caregivers has been a barrier to de-institutionalisation. Other countries can learn from this and invest in programmes and services that provide assistance to families and friends taking care of older people and people with disabilities.

These policies should also take a holistic view of the patient and address the issue that some people will not have informal arrangements available, for example because they lack a supportive social network and environment or because they have severe limitations in everyday activities that require more intensive support. Moreover, having a sufficient and well-trained workforce is crucial for successful implementation. Countries should invest in training and education for health care professionals to ensure they have the skills necessary for modern care models that enable more people to live at home.

2. Effective regulation and oversight are crucial to mitigate the potential downsides of privatisation in long-term care

The case studies highlight various strategies employed in the countries to address the increasing demand for long-term care services through allowing private initiative. These strategies include allowing private provision of long-term care services, enabling private for-profit care institutions to qualify for public funding, contracting beds in commercial long-term care homes, introducing market incentives and personal care budgets, and fostering private sector participation through changes in the regulatory framework. While these approaches aim to meet the growing need for long-term care services, they also come with potential negative effects that must be carefully considered and monitored.

Privatisation in long-term care can pose challenges such as difficulties in monitoring and maintaining quality standards, leading to variations in care quality and increasing the risk of abuse against vulnerable care users. It can also result in equity issues, with access to high-quality care often favouring those who can afford private services. Perverse incentives may arise, where private providers prioritise patients with less expensive care needs over those with more complex and thus costly requirements. Additionally, there is a risk of insufficient investment in preventive and rehabilitative care. Privatisation can lead to service fragmentation, making it harder for users to navigate a complex system with multiple providers. Furthermore, inadequate workforce capacity and access inequalities between urban and rural areas have the potential to deepen disparities in care provision. Effective regulation and oversight are crucial to

mitigate these potential downsides and ensure that privatisation in long-term care aligns with the goals of quality, equity, coordination and patient-centredness in care delivery.

3. Digital solutions have the potential to boost access and efficiency in long-term care when thoughtfully implemented to address unique contextual needs and challenges

Digital technologies can play a pivotal role in transforming the landscape of long-term care services, with the potential to enhance the quality of care and the overall wellbeing of older people, their families and care-givers. These technologies, when accompanied by proper user support and training, enable improvements in daily activities and quality of life. Robust digital infrastructures facilitate communication between health care workers, long-term care recipients, their families, informal care-givers and local communities. Digital tools can facilitate remote monitoring by providers, enhance safety through ‘smart home’ technology and enable telecare and telehealth, promoting seamless interaction among care users, formal providers and informal caregivers. This integration strengthens the efficiency of care provision across different long-term care and health care services, ultimately allowing individuals with long-term care needs to remain in their homes or communities, reducing the need for more expensive residential care.

However, the widespread adoption of ICT in long-term care carries the risk of further deepening existing inequalities in access. While the use of digital technologies has grown significantly among healthy older people in Europe, implementation and utilisation of digital tools can be challenging, particularly when individuals lack access or digital literacy. Ensuring the mainstream use of digital technology in long-term care requires continued investment in digital literacy for care users and their families. Furthermore, it creates a demand for new professional roles and skills, necessitating training and capacity building as well as the involvement of professional end users in the development of new systems. This shift also raises ethical concerns related to data privacy, fairness and human oversight of digital and automated solutions. Moreover, disparities persist between European countries in terms of connectivity, internet service use and digital product adoption, highlighting the context-dependent nature of ICT implementation in long-term care.

4. Successfully implementing integrated and well-coordinated long-term care requires a common vision and careful planning

Several countries have embarked on long-term care reforms to enhance coordination and integration. Initiatives have been taken to establish integrated networks of home care services, care management systems and collaborative programs that bridge medical and social care. Improved coordination and integration of long-term care services offer numerous benefits in terms of access, efficiency and overall quality of care. In many countries, long-term care services encompass a wide array of providers and funding schemes, often leading to fragmentation and overlapping responsibilities. This can result in poorly coordinated care that falls short of being patient-centred. A solution to this challenge is the integration of services within the long-term care spectrum and the broader health care system. Such integration involves targeted community-based care, collaboration among various professionals in interdisciplinary teams, and proactive patient care coordination throughout the continuum of care. This approach aims to provide a more seamless, effective and positive care experience, particularly for individuals with complex health needs.

However, it is important to note that while integration can bring substantial benefits, it also presents challenges and potential negative effects if not executed carefully. This includes issues related to care quality, workforce training, ethical considerations and the need for robust communication and cooperation among providers. Moreover, during crises like the Covid-19 pandemic, integrated perspectives on long-term care provision have sometimes been overlooked, resulting in underperforming long-term care systems. Thus the successful implementation of integration policies requires a common vision across stakeholders, careful planning, adequate workforce preparation and a commitment to addressing the unique needs and challenges of each context.

4.5 Conclusion

The landscape of long-term care is evolving rapidly, driven by factors such as ageing populations and a corresponding rise in multimorbidity and demand for support, changing family structures, and shifting societal expectations – all against a background of persistent

workforce shortages. This chapter has shown how these major challenges have given rise to new trends in long-term care provision, i.e. increased integration, the shift from residential care to home-based care, as well as the emergence of the private sector and new digital solutions. The country case studies emphasise the critical importance of recognising the context dependency of long-term care systems and the absence of a one-size-fits-all approach. The evolution of long-term care systems must therefore take into account the unique socio-cultural, economic and demographic circumstances of each country.

Key takeaways for improving long-term care systems include prioritising de-institutionalisation by shifting to community-based care, promoting home care services and supporting informal caregivers, all of which contribute to improved access and health system efficiency. Effective regulation and oversight are crucial when considering privatisation in long-term care to ensure quality, equity and coordination. Implementing IT digital solutions in long-term care can enhance communication, monitoring and care coordination, thereby streamlining access to services and increasing overall health system efficiency, but this requires addressing digital literacy, ethical concerns and disparities. Coordination and integration of long-term care services can improve access by reducing fragmentation and it enhances quality, contributing to health system efficiency. However, challenges related to care quality, workforce training and ethics must be managed carefully to achieve these goals. Successful long-term care reform necessitates a common vision, planning, workforce preparation and stakeholder commitment to address the unique needs and challenges of each context, ultimately leading to improved access and efficiency within the entire health system.

4.6 References

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5 *Financing of long-term care*

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5.1 Introduction

As more people live longer lives all over the world and as fertility decreases, the numbers and share of older people worldwide have been projected to grow from 10 per cent in 2022 to 16 per cent in 2050 (UNDESA, 2022). Increased longevity is a major achievement that also requires changes in labour policies and pensions, the orientation of health systems and, not least, ensuring that countries have well-developed and robust long-term care systems.

While for many increased longevity will be experienced as a longer period of life in good health, there will also be a very substantial increase in the numbers of people who will experience disabling health conditions such as dementia, and who will live longer with those conditions. Based on the current characteristics, health-related behaviours, and circumstances of the population who will be older in 2035, a study in the United Kingdom found that, while the prevalence and numbers of people with care needs will fall for young-old adults (those aged 65 to 74), the numbers with high dependency among people aged 75 and over will almost double, suggesting that the capacity of care systems will need to increase very substantially (Kingston et al., 2018).

In the Majority World, i.e. the areas in which most of the world's population lives and where most of the world's land mass is located (areas that have been referred to as 'the developing world', the 'Global South' and which encompass many LMICs), population ageing is occurring at unprecedented rates. Furthermore, population ageing is often correlated with functional decline, occurs disproportionately among women (with the gender gap increasing with age), and is negatively correlated with socioeconomic status (Aranco et al., 2022).

Although age is associated with increases in functional limitations, this relationship is not static. For example, some high-income countries have seen decreases in the proportions of people experiencing cognitive

impairment and dementia over time; however, total numbers of people with dementia have still increased (Matthews et al., 2016; Langa et al., 2017), in part due to people living longer with the condition.

There are further opportunities to reduce the risks of needing care throughout the life course and to regain functioning through primary, secondary and tertiary prevention (Bennett et al., 2022). Harnessing these opportunities to reduce disability requires addressing wider (health) inequalities. Global evidence shows that the least affluent people spend more years living with disability (Valverde et al., 2021; Zhang et al., 2021), and that these inequalities have risen over time (Bennett et al., 2021).

This chapter discusses the multiple ways in which long-term care is financed. Financing is understood as the approaches used to raise funds for a particular activity or set of activities. In the case of long-term care, particularly if taking a global perspective, it makes sense to consider not just monetary resources, but also in-kind support from family members as well as OOP payments for care, tax-financed care, social insurance schemes, and private insurance products.

We start by describing the main forms of long-term care financing found internationally, first considering the mechanisms available for private and public financing. By private financing we refer to all the monetary and non-monetary resources contributed by individuals and their families to the care process, whereas we use public financing to cover all government-managed programmes (whether at national, regional or local level) that ensure pooling of funds from different sources in support of long-term care services and benefits provision. Within public financing, we look at the main approaches to raising funds, policy choices in terms of public care coverage, and also consider the financial protection provided by long-term care financing approaches. We include short case studies as illustrative examples of how these different financing mechanisms function in practice. We then consider long-term care expenditure in the context of trends in population ageing.

5.2 Private long-term care financing

Private long-term care financing includes unpaid care (provided in kind by informal caregivers), direct purchase of services by care recipients using their own income and wealth (their savings or assets),

co-payments for services that are partially publicly funded, private long-term care insurance products and charitable spending on long-term care.

Private in-kind resources: unpaid care

In most countries, most long-term care is provided in kind by unpaid carers such as family, friends and neighbours. While the reliance on family care is the norm in the global Majority World (see for example WHO, 2017), it is also the case even in countries with relatively high levels of public expenditure on care (Spasova et al., 2018). While typically there is no monetary exchange for care, the economic contributions of unpaid carers to care systems are enormous across all countries (Folbre, 2014; Dong & An, 2015) and the economic impact on families can be very substantial. For many carers, there are opportunity costs in terms of lost earnings from employment, impact on health and wellbeing, forgone leisure time – every aspect of a carer's life can be affected by their caring role. There is concern, for example, about the impact of caring obligations in hindering efforts to increase education, employment and economic opportunities for young women and girls in Sub-Saharan Africa (WHO, 2017). In high-income countries there is evidence that reduced labour force participation as a result of providing informal care reduces carers' lifetime earnings and pension entitlements, contributing to poverty in later life, particularly among women (Korfhage, 2019; Skira, 2015). These effects are discussed in more detail in chapter 10 (in relation to the effects on the wider economy) and chapter 8 (in relation to the effects on families). The complexity of these economic impacts means that it is important to ensure that the economic costs of unpaid care are measured fully, so that resource allocation decisions do not lead to additional burden on carers (Comas-Herrera et al., *in press*).

Unpaid care is provided in kind, mostly by women, and it is provided more intensely among people with lower socioeconomic status or minority ethnic populations (Bauer & Sousa-Poza, 2015). Intense unpaid care provision has been shown to increase economic inequalities (Gammage et al., 2019; Korfhage, 2019), particularly for younger carers (Brimblecombe et al., 2020) and to negatively impact the health and wellbeing of carers (Bom et al., 2019). In some countries, such as Denmark, Sweden and Finland, relatives and other carers with

a personal connection are formally recognised and can receive cash benefits, compensation for lost earnings or a carers' allowance (WHO, 2019; Ylinen et al., 2021; Johansson & Schön, 2017). In the countries of the Majority World, families usually have to bear the costs of care with little support (Govia et al., 2021).

Access to unpaid care is unequal, determined as it is by having family or friends able and willing to provide care. Also, not all families are able to provide enough care, nor to provide care of adequate quality. This is particularly the case for families in contexts of poverty and vulnerable employment and may result in very negative outcomes for people in need of care (Schröder-Butterfill & Fithry, 2014; WHO, 2017).

Historically, public involvement in long-term care in most countries has begun with the state providing support to people without family and without the financial means to pay for care. Reliance on family care as the main form of support is common, with unpaid carers comprising a sizeable proportion of the population in many countries. Estimates vary according to the methods used but the share of the population who provide unpaid care has been estimated to range from 21.3% in the United States to 4.5% in Taiwan, China according to the International Alliance of Carer Organizations (IACO), 2021). This reliance on family care will become increasingly problematic due to demographic changes and decreasing availability of family carers, increased migration and increased female participation in the labour force (WHO, 2015; UNDESA, 2020).

Case study: Jamaica

In Latin America and the Caribbean, the rate of change in the proportion of the population aged 60 years and older is occurring markedly faster between 2015 and 2050 than it took to happen in Europe and North America (Cafagna et al., 2019; Aranco et al., 2022). Jamaica is one of the countries in the region where this ageing process will be particularly pronounced. By 2050, 28% of the population will be aged 60 years and older (compared to 13% in 2015 and 19% by 2030), and 6.5% of the population will be 80 or more years old (compared to 2.5% in 2015 and 3% by 2030); approximately 26% of persons aged 60 years and older were living alone in 2014 (Cafagna et al., 2019). At least 71% of the population lives with one chronic health condition. Similar to other countries in the region, need of care in Jamaica rises with age, occurs disproportionately with women (with this gap

increasing with age), and is negatively correlated with socioeconomic status (Aranco et al., 2022).

In this high-risk context, the long-term care system is unsustainably reliant on informal care, both unpaid and paid. Unpaid care is provided mostly by female relatives (regardless of household income), and paid care by domestic workers, often low-income migrants from rural communities. Domestic workers are crucial to the provision of long-term care but are paid for general household work and not specifically to provide long-term care (without employment contracts). Further they are not trained for the caregiving duties they end up assuming in these households, assisting with ADLs, for example, without formal training to do so. They also support unpaid carers from higher socioeconomic groups (Govia et al., 2021). This untrained workforce bears the burden for long-term care. Community-based long-term care services (such as respite care, home visits or assistance) are limited, and mostly provided by volunteers from charities or churches (Govia et al., 2021). The formal care system consists of nineteen state-funded residential homes for older people who are unable to care for themselves, and over 200 unregulated private care homes (Govia et al., 2021; Ministry of Health, 2015). There is some long-term care provision through public general hospitals, where people with mental health and older people with dementia may need to stay if they have no family care available. There is no government strategy for long-term care, and service development has not been encouraged either through tax breaks or other forms of financing.

Case study: India

According to the International Alliance of Carer Organizations (IACO, 2021), there are an estimated 138 million unpaid carers in India, which accounts for approximately 10 per cent of the population. The long-term care system in India relies primarily on care provided by these unpaid or family caregivers. There are some residential care facilities (e.g., nursing homes, day care centres) which may be supported by private organisations, not-for-profit organisations or the government. (Johnson et al., 2018; Tripathy, 2014; UNESCAP, 2016). There are also paid home-based care services offered by private organisations in certain cities and states (Agarwal & Bloom, 2022; Ponnuswami & Rajasekaran, 2017). Independent of availability and accessibility of services, residential care arrangements in particular are unlikely to be

popular in the Indian context where legislative and socio-cultural factors place the responsibility on adult children to care for their older parents and contributes to a preference for care to be provided at home by the family (Brijnath, 2012).

Unpaid care provided by families has a substantial impact on overall wellbeing of caregivers. A recent study (Chakraborty et al., 2023) analysing data from the Longitudinal Ageing Study in India (LASI) wave 1 reported that among unpaid caregivers that provided full-time care (over 40 hours per week), 49 per cent had symptoms of depression.

In addition to impacts on health and wellbeing, the economic impact of caregiving on families is considerable. Taking care for dementia as an example, evidence has demonstrated that the costs of care for dementia are relatively high in India (Rao & Bharath, 2013). Indirect costs especially contribute substantially to dementia related costs in LMICs (Mattap et al., 2022). Family carers of persons with dementia in India have reported experiencing a range of indirect costs including impacts on earnings, employment and higher education opportunities because of their caregiving role (Rajagopalan et al., 2022). Given the impacts of unpaid care provision on families and also considering the factors contributing to reduced availability of family care arrangements for older persons in India (e.g., changes to family structures, internal and external migration, increasing female participation in the service sector, etc.), this system of long-term care provision may not be sustainable in the long run (Agarwal & Bloom, 2022; Costa-Font & Raut, 2022).

Private monetary resources without risk sharing: income, savings and assets

Income, savings and assets are a key source of OOP financing for long-term care and can be used to purchase services directly or to meet the costs of co-payments for publicly organised care services, depending on the system. In some countries (e.g., United States, England), people with income or assets over a certain threshold are not entitled to publicly funded social care and need to cover their costs in full from their own financial resources (Hashiguchi & Llana-Nozal, 2020). It is very difficult to estimate the size of private spending on long-term care as most countries do not monitor long-term care service use and spending by self-payers (Angrisani et al., 2022). In England a recent

estimate from the Office for National Statistics found that nearly 35 per cent of care home residents were self-funders in 2021–2 (ONS, 2022a).

As a form of long-term care financing, over-reliance on private resources is not optimal for several reasons. From an individual perspective, using private resources is only possible for those with sufficient income, savings and assets to cover the costs of their care. This leads to large inequities in access to long-term care services in primarily privately funded care systems, in the absence of any means of sharing the risk of high costs of care with others through an insurance mechanism (Guillén & Comas-Herrera, 2012). As discussed above, there is a risk that people may rely excessively on unpaid care, which can act as a vehicle for intergenerational transmission of inequalities and exhaust the totality of their income and assets, putting them at significant risk of poverty in old age. In particular, low-income individuals who do not have access to informal care will have unmet care needs. From a macroeconomic perspective there is also the risk that people may over-save to protect themselves and reduce consumption, which could dampen economic growth as the population ages, as discussed by Katherine Swartz in [chapter 10](#) of this volume. On the other hand, there are concerns that people may not save enough due to underestimating the risk of needing long-term care in the future, underestimating the cost of long-term care, or mistakenly believing that costs will be covered by health insurance (Barber et al., 2021).

In practice, most high-income countries have some form of long-term care publicly funded support, and even countries with a more familialist or residual public care system where access is means-tested (Horstman et al., 2023) tend to have some form of social assistance to cover people with lower income or assets. It is important to note that, in countries where people with income or assets above a means-tested threshold have no government support in accessing long-term care, private payers may be disadvantaged in terms of the prices they have to pay, as the public authorities are able to negotiate more favourable terms. For example, the fees for self-funded places in care homes in England were on average 41 per cent higher than the fees paid by local authorities when they commissioned publicly funded long-term care provision in the same homes (Competition and Markets Authority, 2017).

Private resources with risk sharing: private insurance schemes

Insurance products provide a mechanism for pooling risks with others, so that the risks of everyone covered by a scheme are shared collectively, and resources pooled between members of a scheme are used to cover the costs of their care. This implies that some people pay more than, and some people less than, the actual costs of their care. Individuals can purchase coverage voluntarily from private providers by paying an insurance premium, which is based on the estimated risks of the individual making the purchase, the group risks estimated for all insurers, and the benefits to which they will be entitled. Whereas private health insurance products are typically purchased for immediate coverage, long-term care insurance products are typically purchased when individuals are younger, to cover the future costs of long-term care should they need it. This makes the pricing of long-term care insurance products particularly challenging, as insurance companies need to factor in the group probability of individuals living to advanced age, the probability of their needing care, the length of time that care will be needed, future costs of services and investment returns, all of which are subject to significant uncertainty (ABI, 2010).

The experience of the United States, where voluntary private long-term care insurance was expected to insure against the full costs of care for those who were not eligible for the means-tested public system, shows that in practice voluntary private insurance for long-term care faces major difficulties. A key difficulty is affordability, particularly as, at younger ages when people's incomes tend to be higher and insurance policies are thus more affordable, people face competing financial demands and long-term care may not seem to be a high priority. Other demand-related factors include a tendency to underestimate the probability of needing long-term care and the (erroneous) assumption that there is public coverage in place to which they will be entitled (Frank et al., 2013; Brown et al., 2012). Private long-term care insurance also poses many problems to insurers due to the potential for adverse selection, in which people who know that their risks will be higher tend to buy in more often than those who consider their risks to be lower, thus increasing the risks to the scheme (Feng & Glinskaya, 2020) and also due to the costs of care increasing faster than projected (Frank et al., 2013).

Due to affordability and market failure problems, relying on private long-term care insurance as a full solution to long-term care financing would require substantial subsidies and potentially compulsion, which overcomes the problems of adverse selection by requiring people to opt in regardless of their level of risk, real or perceived (Barr, 2010). However, in a few countries where there is a public long-term care system that provides partial entitlement to long-term care support and where there is clarity on the rules of entitlement to public long-term care and the levels of co-payments (such as Austria, Germany and France), there is a market for voluntary private insurance products that can be purchased to supplement public coverage (OECD, 2021b; Wiener et al., 2018b; Comas-Herrera et al., 2012). If regulated properly, this could potentially support the sustainability of public long-term care financing.

In some countries, private long-term care insurance products are also sold as part of other insurance products (usually health and life insurance). A report by the OECD identified examples of this in Belgium, Costa Rica, the Czech Republic, Finland, Israel, Japan, the Republic of Korea and Switzerland (OECD, 2021b). The same report also identified countries where there is currently no market at all for private long-term care insurance: Australia, Chile, Colombia, the Netherlands and the United Kingdom (OECD, 2021b).

Case study: United States

In the United States, the majority of total long-term care expenditure is publicly financed, primarily by Medicaid (a means-tested welfare programme for people with low income and disabilities that covers health and long-term services and supports), with the rest funded by private sources. Medicare (an entitlement health insurance programme for people age 65 and older and certain younger adults with disabilities) covers short-term post-acute care but excludes long-term care. In 2020, total long-term care expenditure amounted to USD 475.1 billion, of which USD 343.5 billion (72.3%) were paid for by public sources and USD 131.6 billion (27.7%) by private sources (Colello, 2022). Among the public sources, Medicaid and Medicare accounted for 42.1% and 18.2%, respectively, of total long-term care expenditure, with the rest from federal Covid-19 pandemic assistance (6.3%) and other public payers (5.7%). Among the private sources, direct OOP payments accounted for 13.5% of total long-term care

expenditure, private insurance for 7.8%, and other private sources for 6.5% (Colello, 2022).

There are both demand and supply factors that have limited the appeal of private long-term care insurance. The costs of such insurance are high and many people who are not eligible for public support through Medicaid or Medicare cannot afford private insurance either (Wiener et al, 2018b), as a result of which only about 10 per cent of adults purchase long-term care insurance (Gusmano & Grafova, 2018; Khatutsky et al., 2017). The private market for long-term care insurance in the United States has been contracting, with new stand-alone policies falling from 372,000 in 2004 to just under 70,000 in 2017 (Upadhyay & Weiner, 2019).

It has been estimated that about 75 per cent of people who need long-term care in the United States rely on unpaid carers, and that 41 million Americans are unpaid carers (Upadhyay and Weiner, 2019). Thus, the cost of long-term care represents a significant financial risk for older people and their families. A study estimated that, on average, an adult child providing care to an older parent faces financial losses equivalent to USD 100,000 a year primarily as a result of lost employment (Coe et al., 2018). Among those who do purchase private long-term care insurance, there is evidence that this improves their financial wellbeing, potentially by reducing incentives to dispose of assets to become eligible for Medicaid, providing incentives to save more and reducing intergenerational wealth transfers (Dong et al., 2019).

The Covid-19 pandemic prompted renewed calls for a comprehensive and universal approach to financing long-term care in the United States that supports both home-based care and the improvement in quality and affordability of residential care options (Werner et al., 2020). In the United States where the current approach to financing long-term care is quite fragmented, it is suggested that the introduction of a new long-term care benefit at the federal level could aid in reducing disparities in services coverage across states and in rates of payment (Werner & Konetzka, 2022).

Co-payments where public schemes cover part of the costs of care

The use of co-payments for publicly organised care is common in many countries, including in social insurance-based systems. The

size of co-payments vary between countries, with some being means-tested. In some countries means tests may take into account income alone, whereas in others both income and assets are considered (Hashiguchi & Llana-Nozal, 2020). For example, in Japan co-payments range from 10 per cent to 30 per cent based on income, although 90 per cent of users pay only 10 per cent. In Korea, co-payments differ between home and community care (15 per cent) and residential care (20 per cent) (Wyse & Walker, 2021). In Spain the size of co-payments has been estimated to be 24 per cent of all direct costs of services nationally, but there are important differences between regions, ranging from an estimated 15 to 33 per cent (Rodríguez Cabrero et al., 2022). In contrast, in Germany, there is mandatory long-term care insurance where people are entitled to a fixed amount of benefits from the social insurance system taking into account their level of need, and thus have to cover the difference between the amounts provided by the social insurance benefit and the actual costs of the services themselves (Frisina Doetter & Rothgang, 2017). People are usually required to contribute to residential care, and even in the countries with the most generous publicly funded care systems, food and board costs tend not to be covered. For example in Denmark home-based care is free at the point of use, whereas there are co-payments for residential care (WHO, 2019).

Charitable funding

Charitable funding plays a role in long-term care, particularly in countries with less developed public long-term care systems. Charitable funding may be provided to offer care and support to people who have no family or economic resources. There are many examples of international non-governmental organisations (NGOs) such as HelpAge International, Red Cross and Caritas (in Europe) and national NGOs involved in delivering care, often relying on volunteers to deliver care and support, such as in Ghana, South Africa and the United Republic of Tanzania (WHO, 2017). Religious institutions often provide care that is resourced both in kind by volunteers and through donations, as per Jamaica (Govia et al., 2021) or Malta and Gozo (Fenech et al., 2020). There are also examples of government schemes that organise volunteers to provide home care in Costa Rica (Progressive Attention Network for Integral Elder Care established in

2010) and Thailand (Home Care Service Volunteers for the Elderly programme established in 2003) (Lloyd-Sherlock et al., 2017).

In some high-income countries, charities have an important role in both providing and funding aspects of care that are not covered by the public long-term care systems. One example is the United Kingdom, where palliative care, support for social participation and community engagement, cultural and artistic activities, peer support and community building activities are all provided by charities. In 2020, total long-term care expenditure on personal care in the United Kingdom was estimated to be GBP 54.1 billion; of this, GBP 36.4 billion was government spending, GBP 13.0 billion was OOP expenditure and GBP 4.7 billion (8.7% of total long-term care expenditure) was from not-for-profit institutions serving households (Office of National Statistics, 2022b).

5.3 Public long-term care financing

In most countries the public sector has some involvement in long-term care, even if there is no explicit public long-term care system or policy. At the very minimum, public involvement may take the form of support for the long-term care needs of people who do not have family or financial resources, perhaps through the health system (long-stay hospital wards, support from community health workers) or through schemes for people with social needs, for example homes for people who are considered to be destitute, or community support through local governments. Pensions for older people and people with disabilities are also an important resource to support access to care in many countries without formal long-term care systems (Lloyd-Sherlock, 2019; WHO, 2017). In Poland for example there is a small 'nursing supplement' for all persons aged 75 years or more that is intended to help with potential costs of care (Golinowska & Sowa-Kofta, 2017).

Important motivations for the development of public long-term care systems are: awareness of ageing populations and of the decreasing availability of unpaid carers; increased understanding of the distortions to the economy created by individuals reducing consumption in order to save for their future care needs (Barr, 2010); the impossibility for many individuals to save enough (Barber et al., 2021); awareness that

lacking long-term care services may result in increased hospitalisation; and to missed opportunities for prevention (Wyse & Walker, 2021). There is also increased policy support for the development and design of long-term care services that are centred around a more rights-based approach that empowers older people to claim their rights and to hold states accountable in their role as duty bearers (Schulmann et al., 2019).

The main differences between public long-term care systems can be observed in the following:

- Coverage: The coverage of long-term care systems is a key question for financing public long-term care, with decisions about who in the population is covered, which services are covered (what will the eligible population be covered for), and the extent of financial coverage or protection (how much people pay out of pocket. (Wyse & Walker, 2021).
- How public funds are raised and allocated: Virtually all long-term care systems rely on a mix of public and private financing sources to raise revenues for needed care services. Public revenues are most commonly raised through taxation, social insurance or private insurance schemes, while private revenues encompass OOP payments and co-payments required from long-term care users.
- Financial protection: Long-term care schemes provide a mechanism to mitigate the risk of an individual being exposed to catastrophic costs of care, so that the financial risks are collectively borne by the scheme. This risk protection can take many different forms, ranging from contribution to a national public long-term care system, through general or local taxation, to social insurance contributions, to individual or group-purchased private insurance (Guillén & Comas-Herrera, 2012).
- Integration between the financing mechanisms in place for (medical) health care and long-term care: Policy choices for funding long-term care are greatly influenced by the system that countries already had in place for funding health care. High-income countries that finance health care through taxation have tended to fund long-term care in the same way, and countries with social insurance for health have tended to use social insurance for long-term care as well, with the exception of Austria (Trukeschitz et al., 2022).

The remainder of this section looks at each of these issues in turn.

1. *Coverage of public long-term care*

The choices governments make in relation to coverage in effect determine the division of financial responsibilities between individuals, families and the state (Wyse & Walker, 2021).

Eligibility is based on criteria related to care needs (determined by a care assessment and benefit package). A key mechanism for controlling costs is the threshold for care needs deemed eligible for publicly funded long-term care (Wyse & Walker, 2021).

Universal long-term care coverage

Systems with universal long-term care coverage usually provide publicly funded care to all eligible individuals according to their care needs. The systems may cover mainly older populations (e.g., Japan, the Republic of Korea), or everyone with care needs irrespective of age (e.g., the Kingdom of the Netherlands).

In universal systems everyone is eligible for long-term care according to their needs, regardless of financial status (Wiener et al., 2018a), creating an entitlement to care which is usually similar to the entitlement to medical care. This ensures equitable access and eliminates the stigma of means-tested long-term care (Feng & Glinskaya, 2020). Universal coverage is only available in a few countries, and it is financed mainly through public social insurance (e.g., Germany, Japan, Luxembourg, the Netherlands, Republic of Korea) and/or general taxation (e.g., Denmark, Finland, Sweden, Spain). The premise for universal long-term care coverage is that the financial risks resulting from long-term care needs require a collective arrangement for social protection (Feng & Glinskaya, 2020) and countries that have adopted this principle, such as Spain, refer to the public long-term care system as the fourth pillar of the welfare state (Peña-Longobardo et al., 2016). It is important to note that there are important differences between countries with universal long-term care coverage in the generosity of the entitlements and the size of co-payments. In addition, universal or generous long-term care systems may also need to increase the strictness of their eligibility criteria when faced with financial pressures. For example, in Denmark needs assessments were made more stringent and home care hours allocated were decreased due to concerns over the financial sustainability of the public scheme (Rostgaard et al., 2022).

Means-tested long-term care coverage

In means-tested long-term care financing systems, sometimes referred to as ‘safety net’ systems, publicly funded long-term care is only available to people with the greatest needs and with the least financial means, subject to certain eligibility criteria, usually determined by income and/or assets. People whose income or assets are above a certain threshold (the means test) need to cover the costs of their care in full and they often have no support in finding and arranging suitable care. Means-tested systems are in place in England, the United States and in some Eastern European countries.

The use of stringent eligibility thresholds creates concerns about fairness and equity in access to long-term care; for example in many countries there is a large ‘squeezed middle’ between those on the lowest incomes and those who can comfortably afford the costs of long-term care and who usually miss out on public support (Feng & Glinskaya, 2020). Particularly where eligibility criteria are very stringent, fear of high costs and lack of affordability may result in unmet needs and very high unpaid care costs (Barber et al., 2021). A 2020 OECD report found that even among older adults with moderate care needs, the cost of home care is likely to be unaffordable when considering the average disposable income of older people (OECD, 2020a).

As discussed earlier, in some universal long-term care systems there may be means-tested OOP payments; however the key difference is that in a universal system everyone who meets the needs-based eligibility criteria is entitled to some public long-term care support.

Case study: England

England is an example of a means-tested approach to long-term care financing. Although health care is free at the point of use, social care is means-tested, and individuals and their families with income or assets above the means-tested threshold pay in full for the cost of care. In England all the services not delivered by a health professional are considered to be social care, even if the needs are the result of health conditions. This distinction between health and social care creates inequity as people whose needs are recognised as ‘health’ may be able to access long-term care via the National Health Service (NHS) continuing health care scheme (which is not means-tested), but people with personal needs and no recognised medical requirements are subject to

a means test to access long-term care (Byrd et al., 2022). Under means testing, unpaid carers still provide a large share of resources for long-term care in England. For example, it has been estimated that the public sector funds only around one third (32.6%) of the costs of dementia, and users and families have to cover the rest of the costs through care fees and unpaid care (Wittenberg et al., 2019).

Public social care provision in England is funded through a combination of grants from central government to local authorities and local revenue raising mechanisms (such as a tax on housing). Local authorities organise and fund social care for eligible people. Local authorities set their own eligibility criteria for publicly funded care and commission services. The funding for social care is not ring-fenced so local authorities can decide how much of their budget they allocate to care. Prior to the Covid-19 pandemic local authorities had suffered 50 per cent funding cuts over the preceding decade, and thus faced pressure to spend less on care. This led to variation in care eligibility between local areas (NAO, 2018).

Access to social care is determined by need and means assessments, i.e. regardless of need, people with property, savings or income in excess of a threshold must pay for their care, and only individuals with severe care needs whose income or assets are below the threshold may be eligible for part or full state funding (Bottery et al., 2022). Thirty-five per cent of care home residents in 2021–2 were self-funders (paying for their care in full) (Office of National Statistics, 2022a). Recent research has shown that older people who self-fund their social care in England receive little help in seeking and arranging their care, that many of them do not consider themselves rich, that they are reluctant to spend what they consider to be large amounts of money on care, and furthermore that they feel they are treated unfairly compared to people who qualify for coverage under means testing because they have been less frugal (Baxter et al., 2020).

A number of plans to reform long-term care financing have been discussed since the early 1990s, including a 1.25% payroll tax rise and new eligibility rules to raise the assets limits for public funding for long-term care. Most recently, the government announced a reform that would place a cap on lifetime individual personal care costs, irrespective of person's age or income; however in late 2022 these reforms were delayed for two years (Foster & Harker, 2023).

2. *Raising revenue for public long-term care systems*

While the share of private and public revenues varies greatly between countries, typically most countries include some form of taxation in mechanisms used to raise funds for long-term care. Taxation may be the main financing approach, or it may have a smaller role if the country has a social insurance mechanism in place to finance long-term care. OOP payments (through co-payments for publicly arranged services) supplement the revenue raised for public long-term care systems, but are themselves a private financing mechanism.

Tax-funded financing

Taxes levied by governments are the main form of public financing of long-term care globally. Taxes may be raised at local, regional or national level, and may be levied on income, capital or consumption. Special taxes may also be levied (for example, windfall taxes on private utility companies). The redistributive nature of taxes varies; for example, taxes on income and capital gains tend to be more progressive and thus equitable at a societal level, whereas indirect taxes on consumption such as value-added tax tend to be more regressive (van Doorslaer et al., 1999). Local taxes may result in territorial inequalities as some localities can raise more resources than others, so there are often national mechanisms to equalise revenue (see for example the Danish case study below). Despite these mechanisms, pronounced differences in access persist when long-term care services are financed and organised at local level in many countries (Comas-Herrera, 2020).

Tax-based systems have the advantage of a broader range of revenue sources and a wider population base compared to social insurance (Wyse & Walker, 2021; Rothgang & Engelke, 2009; Rodrigues 2019), and are more adaptable in terms of generating revenues and flexibility in providing benefits (Comas-Herrera et al., *in press*).

However, tax-based systems are subject to fiscal and political pressures and are more vulnerable to cuts as other areas of public policy compete for funding (Rothgang & Engelke, 2009). The lack of transparency in funding allocation may impact citizens' willingness to pay higher taxes, but allocating taxes specifically to finance social care (e.g., taxes levied on gambling in Portugal; see Rodrigues, 2019), or enhancing the link between taxes paid and entitlement to benefits could lead to potential solutions (Comas-Herrera et al., *in press*).

Case study: Denmark

The long-term care system in Denmark is universal and primarily funded through taxation. It is a relatively well-funded system, with public spending on long-term care amounting to 3.5 per cent of GDP in 2019 (European Commission, 2021). This high level of spending is attributed to long-term care having strong public and political support (Rostgaard, 2020). Denmark has one of the lowest shares of OOP payments for long-term care in the European Union (European Commission, 2021).

While the national government determines the overall principles of the system, the ninety-eight municipal governments are responsible for the financing and delivery of long-term care. The municipalities allocate resources from the national government and from local taxes and, in order to reduce the potential for geographical inequalities, they can also receive taxes from other municipalities through an equalisation mechanism (European Commission, 2019).

Access to home care is free at the point of use and equally provided, regardless of income, wealth, age and household situation. Eligibility is entirely based on needs assessment and availability of informal care is not taken into account when assessing needs entitlements, a question that is discussed in more depth in [chapter 3](#). There are no means-tested thresholds for in-kind or cash benefits, and no co-payments for long-term home-based care, but people can purchase additional services. There are no cash benefits; however, family carers can be formally recognised and can be employed by the municipality or compensated for lost earnings.

The approach to residential care homes in Denmark is based on the principle that these are people's homes, usually in the form of apartments with a kitchen, own bathroom and living area. People pay rent for the units where they live and cover the costs of services such as laundry and meals. Individuals who cannot afford the rent and fees can receive a housing benefit. Unlike in other countries, in Denmark's residential care the principle is that residential care homes are private dwellings (Rostgaard, 2020; WHO, 2019).

Social insurance

Social insurance is a mandatory tax on employment (with contributions from employees and employers) that raises funds for a specific purpose (Comas-Herrera et al., [in press](#)). It is most commonly used to

fund pensions and some countries also use this to fund health care and long-term care. Compared to voluntary private insurance, it has the advantage of maximising the risk pool across a much larger population and addressing market failures such as adverse selection (Barr, 2010). Social insurance systems are usually somewhat redistributive, so people generally pay according to their means (although, rather than being progressive, payments may be proportionate to income, or even regressive, particularly where there are ceilings for contributions in place) and obtain benefits according to their needs, and contributions are not related to risk (Karagiannidou & Wittenberg, 2022; Wyse & Walker, 2021). They usually rely on other public funding sources, such as taxes, to cover the contributions of those who are not in the labour market or do not earn enough, in order to cover the whole population (Wyse & Walker, 2021).

Although some social insurance systems were set up to operate a surplus in the initial years to fund future demands on the system, in practice they are typically financed by the current generation of workers paying for the care of the current population in need of care, i.e. ‘pay as you go’. This raises concerns about their sustainability as the share of the working population is decreasing in many countries.

Access to benefits is based on contribution records and eligibility criteria (in practice, most countries ensure that all citizens or residents are covered), and on assessment of needs, as discussed in more detail in [chapter 3](#) of this volume.

In contrast to taxation, resources from social insurance are guaranteed for long-term care without having to compete with other public services. The advantages of social insurance systems include clear eligibility and benefit packages (Karagiannidou & Wittenberg, 2022). The governance framework provided by social insurance systems also increases the buying power of governments and has been credited with expanding the number of care service providers in Japan and the Republic of Korea (Wyse & Walker, 2021). However, even in social insurance funded care systems (e.g., Belgium, Germany, the Kingdom of the Netherlands and Luxembourg), taxation is important for covering the contributions of the non-employed population. For example, in Japan and the Republic of Korea there is a relatively even split between tax funding and social insurance contributions (Wyse & Walker 2021).

Social insurance can reduce the economic burden on families. For example, after the introduction of long-term care insurance in Japan, welfare losses for families with disabilities were reduced (Yamada et al., 2009); medical costs decreased in the Republic of Korea (Choi et al., 2018); and hospitalisation costs, length of stay and medical insurance costs decreased in China (Feng, J. et al., 2020).

Compared to funding from general taxation, social insurance tends to be a more regressive form of financing, as wealthier people tend to contribute the same or a smaller share of their overall resources compared to people with lower financial means; social insurance also draws on a narrower source of resources (income from formal employment) than general taxation which also includes capital gains, and some social insurance schemes have ceilings above which income is disregarded and contributions are no longer required (van Doorslaer et al., 1999; Comas-Herrera et al., *in press*). Other disadvantages of social insurance include the risk that employers may evade their responsibilities, limited access of the unemployed population, and the risk of higher employment costs which reduce the competitiveness of the economy as a location for employment or investment (Dixon & Mossialos, 2002; Comas-Herrera et al., *in press*).

The revenue-generating capacity of social insurance is also sensitive to labour market fluctuations. In countries with large shares of informal (or illegal) employment, ensuring people's participation and contribution payments is challenging. Also, ageing populations present a sustainability issue, as social insurance is funded only by working age adults, and the ratio of younger (working) age groups to older age groups is shrinking. In Germany, however, people who have retired from employment also pay social contributions (Holdenreider, 2006).

It is important to note that, when insurance is compulsory, the distinction between public and private provision of insurance becomes less relevant (e.g., in Germany the system is designed and regulated by the public sector, but the sickness funds that run the system and the majority of insurance providers are not public). Furthermore, public social insurance schemes are not incompatible with private long-term care insurance. Often the public schemes provide basic benefits, and care recipients have the option to purchase private long-term care insurance or pay for additional services directly (Feng & Glinskaya, 2020).

Case study: Japan

Public long-term care insurance has been available in Japan since 2000 and is among the most generous systems globally (Ikegami, 2019). As a result, the provision of long-term care has expanded rapidly, currently placing Japan among the OECD countries with the highest long-term care public expenditure per capita (Del Pozo-Rubio & Jiménez-Rubio, 2020). The system emphasises a ‘preventive approach’ to long-term care, as it focuses on helping people maintain their independence and reduce the need for more intensive care in residential and institutional care settings (Wyse & Walker, 2021). The financing of long-term care is based on tax, social insurance and individual co-payments, and its revenue raising mechanisms are flexible and allow for extra top ups in difficult times. About 50 per cent of funding is from mandatory insurance contributions from all Japanese residents aged 40 and older, and other 50 per cent from taxation (Ikegami, 2019).

An assessment of need determines a budget for care, and eligible people receive services rather than cash benefits (Chen et al., 2020). Services available include home care services, community-based services and services at facilities (Ping & Oshio, 2023). Availability of informal care is not taken into account to encourage the use of formal services and to limit the care burden on families (although there is some reliance on unpaid care). Service users pay co-payments (10–30 per cent), which are capped according to income (Ping & Oshio, 2023).

The impact of the ageing population in Japan has been greater on long-term care costs than on health care costs; per capita health expenditure for people aged 90 or over is only 2.4 times that of those between 65 and 69, but long-term care insurance expenditure is 44 times higher, reflecting a well-documented trend of long-term care support needs increasing with age (Ikegami, 2019).

In response to financial pressures and affordability issues, the generosity of long-term care entitlements has been reduced over time (Curry et al., 2018). The main adjustments include:

- 2003, 2006: provider fees were reduced;
- 2005: bed and board charges for residential care residents were introduced, with the exception of those on low incomes (40 per cent of the total);

- 2006: eligibility criteria for those with the lowest levels of needs were made stricter and benefits were reduced;
- 2015: assets and income were taken into account, with high-income residents (those with an income of USD 90,000 or more) no longer eligible for the waiver on bed and board charges;
- increase in co-insurance rates: from 10 per cent for all, to 20 per cent in 2015, and to 30 per cent in 2018 for those with the highest income and/or assets. In practice, fewer than 10 per cent pay 30 per cent co-insurance because a high proportion of older people have low incomes (Ikegami 2019).

Case study: China

In China, informal family caregivers continue to be the mainstay of long-term care for older people, following the age-old Confucian tradition and practice of filial piety (Feng, 2017). Over the past 30 years, formal long-term care services have emerged to meet rising consumer needs among older adults with disabilities. For the majority of older people, however, access to formal long-term care services is dependent on the ability to pay because these services are usually expensive and paid directly out of pocket. Public financing for long-term care is limited and largely tied to China's social welfare system. Eligibility for publicly funded long-term care is strictly means-tested, covering a relatively small number of older adults who qualify as social welfare recipients only if they have no ability to work, no source of income, and no family members to provide support (Feng, Z. et al., 2020).

At the national level, there are no dedicated budgetary resources for long-term care services. Instead, public financing for long-term care is mainly from social welfare lottery funds and from local government budgets, in roughly equal amounts (Glinskaya & Feng, 2018). It goes mainly in the form of subsidies to service providers to encourage private sector investments in China's fledgling long-term care system and, to a much lesser extent, directly to service users. Both the eligibility for and the mix of publicly subsidised long-term care services are determined locally, resulting in wide variation in their accessibility across the country.

Increasingly, Chinese policy makers have recognised the lack of a systematic approach to financing as a major barrier to further growing long-term care services and making them affordable and accessible

for all in need of such services. In 2016, China launched long-term care insurance pilot programmes in fifteen cities (Ministry of Human Resources and Social Security, 2016) and subsequently expanded the pilots to forty-nine cities in 2020 (National Healthcare Security Administration, 2020). The overall policy objective of these pilots is to explore the feasibility of establishing a social insurance-based long-term care financing scheme. The central government provides overall guidance, and individual pilot cities are responsible for formulating and implementing specific long-term care insurance policy measures (Feng et al., 2021).

Although the pilots vary in their design, a common feature is that all of them are financed by earmarking a certain percentage or fixed amount per person from the existing risk-pooled social health insurance funds. They are designed on the principle of social insurance to spread and maximise the risk pool for broad-based long-term care financing. Operationally, all these pilots build on China's nearly universal social health insurance system, with the potential advantage of increasing efficiency and reducing administrative costs of the newly introduced long-term care insurance programme (Feng et al., 2023). Key features of the pilots are outlined below, primarily based on information available from the original fifteen pilot programs.

Target insured population: Currently, five of the original fifteen pilot cities cover Urban Employee Basic Medical Insurance (UEBMI) enrollees only, and the remaining ten cities also cover Urban or Rural Resident Basic Medical Insurance (URRBMI) enrollees (Feng et al., 2023).

Sources of financing: In all pilot cities, the majority of the long-term care insurance funds comes from a yearly transfer from the UEBMI pooled funds. Individual contributions are largely nominal. Employer contributions are absent from the majority of the pilots. Ten of the fifteen pilot cities include local government subsidies as a long-term care insurance financing source (Feng et al., 2023).

Eligibility criteria for benefits: To be eligible to receive benefits, generally an insured person must have severe disability for at least six months, with eligibility criteria varying across the pilot cities. Needs assessment for eligibility determination is not standardised, though all pilot cities use measures of physical impairment based on limitations in performing ADLs. As currently applied across the pilot cities, the

eligibility criteria are rather stringent, implying that long-term care insurance can only serve a small proportion of people with disabilities in need of services (Feng et al., 2023).

Benefit Design: Across the pilot cities, long-term care insurance currently covers a varied combination of three broad categories of services, including services provided at designated health care facilities, residential care or nursing facilities, and home- and community-based services. The reimbursement rates also vary by service provider and across the pilot cities. All pilot cities set a ceiling for long-term care insurance reimbursement for each service type. Any expenses exceeding these reimbursement caps are paid by beneficiaries out of pocket. In all pilot cities, long-term care insurance covers institutional services provided at residential care or nursing facilities. In all but two pilot cities, the insurance covers some form of home or community-based services, although the benefit package varies.

As of 2021, government statistics (National Healthcare Security Administration, 2022) report that over 144.6 million individuals participated in the programme across all forty-nine pilot cities; among them, just under 1.1 million people received long-term care insurance benefits. Systematic evaluation of the implementation, impact and sustainability of China's long-term care insurance programs is lacking, partly due to the paucity of empirical data. There is an emerging body of research on these programs. Some early evaluation studies reported promising evidence of positive impacts on individual health experiences and outcomes, such as reducing medical utilisation and expenses (Deng et al., 2022; Ma & Xu, 2022; Tang et al., 2022), improving self-rated health (Fan et al., 2022; Lei et al., 2022; Liu et al., 2023; Ma & Xu, 2022; Wang et al., 2022), and reducing informal care use to alleviate family caregiver burdens (Chen & Ning, 2022). However, it is premature to draw firm conclusions about the impacts of the pilots.

For possible implementation of long-term care insurance nationally, one critical policy consideration is whether the insurance should be established as a stand-alone programme, particularly in its financing pool. Some researchers view the heavy reliance on the social health insurance funds as the main revenue source for long-term care insurance financing as suboptimal and unsustainable (Chen et al., 2022; Feng et al., 2023). It is also financially and politically challenging to increase both individual and employer contributions given the slowing

down of China's economy. In the long run, it will be desirable and necessary to establish an independent funding pool for long-term care insurance, with mandatory regular contributions from individuals and employers, supplemented by government subsidies (Feng et al., 2023).

3. *Financial protection*

In many OECD countries without public social protection over 90 per cent of older people with severe care needs may be driven into relative income poverty as a result of paying for home care out of pocket (OECD, 2020a). In most countries, public and private long-term care coverage protection systems co-exist and complement each other to different degrees (Guillén & Comas-Herrera, 2012). If eligibility for long-term care is means-tested, the risks for the population are not well covered; in particular, people miss out who are not of a low enough income to qualify for public funding and yet not rich enough to pay for care (Feng & Glinskaya, 2020). In many countries, publicly funded long-term care supports only people with the least financial means, and sometimes only those with highest needs (Wyse & Walker, 2021). Some countries provide some protection against catastrophic costs of care, but this may be challenging to implement equitably. For example, a cap on individual's lifetime expenditure liability in England has been proposed, but how the cap is reached is complicated with further 'built-in' inequalities depending on how different forms of expenditure, income and assets are taken into account.

As discussed in the private financing section, in many countries individuals are expected to make significant contributions to the costs of their care, even with a universal public long-term care system. Therefore, individuals who need care over a long time can face very high accumulated costs of care. As a result, private long-term care insurance can complement the coverage provided by the public system and provide additional risk protection (e.g., in Germany, France and Spain (see Guillén & Comas-Herrera, 2012; Comas-Herrera et al., 2012)).

While private long-term care insurance includes some degree of risk pooling (but is limited in terms of both access and coverage), it can provide additional benefits not covered by public insurance (e.g., Belgium, France, Germany and Singapore). In practice the potential role for private long-term care insurance is dependent on the underlying public long-term care system in each country. In some countries,

the public long-term care system provides a safety net and covers only those who cannot afford to pay for their own care (e.g., England and the US). In those countries, private long-term care insurance can substitute for the lack of coverage by protecting against the probability of having to pay for care, or against potentially catastrophic costs if care is needed for a long time, preventing asset depletion (Comas-Herrera et al., 2012).

4. The relationship between health care and long-term care financing

The first country to explicitly cover long-term care services through social insurance was the Netherlands, through schemes that covered the costs of non-curative health care, such as the Dutch Exceptional Medical Expenses Act (AWBZ) established in 1968 (Schut & Van Den Berg, 2010). Since then, coverage for long-term care has been added to existing health insurance systems in some countries (for example Belgium and Switzerland), while other countries created new social insurance schemes particularly for long-term care (for example in Germany in 1996, Japan in 2000 (as per the case study above) and the Republic of Korea 2008). In contrast, Austria opted to develop a tax-financed long-term care system despite its social insurance tradition in other social protection programmes. In the countries where long-term care was covered by a health insurance system, this was complemented by tax-funded local social services, usually means-tested, creating complex systems with differently financed layers of coverage, which countries have sought to improve over time (Pacolet & De Wispelaere, 2018).

In countries where there is a universal right to publicly funded health care but long-term care is means-tested, such as in England, there is concern that this makes it difficult to progress towards better care coordination and that the different funding approaches translate into ‘diagnostic inequity’, as people whose health conditions are treated by the curative health care systems experience free care at the point of use, whereas people with chronic conditions for which there is no cure, such as dementia, often bear the majority of the costs of care (Alzheimer’s Society, 2018).

In the United States, health care services (such as hospital stays, post-acute skilled care, physician services and prescription drugs) for people

age 65 and over and for younger adults with disabilities are covered by Medicare, a health insurance programme financed and administered by the federal government. Long-term care services are separately covered by Medicaid, a health insurance programme for low-income individuals jointly financed by the federal and state governments but managed by individual states, with eligibility criteria and benefit packages varying substantially between the states. As such, individuals dually eligible for Medicare and Medicaid coverage must navigate a complex system with often varying benefits, programme rules, and regulations mandated separately by Medicare and by state-specific Medicaid programme policies and procedures (Feng, 2018). In particular, beneficiaries with medical, behavioural or long-term care needs often experience fragmented and uncoordinated care across different providers and care settings, due to the misalignment of financing between Medicare and Medicaid programs (Grabowski, 2012).

Fragmented and misaligned financing schemes for health and long-term care services often translate into fragmentation of service provision, difficulties in accessing needed care in a timely manner and as a result poorer care outcomes and experiences of care. This was made evident during the Covid-19 pandemic, during which the poor integration between health and long-term care contributed towards challenges in providing suitable medical care for persons receiving long-term care (OECD, 2021c). In addition, fragmented financing can lead to numerous other systemic inefficiencies and poor incentive structures, including prolonged hospital stays (so-called ‘bed-blocking’), a lack of investment in preventive and rehabilitative care, and competition for limited funding between health and long-term care providers.

5.4 How do different long-term care financing systems compare?

Comparing long-term care financing systems is complex. In all countries multiple financing systems are involved in long-term care and different financing approaches may reflect different cultural and religious values, differences in economic development, labour markets, strength of public sector institutions, which may be expected to result in differences to the extent of formalisation of care provision, and different degrees of involvement of the public sector. In practice, all financing approaches have certain trade-offs, which have to be weighed

against the policy goals prioritised in each specific setting, as well as the institutional and legislative structures already in place. However, existing evidence points to the need for significant public involvement in long-term care financing and provision to ensure equitable access and adequate financial protection.

In countries of the Majority World, the public sector plays a residual role in financing long-term care, supporting the care of people without family support or economic resources to pay for care. However, governments in these countries are increasingly aware of the need to respond to the fast ageing of their populations, as shown in the examples of China and Thailand.

While discussing the advantages and disadvantages of each of the mechanisms used to finance long-term care, it is important to consider that the long-term care system's performance will be affected by aspects other than financing, from its governance and regulatory frameworks, to the approaches for procuring and managing service provision. A key role of the financing system is raising enough revenue to ensure that the long-term care system can function well.

Comparing spending on long-term care between different countries is challenging, as in many countries there are no information systems that gather data on private spending on long-term care, and, as discussed in the introductory chapter of this volume, there are differences between countries in how long-term care is defined, particularly in relation to the boundaries with the health care system (OECD, 2020b). Estimating the total resources used for long-term care would also require having accurate estimates of the total amount of unpaid care provided, as well as a consensus on how to value that care (van den Berg et al., 2006).

On average, countries in the OECD spent 1.5% of their GDP on formal long-term care in 2019. The highest spenders were the Netherlands (4.1%), Norway (3.7%), Denmark (3.6%) and Sweden (3.4%); the lowest include Mexico, Chile, Greece and Türkiye (between 0.1% and 0.2% of their GDP; see OECD, 2020b). This variation is likely to reflect the stage of development of formal long-term care systems and does not include provision of in-kind long-term care by unpaid carers. There may be some underestimation in countries not recording total spending on long-term care (OECD, 2020b). Long-term care spending is low when compared to health care spending (around 8.8% of GDP in 2019; OECD,

2021a). In all OECD countries, public expenditure is greater than the estimated private expenditure (except Switzerland), excluding in-kind unpaid care (Wyse & Walker, 2021). The average long-term care spend is projected to rise to about 2.5% of GDP by 2050.

Demand for all forms of long-term care is expected to grow, even if there is progress in healthy ageing; however, responding to this increased demand for additional spending from public budgets is difficult, particularly given that long-term care is a sector with relatively low political visibility. Increases in taxation or social insurance contributions are unpopular, not only at times of economic hardship. However, long-term care insurance contributions are a revenue source to which people appear to be more willing to contribute than paying higher taxes (Ikegami, 2019). Establishing the link between higher contributions and better or more generous benefits can make it more acceptable to the public (e.g., in Germany, long-term care insurance contributions went up in order to increase coverage and benefits for people with dementia; Nadash et al., 2018).

5.5 The impacts of underfunding long-term care

The Covid-19 pandemic disproportionately affected people who rely on long-term care, particularly those living in residential care facilities (Comas-Herrera et al., 2020), and the difficulties countries faced when trying to mitigate the impacts of the pandemic on the long-term care population were exacerbated by structural features of long-term care systems. In particular, complex governance structures resulting in poor accountability and coordination, underfunding, underdeveloped regulatory systems and lack of information systems have been identified as key factors affecting countries' abilities to respond to the pandemic in the long-term care sector (WHO, 2020). In many countries the pandemic hit the long-term care sector at a time when concerns over sustainability and, particularly for some, the concurrent financial crisis moderated or even decreased long-term care spending (Deusdad et al., 2016; Albesa Jové, 2021) despite increases in need. This section discusses some of the potential impacts of underspending on long-term care, many of which became particularly challenging after the start of the Covid-19 pandemic.

Workforce shortages

Shortages of skilled care workers are common in many countries, resulting mainly from poor working conditions and low pay. For example, there is a care workforce crisis in the United Kingdom, with an estimated 100,000 vacancies out of a 1.6 million workforce (European Commission, 2022b). Other OECD countries such as Germany have introduced several regulations to improve conditions in the sector through increasing minimum pay for long-term care workers and funding additional long-term care jobs (European Commission, 2022a). Efforts have also been made in certain LMIC settings to address workforce shortages in the care sector. For example in China there are over 40 million older people with disabilities who need care (mostly provided by family carers) and only an estimated 300,000 registered long-term care workers. To improve care capacity, professional educational programmes for long-term care have been developed (increasing in number from 86 in 2015 to 186 in 2018), but interest has been low due to negative attitudes towards long-term care workers, low wages, demanding work conditions, limited opportunities for career development, and low job satisfaction (Feng et al., 2020).

Unnecessary hospitalisations

There is a growing demand for long-term care as a result of ageing populations. The poor alignment of the financing framework between long-term care and medical care, however, is common and contributes to perverse incentives for hospitalisation (Phua et al., 2021). It is essential that services support older people's health and social care needs, help them maintain their independence and quality of life, and reduce the need for more expensive hospital care (Barber et al., 2021). [Chapter 7](#) of this volume discusses the relationship between health care and long-term care in greater depth.

Impact on unpaid carers

Support for unpaid carers is non-existent or underdeveloped in many countries. Due to the absence of formal support, informal carers bear the consequences of providing unpaid care, which includes an impact on

their physical and mental health, as well as financial impacts such as lost earnings. There is increased awareness of the lack of sustainability of high reliance on unpaid care, particularly as decreases in the share of population of traditional working age and increased educational attainment among women increases political awareness of the opportunity costs for women in formal labour markets (Keating et al., 2021; Vos et al., 2022). These issues are explored further in [chapter 8](#) of this volume.

Impact on the economy

Unpaid care work contributes considerably to economies of countries. For example in Spain the total monetary value of unpaid care was estimated at 1.7–4.9% of GDP in 2008 (Oliva-Moreno et al., 2015). In Portugal, including unpaid carers among people aged over 55 years in employment figures would have increased the employment rate by almost 13% in 2014 (Cylus et al., 2018). In addition, older people who are not working still contribute to public revenue generation through taxation, for instance taxes on non-labour income and assets and consumption taxes (Cylus et al., 2018). Similarly, a lack of mechanisms to share the risk of high costs of care may result in people over-saving, which may decrease consumption-related spending and negatively affect economic growth (Barr, 2010), or if a means-tested residual public system is available, provide an incentive to dispose of assets (Mayhew, 2017). The relationship between long-term care and economic growth is explored in greater detail in [chapter 10](#) of this volume.

5.6 Conclusion: long-term care financing reforms, sustainability and political will

A key challenge for policy makers in all countries is to find a comprehensive solution to financing long-term care services to make them widely accessible, affordable and equitable for all those in need (Feng & Glinskaya, 2020). An optimal system of long-term care would span both the public and private sectors, achieve a balance in access, cost and quality of care, and also cope with the increasing care needs of ageing populations (Phua et al., 2021). This optimal long-term care system can be expected to look different in each country, or within subnational systems in the same country, given the different political, social, cultural and broader health care and welfare system contexts.

The Covid-19 pandemic highlighted inadequacies in the governance, financing, regulation and labour policies in long-term care systems all over the world, showing that many countries lacked mechanisms to implement policies and measures to respond rapidly and effectively to the pandemic. These inadequacies in many cases stem from a lack of comprehensive system-wide reforms to both the governance and the financing of long-term care which has resulted in fragmentation of responsibilities and underinvestment in the long-term care workforce and infrastructure.

As older people represent an increasing share of populations world-wide, it may become politically unsustainable not to address long-term care financing, particularly given the implications this has for the sector being able to attract, train and retain staff in increasingly challenging labour market conditions, and increased awareness of the lack of sustainability and opportunity costs of relying excessively on unpaid care.

It is to be hoped that the tragic outcomes of the pandemic may have a positive side if, in increasing the visibility of the sector, more countries are galvanised into taking action to strengthen their long-term care systems. There are some early signs of this happening: for example the European Care Strategy recommends that member states draw up national action plans to make care more available, accessible and of better quality, and include as one of the key mechanisms to carry this out that countries mobilise adequate and sustainable funding for long-term care (European Commission, 2022c).

Ultimately, a well-functioning long-term care financing system would ensure that the amounts that are spent on long-term care match the value that the population attributes to care. While historically this value may been low, now that many more people are living longer with care needs and there is increased awareness of the importance of well-functioning long-term care systems, it can be expected that, at the very least, long-term care systems will be able to keep pace with population ageing.

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6 *How have countries worked to improve the quality of long-term care?*

JULIETTE MALLEY, VALENTINA ZIGANTE

6.1 Introduction

Securing high-quality long-term care is an important goal for all countries (OECD/European Commission, 2013). In this chapter we review the different ways countries are seeking to improve the quality of long-term care for older people, and the impact of these strategies on quality. Since long-term care is a relatively new element of welfare systems, the evidence base regarding how to improve quality is fairly limited. The scant data for most countries about the quality of long-term care makes it difficult to assess the impact of strategies and compare countries (OECD/European Commission, 2013; Cès & Coster, 2019). Consequently, in this chapter we provide an overview of different approaches for improving quality, drawing on evidence, where available, to understand the impact of these strategies on the quality of long-term care.

Although we present the strategies as options for improving quality, it is important to reflect on the extent to which these strategies would be feasible and valuable in different countries given differences in both the maturity and organisation of long-term care systems. In many Eastern European and middle-income countries, long-term care systems are more emergent, with lower levels of public expenditure and a more limited range of services on offer (Spasova et al., 2018). As interventions to assure and improve quality tend to lag the development of new forms of provision, the maturity of the long-term care system is an important factor determining existing strategies and the direction countries might take to improve the quality of long-term care. Additionally, while most countries rely on ‘quasi-markets’ for care delivery, they vary considerably in terms of purchasers, rules around providers and the availability of funding (Colombo et al., 2011; Rodrigues et al., 2014), as discussed in chapter 5 of this volume. The range of services and professions involved in the delivery of long-term

care varies, as does its governance, with services split across policy domains (e.g., in the United Kingdom long-term care is split across social services and the NHS) or designated as a new ‘pillar’ of social insurance (e.g., Germany). These differences in the organisation of systems affect what might be considered the most important targets for intervention to improve quality, the range of options countries can pursue and how quality is conceptualised.

This chapter is structured as follows. The [next section](#) discusses how quality of long-term care is conceptualised. The [following section](#) provides an overview of strategies to assure and improve the quality of long-term care, looking at the three levels where quality strategies might impact, that is, the individual, the care provider organisation and the care system. We provide an overview and review of the evidence on strategies available at each level.

In each case, we discuss both the promise and the limitations of the described strategies, before summarising and offering reflections for policy makers in the conclusion.

6.2 Conceptualising quality

Before reviewing strategies to assure and improve quality, it is helpful to define what we mean by quality in this context and explore how it can be, and is, measured, since many strategies depend on being able to monitor and measure quality.

Many competing conceptualisations of long-term care quality feature in the literature. A popular approach is to identify dimensions that are most relevant to care. The OECD’s (2013) report, *A Good Life in Old Age*, provides a leading example of this approach. Through a review of national assessment frameworks for long-term care in OECD countries they derive four dimensions of quality: care effectiveness; user safety; person-centredness, responsiveness and empowerment; and care coordination and integration. Donabedian’s (1980, 1988) work provides another approach. He defines care quality as having three components: the outcome, which captures the end results of care; process, which relates to care delivery and captures what is done in providing care; and structure, which refers to relatively stable physical and organisational characteristics of care. Although originally developed for medical care, Donabedian’s approach has been influential in the long-term care context for developing quality measures and

as a way of structuring assessments of quality in national frameworks (see e.g., Castle & Ferguson, 2010; Milte et al., 2019; Igarashi et al., 2020; Everink et al., 2021).

The relative importance of the different dimensions and components of long-term care quality, how they are understood in practice and developed into indicators of quality varies between countries, depending on aspects such as the organisation of the long-term care system, the professional base and its values, and the type of care being delivered. For example, in countries where the nursing profession has a strong influence over delivery, as in Germany and the United States, historically there has been more emphasis on assessing care effectiveness through ‘clinical’ outcome measures (e.g., weight loss, pressure sores, dehydration) than on wellbeing and quality of life measures. By contrast, in England where the social work profession has more sway, ‘social’ outcomes like wellbeing and quality of life have been seen as critical measures for assessing care effectiveness for many years (Kane, 2001; Malley & Fernández, 2010). Another important difference is the greater availability of structural indicators of quality for long-term care services that have a physical building like nursing homes, compared to services like home care that involve a care worker visiting people in their homes to support them with daily activities. (Further examples of quality indicators used by countries and their relationships to the concepts in these frameworks are given in [Box 6.1](#).) The way in which the context and type of care affects how dimensions and components are interpreted is a reason why it is difficult to compare the quality of different forms of services and support and to compare the quality of long-term care between countries.

Both Donabedian’s and the dimensions approach are valuable ways of conceptualising quality for the purpose of measurement and assessment. In our view, however, they are less useful for structuring thinking about strategies for improving the quality of long-term care – the focus of this chapter. In previous work (see Malley et al., 2015), we categorised strategies by their aim and how they influence the behaviour of actors in the system. Here we use the intended level or object of quality improvement strategies (i.e. individual, organisational and system level) to categorise the strategies, as we are able to show the links to areas of policy debate more clearly (see Nies et al., 2010). This is not to disregard the conceptual frameworks mentioned nor the importance of developing good ways of measuring and assessing quality and better

Box 6.1. Examples of quality frameworks and indicators**InterRAI (Resident Assessment Instrument)**

Used worldwide (e.g., Japan, Israel, Germany, Finland, Sweden; the United States includes the minimum data set) and has been adjusted for different services including residential care and home care. The instrument includes among others social outcomes indicators such as distress and loneliness, clinical indicators including falls and pain management, and functional indicators related to communication and cognition.

Consumer Quality Index Long-term Care

The index was developed and is used in the Netherlands. The index includes process indicators such as meals and reliability of care-givers, users' involvement in care planning, and outcomes indicators including mental and physical wellbeing and the users' sense of autonomy.

Elderly Guide

The guide is used in Sweden and the data collected are made publicly available on a dedicated website. It is focused on process measures such as users having a dedicated contact person, and outcome measures reported as users' perspectives on services including overall satisfaction with the service, and users' influence over the care they receive.

The Adult Social Care Outcomes Framework (ASCOF)

Used in England. Includes largely outcomes indicators, such as average social care-related quality of life (SCRQoL) which is measured using the ASCOT instrument (Netten et al., 2012). The ASCOT measure is constructed using responses to survey questions covering the eight domains: control, dignity, personal care, food and nutrition, safety, occupation, social participation and accommodation.

data. Indeed, we see this as a critical issue for improving quality, since good measurement of quality underpins the implementation and evaluation of all quality improvement efforts. The challenges of quality measurement and assessment are beyond the scope of this chapter

and we refer readers to Malley et al. (2015) and Malley & Fernández (2010) for a discussion of the issues.

6.3 Delivering high-quality long-term care for older people

Our overview of strategies to assure and improve the quality of long-term care is structured around the three levels at which quality strategies might impact, that is, the individual, the care provider organisation and the care system. For each strategy, we outline how it is intended to either assure or improve the quality of long-term care, experiences with its implementation and the evidence for its effectiveness, and we identify some of the countries where it is being employed. The list of strategies outlined in this chapter is not exhaustive. In selecting strategies, we have concentrated on what we consider to be those most frequently employed by high-income countries over the last thirty years. We focus on high-income countries because long-term care systems are most developed in these countries and therefore the accumulated experience is greater.

Individual actors: the care user and carer relationship

At the individual level, the quality of care is intrinsically tied to the relationship between the user and the carer (Malley & Fernández, 2010). Although some older people may require specialist medical care or use assistive devices to manage their daily lives, most long-term care involves a carer helping the older person with activities related to daily living. Such care is highly personal, involving intimate tasks, such as washing and dressing, over which care users are likely to have strong preferences and views. For care to be high-quality, carers need to take account of users' preferences, and carers and users need to work together to get the care tasks done. A key strategy for improving the quality of long-term care is therefore to maximise the efficiency of the care user-carer relationship. There are broadly two areas of policy debate: empowering care users, and professionalising and investing in the workforce.

Empowering care users

For many years now a narrative of empowering care users has featured heavily in international and national policy debates about improving the quality of long-term care. The argument for empowering care users

is rooted in an understanding of autonomy as critical to a person's quality of life and therefore to successful ageing (Clark, 1988). The idea of increasing the autonomy of users of long-term care services has been implemented in various ways in many countries, for example Israel, Japan, the United States, many European countries and Taiwan, China (Moilanen et al., 2021). Initiatives to empower older people have been closely associated with the consumer movement of the last century and marketisation reforms. They have frequently emerged as a reaction against paternalistic services that tend to overwhelm individual preferences and expressions of control, as captured by the concepts of 'total' institutions or 'one-size-fits-all' services. In many countries, initiatives to develop more modern services that give people greater autonomy have coalesced around the concept of 'personalisation' or 'person-centredness', which broadly require that people can direct decisions about their care and services are designed around the person (McCormack et al., 2012).

To give older people greater autonomy over their care, the most significant policy has been cash for care schemes (Lundsgaard, 2005). Under these schemes people are given cash payments in lieu of services. The rationale is that care meeting the older person's preferences can best be met through giving them the money to choose the care they want. In addition to the positive effect of this increase in autonomy on their quality of life, through exerting their choice in markets it is argued that older people will drive quality improvements in care. Although such schemes are found in many countries (e.g., the Netherlands, Germany, the United Kingdom and Taiwan, China) there is substantial variation in how cash for care schemes operate and the rules around how cash can be spent. Differences tend to reflect the reason for offering cash benefits, such as encouraging informal care provision, and range from having choice over the type of services or care provider to being able to hire and supervise care staff (personal assistants) (e.g., England) or employ family members (e.g., the Netherlands) (Zigante, 2018; da Roit & Gori, 2019).

Despite the growth of cash for care schemes internationally there is limited evidence about their impact on the quality of long-term care. In one of the few literature reviews, Low et al. (2011) found that cash for care schemes improve satisfaction with care and community service use but had little effect on care outcomes. The review includes findings from an evaluation of the Individual Budgets programme in England (a form

of cash for care), which showed that individual budgets made users feel more in control of their care but an impact on other aspects of quality of life was not identified. Given the current era of austerity, there are also concerns about how well cash for care schemes work in practice (Pearson & Ridley, 2017). Issues are reported around the level of the cash payments (da Roit & le Bihan, 2010) and this has given rise to concerns over whether they are large enough to cover the care package the older person needs (let alone wants) and equally, whether there is a workforce in the local area willing and able to take up the work. Some argue that in European countries, cash for care schemes have ‘de facto converted into policies supporting either informal care, low-paid market care, or both’ (da Roit & Gori, 2019: 518), with consequences for quality (see discussion around professionalisation below).

Cash for care schemes focus largely on giving older people greater choice over their care, but empowering older people is not simply about offering them choice (Kane & Kane, 2001). For older people to be empowered with respect to long-term care, there is a need to address wider structures within society and long-term care systems that influence how older people are seen and treated, especially around attitudes towards safety and protection that can unnecessarily limit what people can do, with impacts on their quality of life (Kane & Kane, 2001; Clarke, 2007). There is also a need for a more nuanced debate around how autonomy can be realised in practice. Research illustrates that many older people can be reluctant to take control of decisions about their care (Baxter et al., 2013; Ottmann et al., 2013). Greater attention needs to be given to how older people can be enabled to strike a balance between being independent and receiving support as they age, including enabling them to make informed choices. Public reporting of quality information, discussed later in this chapter, is an important aspect of this.

Professionalisation of care work and investment into the workforce

For many countries, professionalising the workforce is a key strategy for improving the quality of long-term care. With respect to improving quality, the aim of professionalisation is to ensure that workers have the right skills, experience and up-to-date knowledge to deliver high-quality and safe care. Professionalisation includes a number of strategies such as: registration and regulation of the workforce; education, training and continuing professional development; and improving pay, progression and working terms and conditions

(OECD, 2020; Hemmings et al., 2022). Countries take different approaches to professionalisation, mixing strategies within these three broad areas, but much of the evidence examines the effects of professionalisation on recruitment and retention of workers as opposed to long-term care quality. This is because these strategies are also, even if not primarily, motivated by attracting and retaining workers to address the challenges almost all countries face of finding enough care workers to meet the demand from an ageing population (OECD, 2020), as discussed in [chapter 2](#) of this volume.

Educational and training requirements for long-term care workers are generally low across OECD countries, and in many countries no qualification is required to become a care worker (OECD, 2020). It is increasingly recognised that this is problematic: as older people are living longer with multiple long-term conditions their needs have become increasingly complex and care work is becoming an increasingly skilled job. This makes upskilling through training and continuing professional development more important for quality. Countries have tried different approaches including mandatory training requirements, granting workers rights to training, integrating training with the health sector through placement rotations and training in health interventions, and training targeted at underrepresented groups, such as men and younger people (OECD, 2020; Hemmings et al., 2022). While there is not evidence for the impact of all of these approaches, the evidence does show that quality of care is influenced by the skills and expertise of staff as well as the environment and culture in care facilities (Haunch et al., 2021), and that quality, as measured by clinical outcomes such as pressure ulcers and urinary tract infections, is better in nursing homes with higher levels of more qualified staff (Clemens et al., 2021). Indeed, Clemens et al. (2021) argue their review suggests that as the complexity of older people's needs increases, replacing more qualified staff with less qualified staff risks negatively affecting the quality of care.

Too strong a focus on professionalisation of the workforce also poses risks with respect to quality. A highly professionalised workforce is likely to be a more expensive workforce. Long-term care is already seen as unaffordable by many and governments have not shown a willingness to spend proportionately more public money on funding long-term care. Without sufficient funding and with strict enforcement

of professional staffing requirements, there is a danger that workloads increase or more expensive workers, such as nurses, may be displaced by less expensive or unqualified workers, undermining the goal of professionalisation. Therefore, any steps to professionalise the workforce need to be planned carefully so as not to adversely affect retention or increase the unqualified workforce (Hemmings et al., 2022). However, as discussed in [chapter 8](#), improvements in workforce training, and consequently in the quality of the long-term care provided, can boost economic growth as it can induce family caregivers to remain in jobs and/or choose more productive careers, because those they provide care to will instead receive care from trained aides.

The unqualified workforce is already significant in most countries given the heavy reliance on what is known as informal, or unpaid, care (provided by family members, neighbours and friends) (OECD, 2020). Given the importance of informal carers to long-term care, it is argued that governments should also aim to enhance the quality of care they provide (Schneider et al., 2015). Some countries, including Sweden, Germany, the Netherlands, Spain and England, have invested in training and support schemes for informal carers to support quality, but this approach is patchy and often dependent on local provision (see Zigante, 2018 for an overview).

Arguably more problematic with respect to long-term care quality, forms of temporary contracts are common in the long-term care sector (e.g., Japan, Spain, France, United Kingdom) and undeclared employment by migrant workers is a concern (OECD, 2020). The latter is found particularly in countries with policies that support the private hire of personal assistants in the home (e.g., cash for care, substantial co-payments for home care services and an undersupply of home care services). In Western European countries with access to relatively cheap labour in Central and Eastern European countries, these workers are often migrant carers who live in private households (Schwiter et al., 2018). There is evidence of substandard care and poor working conditions among this workforce (Simmons et al., 2022). Although some countries (e.g., Austria) have taken steps to regularise these workers, the lack of oversight and regulation of this workforce in other countries (e.g., Italy) raises ongoing concerns about the quality and safety of care for older people as well as precarity of employment for the care workers (da Roit & Moreno-Fuentes, 2019).

Care organisations: the care setting and the management of care delivery

Since much care is delivered by provider organisations, strategies to improve the quality of long-term care can also focus on these organisations and the range of care they deliver. Particularly where care providers compete for older people, theory would suggest that some of the strategies for improving quality are likely to be adopted by organisations for strategic reasons, without necessitating government intervention. As we discuss in the subsequent section, however, there are many reasons why organisations will not respond in this way in competitive markets. Governments may need to intervene to influence the balance of types of care and the adoption of innovative models that offer more effective and better-quality provision. Strategies for improving the quality of care organisations deliver revolve around these concepts: ageing in place, changing the culture of congregate living, the role of technology and the management of quality.

Ageing in place

Formal care systems have traditionally been focused on residential care forms of care, such as nursing homes, but for many years there has been a drive towards 'ageing in place'. This has been defined as 'the ability of older people to live in their own homes and communities safely, autonomously, and comfortably, regardless of age, income, or functional limitations' (Low et al., 2021:1). It is argued that more personalised (i.e. better-quality) care can be provided in the older person's own home and that it can help people to maintain connections with family and friends (i.e. better outcomes) (Wiles et al., 2012; Stones & Gullifer, 2016; Low et al., 2021). The evidence suggests that older people prefer to remain in their own home and communities as they age, at least until such time as they perceive that their care needs are too great (Lehnert et al., 2019). Yet, it is very difficult to find evidence in favour of ageing in place over institutional long-term care on grounds of quality, since an unbiased comparative evaluation of these alternatives is extremely difficult.

While ageing in place is a valuable ambition for long-term care systems, it is clear that it is not a panacea. Importantly, it brings new challenges for quality. The neighbourhoods in which people live can become more hostile and challenging as people age; in particular urban environments across the world have been found to lead to exclusion

and loneliness (Judd et al., 2020; Lewis & Buffel, 2020). Ageing in place is generally considered to be cheaper than the equivalent care in an institution, but it can become more expensive (Bakx et al., 2020), especially where people have very complex needs and live in poorly designed inaccessible housing, which is unfortunately the majority of housing in many high-income countries (Smith et al., 2018; Judd et al., 2020; Mulliner et al., 2020). Indeed poorly designed housing can precipitate care needs, for example where there are many steps, or where people are no longer able to maintain their properties causing them to become hazardous (Braubach & Power, 2011). There may also be safety concerns around people being left without supervision, for example if they have dementia, or without access to support when needed, for example for toileting or when thirsty. These factors limit the potential of ageing in place for people who live alone. As we discuss later in this section, innovative solutions are emerging to manage some of these problems (e.g., technologies to support people's independence), but many of the problems identified require massive, long-term investment and major infrastructure improvements, for example building lifetime homes, renovating the housing stock and making cities and places 'dementia-friendly' and 'age-friendly'. Hence, while it may be possible to improve the balance of care in favour of home-based care, institutional forms of care seem likely to remain a part of the long-term care mix in all countries for the foreseeable future.

A further challenge to ageing in place is dissatisfaction with home care, which has been the cornerstone of most countries' strategies for ageing in place (Genet et al., 2011). Home care services typically involve visits from care workers to older people's homes to help them with ADLs such as getting up, getting dressed, washing and mealtimes. Older people report that the timing of visits is frequently unsuitable, for example being put to bed at six in the evening, and that the tasks care workers can and will do are not always those that users would like them to do, with support for socialising, odd jobs, activities and outings being frequently mentioned as lacking in the United Kingdom context (Tarricone & Tsouros, 2008; Genet et al., 2011). These concerns over home care relate to challenges in managing busy times of the day and rigid contracting practices. In recent years new forms of home care have developed, such as examples based on the Buurtzorg model of self-managing neighbourhood teams from the Netherlands, that deliver a more flexible and holistic service. The evidence suggests that these

bring increased staff satisfaction, benefits to users' wellbeing and a reduction in costs, but most studies are of low quality and it has not been easy to translate this approach to other countries with different long-term care systems (Hegedüs et al., 2022).

Changing the culture of residential care

In recent years new models of congregate living have been promoted that are designed to overcome some of the more depersonalising aspects of care homes. The culture change movement aims to make institutions more home-like and person-directed. It is particularly strong in the United States, where a network exists to promote it, and it includes a range of models, such as Green Houses and the Eden Alternative (Koren, 2010). The movement has spread to a number of countries (Brownie, 2011), and similar types of models have emerged elsewhere, such as My Home Life in the United Kingdom (Owen, 2013). In Europe, initiatives associated with the movement are sometimes referred to as the household or home model of care, reflecting the preference for specially-designed, small-scale, home-like environments where a small number of people live together (Verbeek et al., 2009; Ahmed et al., 2019). Many of these household models have been developed specifically for people with dementia, including concepts such as group homes, Cantou and more recently the Green Care Farms in the Netherlands (Verbeek et al., 2009; de Boer et al., 2017).

There are difficulties determining the impact of culture change and household models as there are many variants and what is implemented can also vary considerably (Brownie & Nancarrow, 2013; Ausserhofer et al., 2016). Despite these challenges, the evidence suggests they are generally popular with their users. A systematic review found that these programmes are associated with positive impacts on staff outcomes, improvements in the psychological status of residents, and reduced levels of agitation in residents with dementia. These benefits, however, may come at the expense of an increased risk of falls (Brownie & Nancarrow, 2013). Additionally, implementing culture change is far from straightforward, since it depends on existing homes adopting the measures. A key barrier is the cost of introducing environmental improvements. Among other challenges it can be difficult to meet quality regulations (especially around the management of health and safety) while staying true to the model (Verbeek et al., 2009; Miller

et al., 2010; Kapp, 2013; Corazzini et al., 2015). As a consequence of these challenges, although awareness and uptake of these models is growing, they remain on the periphery of provision (Miller et al., 2010).

Technology to enhance and improve care settings

Technology¹ also has a role to play in making services safer and more productive and enabling people to age in place. It has risen in prominence in recent years and particularly so during the Covid-19 pandemic, as people sought ways to keep people safe and connected while minimising face-to-face contact (Chu et al., 2021). There are numerous technologies that can help organisations to deliver better and safer long-term care and help older people to age in place, but evidence of the impacts of these solutions on the quality of care is variable and generally fairly limited (for a recent review see Zigante, 2020). There are also well-known problems with adoption and routinisation of technologies in care settings, including the need for staff training especially if their digital literacy is limited, and acceptability for staff and older people (Greenhalgh et al., 2017). There is a vast array of technologies that can support ageing in place, and we highlight as examples a few for which there is a more substantial evidence base (for reviews see Carretero, 2014, 2015; Czaja, 2016). While our focus here is on how technology can enhance quality, the role of technology in improving efficiency and access to long-term care is also discussed in [chapter 4](#) of this volume.

‘Smart home’ technology is increasingly researched as a means to enhance the quality of long-term care for people ageing in place. This includes technologies that contain a degree of artificial intelligence, such as wearable devices and other sensors, communication devices or connected devices for remote control operation. Marikyan et al. (2019) identified the core functions of smart home technology as offering comfort, access to care and improving users’ safety. Smart homes can provide monitoring and disease management and enable care staff to monitor health remotely and detect life threatening changes early, as well as provide medical care when necessary. Smart home applications can also support virtual medical ‘visits’, meaning

¹ Technology both includes software (i.e. computer programs, ICT) and hardware (devices, assistive equipment, robots) (Mosca et al., 2017).

older people do not have to make tiring and potentially difficult trips to clinics and hospitals (Czaja, 2016). There is evidence that smart homes can improve socialisation and help users overcome the feeling of isolation (Marikyan et al., 2019). There is also evidence that smart home solutions help older people carry out everyday activities, improve physical safety and social communication. Older people reported that smart homes improved their sense of security, quality of daily life and activities, and provided them with information about the care they could receive (Turjamaa et al., 2019).

Another type of technology that supports ageing in place is ICT. A systematic review found that these technologies have a positive, yet short-term, impact on social support, social connectedness and social isolation among older people living independently, although the results for loneliness were inconclusive (Chen & Schulz, 2016). Examples of ICT included in the review were the use of communication tools (landline phones, smartphones, tablet computers, email and online chat rooms or forums) and high-technology apps (Wii, television gaming systems and GeriJoy, a virtual pet companion) which consistently reported a positive effect. Although noting a dearth of rigorous research, the review concluded that older people can benefit from ICT interventions and will use them frequently after proper training (Chen & Schulz, 2016). There is also evidence that ICT can be supportive of high-quality dementia care in care homes (see Goh et al., 2017) and social interaction in care homes, although more evidence is needed (Macdonald et al., 2021).

Management of quality

A key tool for organisations to improve quality is active quality management. Quality management rose to prominence as the quality movement gained momentum, introducing and adapting techniques for quality control from manufacturing to service industries and the public sector. Quality management systems provide organisations with a framework for measuring and monitoring quality and acting on the results. The focus of quality management systems is on achieving continuous quality improvement, and in this way they are different from quality standards and accreditation, which are tools used by governments to control the behaviour of organisations and provide a minimum level of quality. There are numerous examples of systems (e.g., ISO, EFQM, E-Qalin) which have been taken up to different

extents by organisations in different countries (for reviews see Nies et al., 2010; Cès & Coster, 2019). Some quality management systems include third-party certification linked to the use of internal quality management and self-assessment of quality, resembling voluntary accreditation schemes.

Reviews suggest that quality management systems are widely used by provider organisations across countries (Nies et al., 2010; OECD/European Commission, 2013). In some countries, such as England, adoption is high because the care standards require providers to have quality management systems in place. There does seem to be a willingness among providers to adopt these systems and participate in voluntary accreditation schemes because they are seen to signal quality in a competitive market. Their adoption in countries with less competitive markets suggests that this may be as much about attracting older people as it is about attracting and retaining staff (Malley et al., 2015).

Importantly, digital technology also has a place in supporting quality management. To date it has been used more widely for surveillance, such as monitoring the timeliness and duration of visits by home care staff (Moore & Hayes, 2018). Increasingly, however, as organisations introduce digital systems for care records, medicines management and other forms of monitoring (e.g., of vital signs or sleep) the data collected can be used to support audits and spot patterns in behaviours that can be targeted for quality improvement activities (Kruse et al., 2017). At present, however, most provider organisations lack the capacity and skills to analyse the data collected and use it to full effect (Ko et al., 2018). More broadly there is relatively little evidence of care homes developing quality improvement expertise (Chadborn et al., 2021).

The care system: behaviours of actors and relationships between them

From a systems perspective quality is understood in terms of the overall functioning of the care system for older people and tends to be assessed in terms of different aspects of aggregate performance of the sector (e.g., coordination and integration of care and information pertaining to care delivery, equity of access and outcomes, targeting efficiency). Strategies for improving quality within long-term care systems focus on changing the behaviours of and relationships between different actors in the system, and usually require regulation or the design of incentive

structures that encourage desirable behaviours. A key decision is the extent to which long-term care is delivered via markets². Where this is the case, regulatory interventions focusing on quality assurance and oversight, public reporting of quality information and standardisation of care practices generally become more central to discussions about how to improve quality. In addition to these strategies, many countries also consider the role of procurement and how it can be used to improve quality. Interventions to improve coordination between actors across the system are also of relevance, but this topic is beyond the scope of this chapter. (Interested readers are directed to Wodchis et al., 2015; Harvey et al., 2018; WHO, 2022.). Integration as a means of achieving greater efficiency and access in long-term care services is also discussed in [chapter 4](#) of this volume.

Markets for long-term care

As already mentioned, most countries operate quasi-markets for long-term care provision. This generally refers to a situation where state-funded services are provided by a plurality of independent providers who compete for business from state-appointed purchasers (i.e. commissioners/procurers of long-term care) or directly from users. In many cases quasi-markets were introduced as part of the wave of New Public Management reforms that swept across many countries towards the end of the last century (European Social Network, 2021). The rationale tended to be to promote choice for users, improve quality and reduce costs by subjecting providers to competitive forces (Lundsgaard, 2005). The characteristics of quasi-markets vary substantially across countries in terms of how financing works, how and when independent providers are allowed to engage in the market, as well as the regulations that govern the markets. For example, in Sweden certain municipalities allow independent providers while others operate a combination of public and private providers (Zigante & King, 2019). Whether these reforms have produced the desired effects is debated and the evidence around this (which comes largely from studies of the United States nursing homes market) is mixed with respect to its impact on quality.

² This has special relevance in the European context where EU directives around state aid and competition require special designation of services as 'non-economic services of general interest' to be excluded from the directive. If designated as 'services of general economic interest' they need to be procured through public contracts (European Social Network, 2021).

It depends on the methods used, the country (with some positive effects on quality from United States studies and negative from United Kingdom studies) and the presence of certain institutional features, such as public reporting of quality information, meaning it is important to understand the country context. The most consistent finding across studies is that competition depresses prices (for reviews see Forder & Allan, 2011; Yang et al., 2022).

There are many reasons why long-term care markets may not deliver good quality care. These include individual-level factors such as lack of, or difficulties assessing, information about quality of services a priori, reluctance on the part of users and families to switch providers (in particular care homes) and a distorted relationship between price and quality due to co-payments by the user and the local government/the state. There are also structural factors including the market power of public purchasers potentially leading to unsustainable prices, the cost of withdrawing contracts for publicly funded care (even when quality is poor), and market behaviours including private providers cream-skimming (selecting people who are easier to care for) and locating in densely populated wealthier areas (for a wider discussion of market failures, see Corlet Walker et al., 2022, and [chapter 5](#) of this volume. Consequently, it is argued that a range of conditions must be addressed in order to realise the benefits from marketised long-term care provision and that it is crucial for governments to regulate long-term care markets to ensure at least a minimum level of quality. Key mechanisms for influencing the quality of long-term care markets are oversight and public reporting of information which we address next.

Oversight for quality

The goal of quality oversight is to address the problem of ‘bad apples’ by imposing external regulatory controls to ensure a minimum standard of quality and safety across care providers. Oversight systems for quality assurance tend to consist of three elements: a method for setting standards or *directions*, a method of *surveillance* for detecting compliance with the directions, and a method for *enforcing* compliance, should instances of noncompliance be detected (Hood et al., 1999). Responsibility for regulating the entry of providers, inspection and enforcement actions may be held by a single national regulator or multiple regulators, often at arms-length from government, or by a patchwork of regional organisations (Nies et al., 2010; Cès &

Coster, 2019). Countries also vary considerably in how they implement these elements, but often combine a mechanism for regulating entry of new providers to the market (i.e. accreditation, registration, certification) with a form of inspection to ensure providers continue to meet minimum standards while they are in operation (Mor et al., 2014; for a discussion and examples see Cès & Coster, 2019; Zigante & King, 2019). There is often a close relationship between the system for oversight and other mechanisms for quality improvement. For example, in some countries quality management systems are mandated through standards and there is often a relationship with public procurement of long-term care, for example with accreditation/authorisation a pre-requisite for access to public funds (European Social Network, 2021).

As a strategy to improve quality, oversight is often seen as expensive and its effectiveness is debated. Key challenges relate to: the degree of alignment between the standards and the goals of the system, especially in countries that rely solely on structural indicators of quality (e.g., single rooms, staff ratios); how standards can be adequately and appropriately measured; and the costs of surveillance and inconsistencies in measurement, especially for process and outcomes based standards, which rely on assessment by inspectors. In promoting or enforcing compliance, there is a further challenge involved in achieving a balance between strong sanctions and deterrence to identify ‘knives’ on the one hand, and persuasion and education to ensure the system does not crowd out ‘knightly’ motivations on the other (for a more detailed discussion and description of approaches in countries see Mor et al., 2014; Malley et al., 2015; Cès & Coster, 2019; Zigante & King, 2019).

Public reporting of quality information

One reason long-term care markets fail is that they are subject to imperfect and asymmetric information. Older people are unable to assess the quality of care options with certainty prior to purchase due to a lack of easily searchable or comparable information about aspects of quality that matter, such as outcomes and experiential information (for a discussion see Konetzka et al., 2021). The purpose of public reporting is to correct this information problem by providing older people with information about quality that will inform their choice of provider and increase the probability of going to a high-quality

provider. It is also argued that providers will be incentivised to improve their performance, to bolster their reputation and ensure they do not lose market share (Berwick et al., 2003).

Much of the academic research around the effects of public reporting comes from the United States where information about the quality of nursing homes has been available for over two decades now via the website Nursing Home Compare (now Care Compare). In a wide-ranging review Konetzka and colleagues (2021) report evidence for a modest but meaningful change in provider behaviour and older people's choice behaviour, but note that this was only apparent after the (simpler) five-star ratings system for providers was introduced. More negatively, there was also evidence of providers gaming the system, focusing only on improving aspects of quality that were measured, and some indications that the policy is exacerbating disparities by race, ethnicity and income. There is much less evidence of the impact of public reporting schemes from other countries, which differ in terms of the range and format of quality information reported (Rodrigues et al., 2014). However, the evidence presents similar challenges to those found in the United States around the use of information by older people to choose providers. This suggests that the impact of public reporting is not likely to be substantially different in other countries, although it may be tempered by the degree of competition in markets and other features of the long-term care systems.

Notably in countries where public reporting occurs there appears to be fairly low awareness of the quality information that is made available. Questions are also raised about whether the publicly reported information covers the kind of experiential information people want and the ability of older people to play the role of the empowered consumer who actively seeks out detailed quality information. Most older people choosing care (and especially care homes) make this decision at a time of considerable stress, and evidence suggests that they require support to access the information and make use of it. In chapter 3 in this volume, other scholars have discussed how even eligibility rules to public long-term care benefits can be characterised by very different degrees of transparency and ease of access. Mistrust in the information available undermines its use, highlighting the importance of users having confidence in its reliability. Additionally, for most people quality is also not the only consideration – location and availability of places are more

important. The general conclusion from the accumulated evidence is that public reporting is a part of the solution to improving quality, but more effort is required to improve the information, raise awareness and support older people to make use of it (Rodrigues et al., 2014; Trigg et al., 2018; Konetzka et al., 2021).

Standardisation of care practices

Drawing inspiration from the evidence-based practice movement, a further mechanism for improving quality is standardisation of care practice. The aim is to ensure that care everywhere aligns with what is evaluated to be best practice. This strategy differs from standard setting associated with oversight in that it intends to move organisations away from a focus on delivering minimum standards towards a focus on delivering the best standards (OECD/European Commission, 2013). To facilitate the standardisation of care practice, however, an infrastructure is needed for generating evidence of good care practice, evaluating the evidence collected and synthesising it into guidelines. These guidelines then need to be adopted by organisations if they are to lead to the standardisation of care practice across organisations; all the evidence suggests that this requires as much investment and effort in the long-term care arena as it does in others (Diehl et al., 2016).

While there is a tradition of developing and using clinical guidelines in medical care, to date there has been much less attention given to developing and using guidelines to standardise the nursing and social care provided by long-term care workers and organisations. One area of care practice that has received more attention is the process for measuring and assessing needs, where standardisation is lacking (this is discussed in [chapter 3](#) in this volume). All OECD countries use some form of needs assessment to assess the degree of disability and allocate benefits to older people, and in a growing number of countries standardised instruments are mandated (e.g., United States, France, Canada). A popular instrument is the interRAI (resident assessment instrument), which supports the assessment of needs, care planning, resource allocation and the monitoring of changes in needs over time. A major challenge with these tools is that they may not be sensitive enough to the varying needs of such a diverse group of people and can inhibit the tailoring and personalisation of care, hence some countries allow greater discretion in how the tools are applied in practice (for an extended discussion see OECD/European Commission, 2013).

A number of countries (e.g., Australia, Canada, France, Germany, United Kingdom) have developed guidelines for other areas of care practice. While there are guidelines for topics such as social work practice for adults with complex needs and safeguarding of adults in care homes in England, the implementation of these guidelines has not been studied (Bauer et al., 2021). The available evidence focuses almost exclusively on the management of aspects of clinical practice (e.g., oral health, medication review, pain protocols, pressure ulcer prevention) within nursing homes (Möhler & Meyer, 2015; Diehl et al., 2016). The accumulated evidence argues for the importance of having implementation strategies specific to the nursing home setting, identifying particular differences in the skills mix of staff, availability of resources and complexity of needs of residents compared to other settings (McArthur et al., 2021). These studies conclude that greater rigour is needed in the development of guidelines and their implementation within long-term care organisations (Möhler & Meyer, 2015; Diehl et al., 2016; Bauer et al., 2021).

Procurement of quality services

Many countries have some degree of public procurement of long-term care services, which we understand as the purchasing and contracting of long-term care by public authorities from for-profit or not-for-profit care providers. Procurement of services generally takes place at the local/regional level, except in very small countries where this may be managed at the national level. Procurement is common even in countries where long-term care benefits are provided via cash payments or have a substantial self-funder market as in the United Kingdom (European Social Network, 2021). Public procurement is generally highly regulated, and in the EU specific directives apply, but these allow public authorities to consider quality (and other factors) alongside cost in awarding contracts. In theory, the public authority can use public procurement to increase competition on quality by putting a higher weight on quality criteria and asking providers to compete on both price and quality, or by setting the price and output quantity (e.g., care hours provided) and asking providers to compete on quality criteria only (for examples see Malley et al., 2015).

In a review of public procurement practices in European countries, countries report a number of challenges affecting their ability to procure high-quality services. These include the bureaucracy of tendering

procedures, difficulties ensuring the quality of service delivery and problems with the continuity of provision that affects the ability of providers to create good quality secure jobs (European Social Network, 2021). Given the experiential nature of care quality, public authorities find it particularly challenging to assess and select providers based on quality, so despite the fact most respondents in the review report using quality criteria for procurement it is unclear how informative this information is and the degree to which it (rather than cost) influences decisions (European Social Network, 2021). In England, experience has also been that the often inflexible nature of contracts, which can be highly prescriptive around tasks, may not be working in the best interests of care users (Lewis & West, 2014).

Countries have tried a range of mechanisms to improve public procurement practices to ensure that they support and encourage high-quality long-term care. Firstly, some countries (e.g., United Kingdom and examples in Finland) seat procurement within the context of strategic commissioning, which is generally understood as a strategic process of specifying, purchasing and monitoring services to meet the local population's needs, drawing on analysis and evidence of needs and other market insight (for a discussion see Newman et al., 2012). Central to strategic commissioning is the intention that the decision to purchase services is made based on evidence about whether more value will be gained by purchasing services as opposed to delivering them in-house.

Secondly, and relatedly, there are examples in some countries of public authorities trying to establish greater dialogue and more of a partnership approach with providers, with examples of public authorities accompanying contract monitoring with support to improve and involving providers in the design and development of contracts, which seem to build trust and establish a positive approach to quality improvement (Malley et al., 2019; European Social Network, 2021).

Thirdly, in some countries public authorities seek to further incentivise quality, through tying the level of payments to the achievement of quality criteria (i.e. payments for performance), which can include the achievement of specified user outcomes (i.e. outcomes based commissioning) (Malley et al., 2019; European Social Network, 2021). As with any incentive scheme there are concerns that it may induce providers to behave in ways that maximise their profit but are not in the spirit of the scheme, including through gaming measures and cream-skimming. In

recent years more evidence about the impact of these programmes has started to emerge, largely from the United States. Studies present a mixed picture of the effect of pay-for-performance schemes on the quality of long-term care, with some showing a modest impact. The technical design of schemes with respect to quality measurement is critical. It is also important to get the target and size of the incentives right, as targets that are too distant will disincentivise actors to improve, while too easy a target can perversely reduce quality on targeted measures as good providers reduce their efforts (Norton, 2018; Li & Norton, 2019).

6.4 Conclusion

This chapter has reviewed different strategies being adopted by countries for improving the quality of long-term care for older people. While evidence about the impact of these strategies is still somewhat limited, we have noted a step change over the last ten or so years with respect to the quantity and rigour of studies investigating their impact on the quality of long-term care. Particularly notable are the increasing number of review articles examining some of the system-level strategies, such as the public reporting of quality information and pay-for-performance schemes. Although these reviews often call for more and higher quality studies (e.g., Li & Norton, 2019), the evidence presented tends to be more conclusive than we have found in previous reviews (Malley et al., 2015). While we cannot on the basis of this review offer a recipe that countries can follow to improve the quality of long-term care, the accumulated evidence points to the limitations and unintended consequences of strategies with respect to quality, with important implications for policy makers.

Reflecting partly the zeitgeist and the countries where much of the research has been carried out, studies to date have focused on the impact on quality of marketisation and strategies that are designed to address market failures. As we have noted, much of the evidence is conflicting about the impact of these strategies on quality. The main conclusion we draw from this work is that there is little evidence that competition on its own leads to higher quality. Policy makers need also to put in place strategies to address the lack of market forces to discipline providers. While there is evidence that public reporting of quality information can positively affect provider behaviour, the impact of

other initiatives (i.e. pay for performance, oversight for quality, and cash for care) is unclear. It is also not clear which strategies are key: both the United States and the United Kingdom have public reporting of quality information and oversight, but findings differ in terms of the effect of competition on quality with the United Kingdom being more negative. It may be that the design of quality information reporting and oversight is better in the United States than the United Kingdom or that other features of the long-term care system are important. Especially given the expense of many of these strategies addressing market failures, countries need to tread carefully if they wish to use market mechanisms to raise quality. More attention also needs to be paid to the assumptions these strategies make about older people's capacity to act in long-term care markets. The empowerment of older people is central and a more nuanced debate is needed around how, as older people age, they can strike a balance between dependence and independence and how this can be realised in practice.

In this chapter we have presented the idea that the balance of care, by which we mean the relative contribution different types of services and care settings make in a given system, is one strategy countries can pursue to improve quality. We include in this general idea calls to support people to age in place, for greater use of technology, and for different models of care (e.g., the household model or new ways of providing home care). Although there are powerful arguments for changing the balance of care, there is little evidence of the actual impact on quality (as opposed to the *potential* impact on quality). In the case of technology and different models of care this is because these options remain on the periphery of provision, limiting their system-wide impact on quality. In the case of ageing in place it is because the poor quality and accessibility of much housing and the built environment, in addition to the capacity of home care services, places a limit on the quality of care people living in their own homes can receive. Changing the balance of care requires an appreciation of the complexity of the system and recognition that investment may be needed in other sectors of the economy (e.g., housing, digital infrastructure, built environment, etc.). Countries wishing to change the balance of care to improve quality need to consider the level of investment required and where it is needed to realise the full benefits.

A clear message from this review is the growing importance of having a skilled and knowledgeable workforce to deliver good quality long-

term care. Problems retaining the existing workforce, combined with the often-substantial unqualified workforce and difficulties recruiting new workers to meet demand, mean there are no straightforward options for policy makers to deliver on this agenda. Investing in the existing workforce must be central to any strategy and in this context, given informal carers provide the majority of care, supporting and upskilling informal carers should be much more central to strategies that seek to improve quality by professionalising the workforce. While comparisons across countries do not reveal a clear direction for policy makers, experiences so far do demonstrate the importance of accompanying policies to professionalise the workforce with a concomitant increase in funding. Without sufficient funding, the experience is that the goals of professionalisation are undermined.

This review has identified some limitations in the evidence base. Specifically, there is far less evidence around how quality management systems and voluntary accreditation, oversight of quality, standardisation of care practices, and approaches to public procurement influence the quality of long-term care. We have also been brief in our discussion of the various strategies to improve quality. We could not do justice to the vast literature around many of the topics covered, such as ageing in place, technology and the care workforce. We focused on the evidence for better known and more prevalent services, technologies and issues. It is clear, however, that innovative solutions have a role to play in improving the quality of long-term care and governments a role in promoting innovations that seem promising.

Finally, we want to emphasise the value of comparative research for improving the evidence base and moving debates about improving quality forwards. As we noted in the introduction, a challenge is the lack of both data and consistent data about long-term care quality across countries. In recent years, however, there have been concerted efforts to harmonise measurement of long-term care quality across countries (Hoffmann et al., 2010; OECD/European Commission, 2013; Edvardsson et al., 2019) – a development that may improve the potential for comparative research. A further problem holding back comparative research is language, with similar forms of care or strategies referred to using different terminology in different parts of the world. This seems to be particularly an issue for more innovative forms of care and was especially evident in the discussion around changing the culture of institutional care. Cultivating opportunities to exchange

ideas will be important for overcoming differences in language and building a stronger evidence base for the international long-term care community.

6.5 References

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7

Does a strong long-term care system benefit the health system (and vice-versa)?

GEMMA FRANCES SPIERS

7.1 Introduction

This chapter investigates the intricate relationship between the long-term care and health sectors. Historically perceived as separate entities, there is a growing recognition of their interdependence, especially when evaluating the health outcomes and health care utilisation of older people. The global ageing population presents a unique challenge to the health sector. As the number of older people rises, so does the demand for both health care and long-term care. In this context, the significance of a well-developed long-term care system becomes evident. Such a system not only enhances the quality of life for older people but also acts as a crucial buffer, reducing the pressure on traditional health care settings that are not designed for and are ill-suited to providing long-term care. By ensuring older people receive consistent and high-quality care outside hospitals and clinics, the likelihood of health crises that necessitate emergency medical attention diminishes.

A core argument presented is the potential benefits of integrating both types of care. The Covid-19 pandemic further underscored the vulnerabilities within both sectors, emphasising the urgency of achieving greater coordination. Through exploring various integration methods, from system level (macro integration) to service-level (meso integration) and clinical processes (micro integration), this chapter sheds light on the complexities of such integration. The evidence is inconclusive at times, and the myriad ways care can be integrated adds to the complexity. However, given the problems that a lack of coordination causes, the question is less of whether integration works, but rather how to ensure that it does. This demands that integration is approached with a comprehensive understanding of its inherent challenges and complexities, and an appreciation that the benefits may take time to be fully realised.

This chapter considers the extent to which current evidence supports the argument that well-developed systems of long-term care may benefit the health sector, by improving people's health and wellbeing and ultimately reducing pressure on health care providers. The first section explores the theoretical foundations of the relationship between the two sectors, including the mechanisms through which access to long-term care may influence health care utilisation. Implicit in this discussion is that the two sectors are distinct entities. In practice, long-term care and health sectors are often integrated to some degree, even when they are funded and organised separately. This is explored in the [second section](#) of this chapter, where the relationship between long-term care and health care is examined through the lens of integration. Here, the impact of coordination between sectors on older people's health outcomes and the health sector are considered, drawing upon current evidence and case examples. In the [third section](#) of this chapter, links to the experience of Covid-19 are highlighted, and the implications for understanding the interface and divide between long-term care and health sectors discussed. Finally, acknowledging empirical challenges, the chapter concludes by presenting key areas where further evidence is needed to strengthen our understanding of the relationship between long-term care and health care.

Given the focus of this chapter – the relationship between health care and long-term care – the ensuing discussion draws upon evidence from high-income countries where *both* types of care exist in some form or other. This typically reflects the location of published evidence. However, many of the issues raised in this chapter are relevant to LMICs, where demand for long-term care will inevitable rise as populations age.

7.2 Can (and does) access to long-term care reduce older people's use of health care?

In most high-income countries, long-term care systems are organised and funded separately to health sectors. Yet both sectors are capable of exerting some degree of influence over the other. This interface between the two can be understood through the lens of older people's access to long-term care and health services. This section explores the ways in which access to long-term care is capable of reducing older people's use of health care, and if current evidence confirms these arguments.

Access: First, what is meant by *access* to long-term care? Access is a term often used within policy, yet its definition is complex. As mentioned in [chapter 2](#) of this volume, one of the most widely accepted and evidence-supported theoretical frameworks of access to care is Andersen's model (Andersen, 1995). In this framework, access is an iterative process through which care outcomes are shaped by environmental, population and behavioural factors, as well as care processes and quality. In a more recent development, Gulliford and colleagues (2003) take a slightly different approach to operationalising access. In their framework, access to care is defined as: the availability and supply of care; the utilisation of care; the equity of care; and the quality and effectiveness of care. More recent, and more patient-centric perspectives, include that proposed by Levesque et al. (2013), which includes five dimensions of accessibility of services: 1) approachability; 2) acceptability; 3) availability and accommodation; 4) affordability; and 5) appropriateness. Five corresponding abilities of persons interact with the dimensions of accessibility to generate access, including: 1) ability to perceive; 2) ability to seek; 3) ability to reach; 4) ability to pay; and 5) ability to engage with care. However, most studies typically operationalise access as the *availability and supply* of care, and the *utilisation* of care. This is also the approach adopted within this chapter.

Now that access is defined, let's consider how access to long-term care could influence older people's use of health care. Two mechanisms may underpin this relationship: prevention and substitution.

Prevention: Care that supports and maximises independence with day-to-day activities can prevent deteriorations in older people's health. The evidence for this argument is convincing. Home care programmes postpone the loss of functional independence (Stuck et al., 2002). Unmet support needs for ADLs predict higher rates of hospital admissions and mortality (DePalma et al., 2013; Hass et al., 2017; He et al., 2015; Lo et al., 2015; Pudaric et al., 2003; Xu et al., 2012; Gaugler et al., 2005; Sands et al., 2006). Good health is enjoyed by those who live with greater day-to-day independence (Gama et al., 2000), and [chapter 3](#) of this volume sets out the evidence that being covered by the public long-term care system leads to higher psychological wellbeing. Underpinning this premise is the basic notion that health and long-term care needs are not divisible, but interdependent. Such interdependency extends to the health and long-term care services

that are designed to address these needs. There is therefore a clear mechanism through which long-term care can prevent the use of health services because support to stay independent has benefits for older people's health. By the same logic, a well-resourced long-term care system should also lower health care demand for unpaid carers. Those who provide such unpaid care are typically at greater risk of poorer health. A long-term care system that supports, or largely reduces the need for, unpaid carers, may likely support better health outcomes for this population. Evidence of reduced unplanned health care use among those using long-term care (and their carers) would support this argument.

The causality potentially runs both ways: more investment in prevention of morbidity earlier in the life course may delay functional decline and care needs later.

Substitution: A package of home support or residency in a care home may substitute for unnecessary stays in hospital. In this scenario, an older person may be well enough to be discharged from hospital, but the stay is prolonged because a long-term care arrangement is unavailable (Gaughan et al., 2015; Forder, 2009). Evidence of shorter lengths of hospital stay for populations within areas with greater long-term care supply would provide support for this argument.

Both the prevention and substitution arguments suggest that access to good quality long-term care can benefit the health sector. Each of these scenarios is possible. Yet a key consideration is the context in which these mechanisms occur. Here, context refers to the conditions of access imposed on sectors by policy. Eligibility criteria, universalism and means testing are important conditions of access (see [chapter 3](#) in this book). The extent to which access to each of long-term care and health care is hindered or enabled by these conditions will also shape the relationship between the two. For example, restrictive or inconsistently applied long-term care eligibility criteria may hinder access to supportive care, resulting in unmet need. As evidence shows, unmet long-term care needs will then increase demand on health sectors (e.g., see DePalma et al., 2013; Hass et al., 2017; Sands et al., 2006), particularly those that are universal and free at the point of use. Similarly, payment barriers to long-term care are likely to shift the resulting unmet need onto health sectors. The degree of successful integration between both sectors is also a critical contextual factor for these mechanisms, which is explored in more detail later in this chapter. [Figure 7.1](#) summarises these arguments.

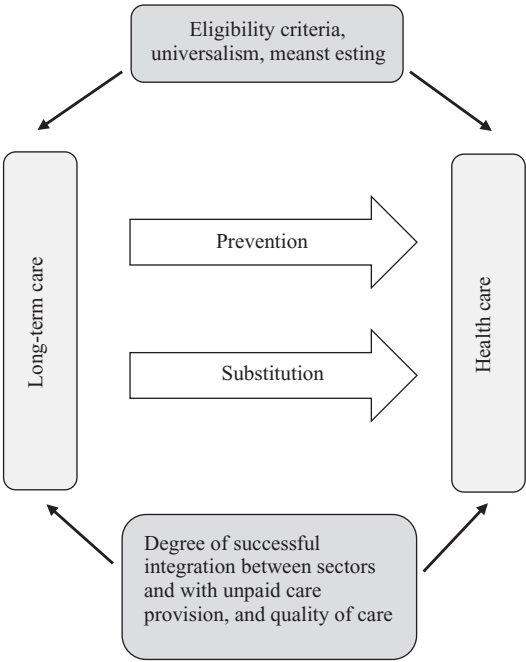


Figure 7.1. The ways in which long-term care can influence health care utilisation

Now that the ways in which long-term care can reduce older people’s use of health care are set out, let’s look at whether evidence confirms this. Three recently published systematic reviews offer a good starting point.

The first is a Cochrane review of ten studies that compared outcomes between older populations using home care or residential care long-term care (Young et al., 2017). This review did not focus exclusively on health service utilisation outcomes, but evidence on the outcome of hospital admission was reported in three of the ten studies. Evidence about the impact of home care compared to institutional long-term care on hospital admissions was uncertain. Two studies favoured institutional long-term care for a greater reduction in hospital admissions, while one study favoured home care. All three studies were subject to methodological biases and the findings should be treated with caution.

Similar conclusions were derived from another systematic review (Spiers et al., 2019a). Drawing upon thirteen studies, this review

reported evidence about the relationship between older people's use of long-term care and their use of health care. Evidence in this review was complex: health care use outcomes were diverse, and compared in different ways. A small amount of evidence suggested that residing in a care home with nursing was associated with fewer hospital admissions or a reduced risk of hospital admission. This pattern was observed when hospital admissions were compared between care homes and usual care, and when compared according to the length of care home stay. In contrast, there was no strong evidence of an association between the use of long-term care and other health care utilisation outcomes, such as length of hospital stay, delayed discharges and use of emergency health services.

The third systematic review examined the relationship between long-term care supply and health care use by older populations (Spiers et al., 2019b). Across twelve studies, evidence was weighted towards an inverse relationship. That is, greater long-term care supply was associated with fewer hospital readmissions and delayed discharges, and reduced length of hospital stay and health care expenditure. The direction of this evidence was not consistent, with some exceptions. However, overall this review suggested that care homes in particular may have a beneficial impact on the health sector. This review also found evidence about the relationship between home care supply and secondary health care utilisation. However, this evidence was smaller in quantity and did not offer a clear view about the benefits of this type of long-term care for the health sector.

In summary, these reviews suggest that a greater supply of care homes is likely to benefit the health sector, and in particular, secondary health care services. In contrast, there is a less consistent message when studies examine the utilisation of long-term care, rather than its supply.

Since the publication of these reviews, more evidence has become available, which adds to this already complex picture. A study by Walsh and colleagues (2020) examined home care supply in Ireland. Their findings support the argument that long-term care benefits the health sector: a 10 per cent increase in formal home care provision corresponded to a reduction of between 0.45 and 1.2 days in hospital. Furthermore, this association was stronger for females than males, but similar effects were found between married and unmarried populations. The impact of home care supply on length of hospital stay was strongest for inpatients who were likely to be those experiencing delayed discharges.

Analyses of English data were published in three studies between 2018 and 2021. One study indicates there is no evidence to link long-term care supply with emergency admissions related to falls or neck of femur fractures, or length of hospital stay (Liu et al., 2021). Another found no evidence that reductions in government long-term care spending was linked to an increase in emergency hospital admissions (Seamer et al., 2019). A third study demonstrated a weak substitution effect between community care contacts and hospital costs (Lau et al., 2021). However, community care contacts in this study were not specific to long-term care and also included community health services.

For convenience, the studies and reviews described thus far are summarised in [Table 7.1](#). From this table we can appreciate the diversity of the evidence: the different types of long-term care, the different ways that access to care is conceptualised, and the range of health care use outcomes scrutinised.

So, how do we make sense of this complicated picture? A balanced interpretation should acknowledge that there is a fairly consistent trend of evidence that care homes have the potential to reduce secondary health care use. The beneficial impact of home care on secondary health care use is less certain, reflecting the heterogeneity of the evidence base.

In terms of the mechanisms outlined earlier, to what extent does this evidence support the arguments? Certainly, the link between care homes and secondary health care use – particularly delayed discharges and length of stay – supports the substitution argument. That is, long-term care can potentially substitute unnecessary hospital care. Although we can be reasonably confident about this relationship, there is far less certainty about the size of the impact of long-term care. The review of long-term care supply, for example, was unable to quantify the size of the impact in terms of potential absolute cost savings and saved hospital bed days (Spiers et al., 2019b). The preventive role of long-term care is also partly supported by evidence of fewer hospital admissions in one review. However, when considering the more recent studies, evidence about hospital and emergency admissions was inconsistent.

Overall, there is some evidence to show that long-term care can benefit health sectors. Yet a fair assessment of this evidence would also acknowledge the heterogeneity within these findings. What may account for this heterogeneity? Four factors are critical in this discussion.

Table 7.1. *Summary of evidence about access to long-term care and health care utilisation*

Study	How is access operationalised?	Type of long-term care	Health care use outcomes	Evidence that long-term care benefits health sectors?
Young 2017	Utilisation	Care homes Home care ^a	Hospital admissions	Yes, for care homes
Seamer 2018	Availability and supply	Public expenditure	Emergency admissions	No
Spiers 2018	Availability and supply	Care homes Home care	Hospital readmissions, delayed discharges, length of hospital stay, health care expenditure	Yes, for care homes Less consistent for home care
Spiers 2019	Utilisation	Care homes Home care ^b	Hospital admissions, length of hospital stay, delayed discharges, emergency health services	Yes, for hospital admissions No for other outcomes
Walsh 2020	Availability and supply	Home care	Length of hospital stay	Yes
Pace 2020	Availability and supply	Public expenditure	Emergency admissions, length of hospital stay	No
Lau 2021	Utilisation	Community care contacts ^c	Hospital costs	Yes, but a weak effect

Notes: ^a Compared home care with care home residency; ^b Comparisons included with usual care, between types of care, and according to the amount of care; ^c Includes community health services

1. The impact of formal long-term care use on health care use depends on the operationalisation of access to care

The way that access to care is operationalised is important. When studies examine the availability and supply of long-term care, the evidence about the impact on hospital use tends to be more consistent. The overall trend of findings would suggest that greater supply of long-term care is linked to reduced use of secondary health care. By contrast, evidence that considers the utilisation of long-term care – and how this relates to older people’s health care utilisation – is less consistent. One reason for this is that the *utilisation* of care is more vulnerable to a range of confounding influences than the *supply* of care (Andersen, 1995; Gulliford et al., 2002). Expectations of and attitudes to care, for example, may determine whether available care is used (Sarkisian et al., 2002). Unpaid care often supplements or replaces paid long-term care services (Davey & Patsios, 1999; Tennstedt et al., 1993). Such use of unpaid care may then moderate the extent to which use of paid long-term care influences health care use.

Inevitably, the measurement of long-term care utilisation is complicated – certainly more complicated than the measurement of whether care is available. It is not unreasonable, therefore, to expect that evidence about the benefits of long-term care for the health sector may lack consistency when studies consider the utilisation rather than the supply of care. Even so, any observed impact of long-term care supply assumes that at some point care has been utilised.

2. The impact of formal long-term care use on health care use depends on the type of long-term care considered: home-based vs institutional care

The studies described above examined two types of long-term care: care homes and home care. These are two very different forms of care, serving populations with different needs. Older people residing in care homes have a greater level of dependency than those still able to manage in community settings (Jagger et al., 2011). Care home residents are therefore more likely to need health care.

Similarly, care homes are designed for people with greater levels of dependency and greater complexity in needs. If a resident’s health deteriorates, care homes should in theory be equipped to manage this when it first occurs. For example, care homes should have access to specialist health staff and primary care. Such features would enable

care staff to manage their residents' health and prevent transfers to hospital where appropriate. In contrast, home care is often delivered by individual or small groups of care staff who work without these links to specialist health expertise. In the context of care delivered at home, a care recipient will more likely be directed to hospital in the event of an acute deterioration in health.

These important differences might explain why a stronger trend of evidence is observed for the impact of care homes on secondary health care, compared to the impact of home care. Even so, this hypothesis assumes such integrated arrangements between care homes and health staff are successful. In practice, such arrangements are rarely formalised (Gage et al., 2012; Iliffe et al., 2016).

3. The impact of formal long-term care use on health care use depends on the regularity of care provision

Care homes may demonstrate a greater impact on the health sector than home care because of the regularity of the care delivered. Long-term care delivered in home settings is episodic. In contrast, populations living in care homes should have access to staffing for assistance throughout the day. A continuous presence of staff should equate to more opportunities for assistance when needed. This, in turn, could prevent deteriorations in health and thus the need for health care. The continuous presence of staff in care homes may also foster responsive relationships between care staff and residents. Such responsive relationships are a key component of high-quality care (Anderson et al., 2016; Wilson et al., 2009), and may enable more efficient management of residents' health. This uninterrupted form of long-term care in care homes may be a critical factor for moderating residents' health care use. Admittedly, this is a rather optimistic hypothesis. The reality is that workforce pressures persist in long-term care, with retention of care staff an ongoing challenge. Thus, while continuity of staffing in care homes may be critical for preventing deteriorations in health (and thus avoiding health care use), the extent to which such continuity is realised in practice can be questioned.

4. The impact of formal long-term care use on health care use depends on care processes and quality of care

Finally, substantial variations in the processes of care and care quality may account for the heterogeneity in findings. These variations can arise from a multitude of factors, including regional differences,

individual practitioner approaches and the unique needs of each patient. Even with standardised care protocols, packages of care will differ from person to person. This is because every individual has unique health needs, personal preferences and circumstances that can influence the type and extent of care they receive. Quality of care is deeply subjective and shaped by expectations, which differ across populations. For instance, cultural norms, personal experiences and societal values can all play a role in shaping one's perception of what constitutes high-quality care. This means that the long-term care being measured is not homogenous. It is a complex tapestry of services, interventions and interactions that can vary widely even within the same health care system. These are the sort of confounding influences that are challenging to correct in any analysis of the relationship between access to long-term care and health care use. Such complexities underscore the need for nuanced and comprehensive evaluations when studying the impact of long-term care on health outcomes.

Summary

The question set out at the start of this section was whether access to long-term care can reduce older people's use of health care. The encouraging answer is: yes, and there is a sensible and intuitive logic to how a high-quality long-term care system can benefit health sectors. However, the effect differs for different types of long-term care and depending on which health care outcomes are considered. Answers to this question should therefore stress the importance of adopting realistic expectations about what this sort of evidence can reveal. The diversity and quality of long-term care, as well as the methodological challenges of isolating this relationship from a vast array of confounding influences, render a clear and consistent trend of evidence unlikely. A degree of pragmatism is called for, and a reflective approach to its interpretation. The shortcomings of the evidence base call for much more significant investment and improved access to various types of data to adequately investigate these issues and provide more precise and reliable answers. As pointed out, this is a highly complex web of interactions and effects that cannot be appropriately disentangled without more powerful studies.

7.3 Improving coordination and integration between long-term care and health sectors: does it make a difference to older people's health and health care utilisation?

So far, this chapter has considered evidence about the relationship between long-term care and health sectors. An assumption underpinning much of this discussion is that the two sectors are distinct entities. While health care and long-term care are often delineated as distinct sectors in discussions and policy frameworks, a closer examination reveals significant overlap and interdependence. Long-term care includes medical as well as personal and social support. Aspects of medical care that fall under the umbrella of long-term care include skilled nursing care, rehabilitation services, medication management, chronic disease management, respiratory care, nutritional support, behavioural health management and palliative care. The implication of this is that the long-term care and health sectors are not truly distinct, even when they are funded and organised separately. The confluence of needs, especially among older populations, often requires services from both domains simultaneously. However, when health care and long-term care operate in separate silos, care recipients can face challenges in accessing comprehensive services, navigating between systems and experiencing seamless continuity of care. Such operational fragmentation can lead to gaps and potential redundancies in care and increased costs, adversely impacting the overall quality of life for the individuals in question.

The question then arises: can a more integrated approach between these sectors lead to enhanced health outcomes and efficiencies? The integration of both types of care offers another lens through which to examine the relationship between long-term care and health care. This section considers evidence about the extent to which greater integration and coordination of care between both sectors improves health outcomes for older people and benefits health sectors. The question of how integration of services both within the long-term care sector itself, and between long-term care and other services, can enhance access and efficiency is also discussed in [chapter 4](#) of this volume.

First, what is meant by integrated care? Although this term is used frequently in care policy and practice, the ways in which care can be integrated are highly variable. Broadly speaking, care can be integrated at the system level (macro integration), the service-level (meso integration),

and at the level of clinical and care processes (micro integration) (Briggs et al., 2018; Valentijn et al., 2012). In the following sections, examples of and evidence for each approach are described. Table 7.2 summarises these case examples for reference.

Table 7.2. Case examples of integration between long-term care and health care

Type of integration	Case examples
Macro integration	Northern Ireland
	Approach
	<ul style="list-style-type: none">• Care commissioned and delivered through single trusts with shared budgets• Health care remained universal while means testing and payment barriers remained for some types of long-term care
	Experience
	<ul style="list-style-type: none">• Resistance to shifting resources away from acute care, even with combined budgets• Integration has not enhanced or protected role of long-term care
	Republic of Korea
	Approach
	<ul style="list-style-type: none">• Introduction of single-payer public long-term care insurance• Long-term care insurance ring-fenced from health insurance
	Experience
	<ul style="list-style-type: none">• Insurance viewed favourably among public• Separate funding streams have hindered coordination of care in practice
Meso integration	Canada
	Approach
	<ul style="list-style-type: none">• Program of Research to Integrate Services for the Maintenance of Autonomy (PRISMA)

Table 7.2. (*cont.*)

Type of integration	Case examples
Micro integration	<ul style="list-style-type: none"> • Integrated health and long-term care service to promote functional independence
	Experience
	<ul style="list-style-type: none"> • Lower rates of functional decline, unmet need, emergency department visits and hospital admissions in areas adopting the programme
	England Approach <ul style="list-style-type: none"> • National Health Service Vanguard programme • Enhanced joint working across long-term care, primary and secondary health care settings and disciplines Experience <ul style="list-style-type: none"> • Stabilised emergency admissions for care home residents, but no difference in hospital bed days • Joint working across health and long-term care is impeded by professional boundaries, separate governance arrangements and different cultures of working between health and long-term care

Macro integration, in the context of blending long-term care and health care, can encompass a variety of meanings, ranging from the consolidation of funding mechanisms, to integrated decision-making processes, potential co-location of services, and unified governance, or a combination of these. There may be an argument that integrating long-term care and health care in this way erases, or at least diminishes, funding boundaries between sectors. The absence of these sort of boundaries could in turn facilitate timelier discharge from hospital into care homes or community packages of support. But is there evidence to support this? Can this type of integration improve outcomes for older people?

A good example of this type of integration is the health and care system in Northern Ireland: both types of care are commissioned and

delivered through single trusts with shared budgets (Donnelly & O'Neill, 2018). Despite this structural integration, conditions of access to each type of care remain distinct. That is, health care is universal while means testing and payment barriers remain for some types of long-term care for older people.

Reflecting on the Northern Ireland experience, Gray and Birrell (2016) conclude that combining budgets and commissioning brought challenges that were not outweighed by benefits. The potential of shared budgets to create seamless moves between acute health care and long-term care did not materialise. Instead, they describe a resistance to shifting resources away from acute care, with concerns raised about the impact on hospital provision. These sorts of barriers are not new. Evaluations of other policy agendas that advocate for greater care delivered in community settings have reported similar opposition from acute providers (Spiers et al., 2016). Furthermore, Gray and Birrell (2016) note that these integration arrangements have done little to protect long-term care spending.

Long-term care funding in the Republic of Korea offers an interesting contrast to this example. As part of the inception of a new long-term care system in 2008, the country opted for single-payer public long-term care insurance that was separate from the country's national health insurance system (Yoon, 2021). This separation of funding mechanisms was intentional: a ring-fenced long-term care insurance was thought to be more attractive to the public, with less risk of placing financial burdens on health insurance. Indeed, the new insurance was viewed favourably among the public (Choi, 2015). However, while this separation has the benefit of de-medicalised long-term care, separate funding mechanisms have challenged coordination between sectors in practice (Choi, 2015; Kim & Kwon, 2021). Thus, experience from two different macro-approaches to integration in the Republic of Korea and Northern Ireland suggests that neither have created a situation in which coordination between sectors has improved.

Others are sceptical about the value and effectiveness of structural integration. Glasby (2017), for example, notes that while structural mergers look good publicly, they offer little success. Indeed, a review of integrated financing and care found no evidence that such approaches reduced secondary care use in the longer term (Mason et al., 2015). A further consideration is that while health care in universal systems is typically funded through a single source (e.g., the taxpayer), long-term

care often receives funding through multiple sources, including both national and regional governments (OECD, 2011). These multiple sources add even greater complexity to integrated funding arrangements.

While macro integration endeavours to bridge the gap between health care and long-term care, the interplay of power relations, resources and operational intricacies cannot be understated. Both the Northern Ireland and the Republic of Korea examples serve as reminders that mere structural adjustments, devoid of deeper systemic recalibrations, might not suffice. These examples also demonstrate the diversity of arrangements that can fall under this umbrella, but do not preclude the possibility of successful approaches to integration. The challenge lies in discerning how best to navigate these complexities for the betterment of care outcomes.

Meso integration does not require combined budgets, organisations and commissioning, but combines services and inputs from different sectors, organisations and disciplines. A multidisciplinary team comprising health and long-term care professionals is a useful example of this type of integration. Given the diversity of what this could look like in practice, it is not surprising that evidence about the benefits is inconclusive. In a recent systematic review, integrated health and long-term care interventions for older people improved wellbeing and satisfaction, but demonstrated an inconsistent impact on outcomes such as ADLs, IADLs, perceived health, physical functioning and quality of life (Looman et al., 2019). Despite this, there are examples that support arguments for the effectiveness of integrating health and long-term care services.

One such example is the Program of Research to Integrate Services for the Maintenance of Autonomy (PRISMA) in Canada (Hébert et al., 2010). The service is designed for frail older people at risk of functional decline and comprises six core elements: coordination between managers locally and regionally; a single point of entry; a single assessment instrument; case management; individualised care plans; and a computerised clinical chart. Quasi-experimental evaluations of this programme have produced promising findings. Lower rates of functional decline, unmet need, emergency department visits and hospital admissions were observed in regions participating in the programme compared to non-participating regions (Hébert et al., 2010).

Given the mixed evidence reported elsewhere, why has this approach in Canada produced more uniform benefits across health and health utilisation outcomes? A number of explanations are possible.

First, the remit of this integrated service is one that would benefit equally from input from both long-term care and health professionals. Promoting functional independence would be challenging without the involvement of long-term care experts, such as occupational therapists. There is therefore a rational pathway to impact, between the integration of health and long-term care professionals, and improved outcomes for older people. Second, in the evaluation by Hébert and colleagues, outcomes were clearly aligned to the service objectives. This is important to ensure that evaluations capture impact where it is most likely to occur. Finally, new service models take time to embed within systems of care. Short evaluation periods risk underestimating impact because new services have not yet had the chance to bed in (Kumpunen et al., 2019). Hébert and colleagues (2010) collected data over four years: this seems a reasonable period in which to expect to see change in older people's health and care as a result of the programme.

Micro integration reflects an adaptation of care processes that facilitates joint working protocols and information sharing in a way to support holistic care. One hypothesis is that this sort of integration could maximise the role of long-term care in preventing deteriorations in health. De Carvalho and colleagues (2017) argue that this type of integration is critical, as this is where clinical care processes can be tailored to promote older people's independence and wellbeing. Even so, evidence that these sorts of outcomes improve as a result of such integrated processes is inconsistent (Looman et al., 2019; Eklund & Wilhelmson, 2009). Furthermore, some have noted that these sort of joint working arrangements risk the medicalisation of long-term care (Carey, 2018).

Micro-level integration sometimes goes hand in hand with meso-level integration, when services are formally combined. A good example of this type of meso- and micro-level integration is England's National Health Service Vanguard programme (NHS England, 2016). With an investment of around £389 million across fifty localities in England, this large-scale programme aimed to lessen dependency on hospital care by shifting care into community and care home settings. Five different models were piloted between 2015 and 2018, in which services were reconfigured to offer greater integration of care and achieve the programme's aims. A key element of these pilot models was to enhance joint working across settings and disciplines.

The Vanguard programme represented a significant investment in care, but did it work? An evaluation published in 2020 indicated that Vanguards were successful in stabilising emergency admissions for care home residents, but made no difference to total hospital bed days (Morciano et al., 2020). Key learning from this ambitious programme highlighted the same sorts of challenges noted elsewhere in the integrated care literature: primarily, that joint working across health and long-term care is often impeded by professional boundaries, separate governance arrangements and different cultures of working between health and long-term care, as well as acute and community care (Maniatopoulos et al., 2020; NHS Providers, 2021; Stocker et al., 2018). These are the key lessons for policy moving forward with agendas to promote greater integration of care.

Summary

Let's revisit the question posed at the start of this section. Does integrating long-term care and health care offer benefits for the health sector and older people's health outcomes? A confident answer to this question is challenged by the diverse ways in which integration is operationalised, delivered and evaluated. Evidence from Canada demonstrates the value of integrated health and long-term care for older people, with a model of care that has a focused remit with tangible objectives. Similarly, the Vanguard programme in England offers some support for greater integrated working with care homes. Yet despite repeated calls for greater coordination of health and long-term care by patient populations, evidencing the benefits of integration is challenging. Furthermore, it is important to question the idea that integration of care produces a linear preventive impact on health and health care use. For example, Mason and colleagues (2015) argue that closer working between health and long-term care can identify unmet need. In turn, this may increase overall care costs in the short term, with reductions more likely observed over the longer term.

Perhaps the most important consideration for this question is not whether care integration works, but what happens if long-term care remains disjointed from health care. As Glasby (2017) points out, even if integrated care fails on certain metrics, the consequences for patients and their wellbeing are much worse when health and long-term care remain fragmented and poorly coordinated. When health and long-

term care operate in silos, patients often find themselves navigating a maze of services, leading to potential gaps in care and diminished overall wellbeing. In such fragmented systems, there is a risk of vital information being lost, of treatments being delayed, and of a lack of continuity in care. These challenges not only strain the health care infrastructure but also place undue stress on patients and their families. Thus, even if integrated care has its challenges, it is crucial to recognise that the repercussions of fragmentary health and long-term care systems can be far more severe for both patients and the broader health care ecosystem. The [following section](#) discusses how this was laid bare by the experience of Covid-19 in the United Kingdom.

7.4 Understanding the interface and divide between long-term care and health care: the experience of Covid-19 in UK

Following the Covid-19 pandemic, the lessons learned and the implications for policy are slowly emerging in the health and care literature. This section offers some early reflections on these experiences of Covid-19. Such reflections are in no way conclusive; at the time of writing, the pandemic was ongoing, and drawing firm inferences at this stage remains premature. Rather, this section aims to briefly summarise some of the key implications of the Covid-19 experience for understanding the relationship between long-term care and health care sectors, drawing on the example of the United Kingdom.

As many have noted, the Covid-19 pandemic highlighted the deeply divided and fragmented nature of the health and long-term care systems within the United Kingdom. High rates of infections and mortality in care home settings led to questions about the factors that account for this, and why care homes were particularly vulnerable to transmission. Daly's (2020) analysis of England's experience highlights the critical differences between health and long-term care in terms of their resourcing, infrastructure and cultural and political capital. Centrally funded and organised, with regulatory bodies, the NHS in the England was inevitably better prepared to respond to a pandemic than a long-term care sector that has been left underresourced. Multiple providers and comparatively poorer arrangements for regulatory oversight within long-term care added further challenges to the sector's ability to respond to Covid-19 (Daly, 2020). Daly's point about political value is also critical. Long-term care within England has often taken a back

seat to health care politically speaking; this became even more apparent during the pandemic. For example, personal protective equipment (PPE) was prioritised in health care settings while care homes received around only 10 per cent of what was needed across the sector (BBC, 2021).

More recent evidence further illuminates how a poorly resourced long-term care sector was hit hard by the pandemic. For example, higher rates of infections were recorded in care homes with more bank agency staff, higher occupancy rates and lower staffing ratios (Tinsley, 2020; Dutey-Magni et al., 2021). Poor workforce conditions likely contributed to the spread of Covid-19: low wages and inadequate sick pay meant that self-isolation came at a cost for care workers (Shembavnekar et al., 2021). The financial loss may have forced some care staff to remain working while infected or showing symptoms (McAnea, 2021). This is supported by some evidence that lower levels of infection were observed among care homes where staff received sick pay (Tinsley, 2020), although other workforce conditions will have also shaped this outcome.

Ultimately, it is clear that in the United Kingdom at least, Covid-19 exposed the fragility of the long-term care system. So what does this mean for understanding the relationship between long-term care and health care? To answer this, it is important to revisit an argument made earlier in this chapter. Health and long-term care needs are interdependent, and long-term care plays a key role in supporting older people's health. Yet to do so – not just adequately, but optimally – long-term care must be properly resourced. If anything, the Covid-19 experience demonstrated what happens when long-term care sectors are not adequately resourced. Perhaps most of all, the Covid-19 experience shows that the chronic political and financial neglect of long-term care is no longer a viable option.

7.5 Implications

The relationship between long-term care and health care can best be characterised by an interdependency that reflects the close link between independence and good health. The evidence explored in this chapter, while at times complex and heterogeneous, provides some support for the argument that, in addition to being a critical resource for older populations, long-term care can benefit health and health sectors. So what are the implications of this? Building on the arguments and evidence discussed, this section considers three questions:

1. What are the risks to health sectors of not developing long-term care for older populations?
2. What further evidence is needed to understand the relationship between access to long-term care and older people's health care utilisation?
3. What are the key empirical challenges and how can these be addressed?

1. What are the risks to health sectors of not developing long-term care for older populations?

Based on what has been discussed in this chapter, what would happen if governments chose not to develop long-term care sectors? The answer is simple. Evidence clearly shows a link between maintaining functional independence and good health (see, for example, the analysis of mental health outcomes presented in [chapter 3](#)). Inevitably, without long-term care to support older people's functional independence and wellbeing, the detrimental impact on health would be absorbed – successfully or otherwise – by already overstretched health sectors. Consequently, health care costs would rise, obliterating policy efforts to contain demand and expenditure.

Yet the focus should not solely – or even primarily – be on the cost implications of poorly developed, underresourced long-term care. A failure to develop and invest in long-term care will inevitably undermine efforts to support people to age with dignity and have a good quality of life. Hospitals are not designed for long-term care; nor are long hospital stays conducive to overall health and wellbeing. An absence of long-term care in community settings will also have broader societal consequences. Unpaid care often absorbs the unmet need resulting from insufficient coverage of paid services, with adverse financial, social and health impacts for those faced with increased care responsibilities.

2. What further evidence is needed to understand the relationship between access to long-term care and older people's health care utilisation?

To date, research about the relationship between access to long-term care and health care utilisation suffers from two key limitations. First,

evidence typically focuses on care home settings and secondary (hospital) care. Comparatively less research has explored the impact of long-term care delivered in home and community settings. Going forward, a greater focus on the role and impact of home care is important. This would not only address an evidence gap, but also ensure investment in long-term care is targeted appropriately.

The immediate challenge to this is that community support, particularly home care packages, are highly personalised and thus heterogeneous. Indeed, measuring the receipt of home and community care alone may be futile. Perhaps more worthwhile is a focus on the quantity, frequency, focus and quality of care delivered in home and community settings. These are important dimensions of care that could be critical for moderating health care use, and future work could explore these further. Such work could be supplemented by qualitative investigations to unpack the consequences for health care use, including comparisons between those who do and do not receive the community long-term care they need.

Second, research to date has focused on the implications for secondary health care, with a particular dominance observed for hospital admissions and bed days. These outcomes make sense, because this is where most of the impact might be expected. Primary and community health care is overlooked in the current evidence. Yet this is a key part of the health sector that could be optimised to support and integrate with long-term care – particularly in terms of preventive approaches and models. Future research could explore the relationship between long-term care and primary and community health care. This might include consideration of the impact on service utilisation and the ways in which care across these settings could be integrated to optimise support.

It is also worth noting that current approaches have yet to fully exploit comparative case study methods at country level to explore the relationship between long-term care and health care utilisation for older populations. Few long-term care sectors are developed and implemented with a clear before and after baseline, while diverse contexts (health sectors, socioeconomic and political) render robust comparisons challenging. Even so, where a full, wide-scale reform of long-term care is implemented, this offers a valuable opportunity to track health sector outcomes over time from the baseline, and where possible, to compare outcomes across similar contexts. Doing so would help to

elucidate evidence about the nature of the relationship between both sectors, and the mechanisms (prevention and substitution) underpinning this. A wave of reforms to long-term care has been instituted in Europe and elsewhere in the wake of the Covid-19 pandemic. This is a unique opportunity for policy makers at national and regional level to ensure that reform efforts are paired with evaluation and detailed research into the outcomes and impact of new models of care.

3. What are the key empirical challenges and how can these be addressed?

As noted earlier in this chapter, providing clear evidence about the relationship between access to long-term care and health care utilisation is challenging. Heterogeneous forms of long-term care and confounding influences are two of the key obstacles highlighted. Greater detail about the type, volume and frequency of care received within data may help to unpick some of this diversity in care. Similarly, collection of data on a range of important confounders such as expectations of care, unpaid care and financial resources would enable researchers to adjust for these within their analyses. These issues link to a wider obstacle: that there are limited data available from which to explore this topic. Administrative data and cohort studies form the two common data sources, but such data are not designed or optimised for exploring the relationship between access to long-term care and health care. Going forward, research on this topic would benefit greatly from more comprehensive data about the use of long-term care, including how usage changes over time. Finally, as indicated earlier, evaluations must accommodate the time it takes for new policies to bed in, and for initial investments to pay off. This is an important message for politicians, who may seek quick wins on shorter time scales to demonstrate value to the public. Tracking outcomes over longer periods will likely offer a more fruitful approach to evaluating and demonstrating the impact of long-term care on health and health sectors.

7.6 Conclusions

The health and long-term care needs of older people are symbiotic: when independence is maximised, good health follows. The relationship between long-term care and health care reflects this interdependency,

and underlines why strong long-term care sectors can potentially benefit health sectors. A further argument identifies long-term care settings as a substitute for health care, with the potential to lessen demand on hospital services.

While there are reasoned arguments as to why long-term care can benefit health outcomes and health sectors, evidencing this relationship is challenging. The heterogeneity of long-term care, data availability and a range of confounding influences are important methodological limitations to understanding this relationship. As such, our expectations of this evidence should be pragmatic. Certainly, some types of long-term care are linked with reduced secondary health care utilisation. Inconsistencies observed in other sections of this literature are not that surprising given the limitations discussed, but they underline the importance of concerted investment in robust evaluations to generate evidence from which more confident conclusions can be drawn.

Yet the risks of not investing adequately in long-term care are starkly evident. Without a strong long-term care system, working in close concert with health care services, the burden on health care services increases, and the quality of life for older people diminishes. The societal implications, from over-reliance on unpaid care to increased health care costs, further emphasise the urgency of the situation. Hospitals, while essential, are not equipped to provide the specialised care that many older people require. Furthermore, the reliance on unpaid care, often shouldered by family members, can have significant social, financial and health implications.

Critically, simply doing nothing with long-term care is far too risky. Investment in this sector is critical to maximising the enormous potential of long-term care for improving people's health and for upholding the efficiency of health sectors in the longer run.

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8

Sharing the burden: the impact of long-term care on the financial situation of families in Europe

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8.1 Introduction

Demographic ageing has increased the number of older people who find themselves in need of help and support with everyday activities, such as dressing or getting out of bed. As a result, public expenditure on long-term care in European countries is projected to almost double by 2070, according to projections from the European Commission, albeit in some cases from a very low base (ECOFIN/AWG, 2018). However these estimates do not consider the costs borne by users themselves or their families, nor is it clear that this increase in public expenditure will be sufficient to meet the needs of older people, or protect them from the risk of catastrophic expenditure arising from meeting those same needs. The need for long-term care tends to have a very high degree of uncertainty and the potential to be long-lasting (Forder & Fernández, 2009). Given the lack of individual private insurance schemes offered by the market and the actual costs of care, even middle-income groups would likely be unable to afford long-term care without the support of public welfare systems (Colombo et al., 2011, Oliveira Hashigushi & Llena-Nozal, 2020).

This chapter focuses on the costs of long-term care borne by users and their families and the related question of how much current systems protect individuals from the costs arising from care needs, and

what kind of policies are needed to insulate individuals from such costs. We focus on home care services – where the gap in the existing evidence on affordability of care is arguably greater – as it is widely acknowledged that persons in need of care overwhelmingly favour being cared for at home (Roy et al., 2018). Persons in need of care living at home also represent the majority of users of long-term care across Europe (Rodrigues et al., 2012). While decision making concerning the use of home care services is based on the users' wellbeing in the first instance, financial considerations also play a role and impact choices related to care arrangements.

Among the costs borne by users and their families are direct financial contributions to the costs of long-term care in the form of OOP payments. Across nearly all countries in Europe, some sort of OOP payments are required from users. These can correspond to the actual (or market) costs of long-term care for people who purchase services directly on the care market (e.g., because they do not meet the eligibility criteria for publicly funded long-term care). More commonly however, OOP payments refer to the contributions to the costs of public or subsidised long-term care that are required from users and are subject to varying rules and degrees of coverage for the actual costs of care (see Spasova et al., 2018; Oliveira Hashigushi & Llena-Nozal, 2020; and chapters 3 and 5 in this volume on eligibility and financing respectively).

OOP payments are often put in place with the goal of both increasing the financial resources for care and reducing moral hazard in the use of services (i.e. inefficient use of care services). An important consideration underlying such payments is that their amounts should be 'fair' by reflecting people's ability to pay across the income distribution. In most long-term care systems, OOP payments are regulated by the state and often vary with income or have exemptions for individuals with fewer financial resources, with only those with resources above a high threshold being required to pay the costs of long-term care fully out of their own pocket. This should make long-term care an eminently redistributive tool. However, despite some single-country studies which mostly focus on residential care costs, there is a dearth of information on the actual amounts of OOP payments and how they are distributed across population groups (see Hancock et al., 2013; Fernández & Forder, 2010; Rodrigues et al., 2022). The first section of this chapter provides a brief overview of the type of OOP payments that are in place for long-term care, distinguishing between income- and asset-based OOP payments as

well as those levied on family members, and existing evidence of their distributional impact. While the focus of the chapter is on home care, where relevant we also review evidence from residential care.

The lack of an internationally agreed definition for long-term care needs and diversity in long-term care systems (discussed in [chapters 3 and 4](#) of this volume) have hampered comparability of OOP payments between countries, apart from a few existing international studies using hypothetical or stylised cases (i.e. examples of different types of representative users) (Oliveira Hashigushi & Llena-Nozal, 2020). To bridge this gap, the [second section](#) of this chapter uses data from SHARE to estimate amounts and distribution of OOP payments for home care services across the income distribution of a varied set of European countries. This provides a first measure of fairness or equity by analysing whether OOP payments are disproportionately concentrated among individuals with lower financial resources. To assess the degree of protection from excessive costs that is provided by different welfare systems and provide an additional measure of how equitable OOP payments are (i.e. whether they place a disproportionate financial burden on people with fewer financial resources), we use the concept of *catastrophic payments* – out-of-pocket spending by users of services which are purported to cause some degree of financial hardship (Cylus et al., 2018) – and estimate their distribution across income quartiles. By using survey data rather than stylised exemplary profiles of need and household composition, we ensure the findings reflect the distribution of needs and payments in a given country (i.e. its representativeness) as well as the actual amounts paid.

As highlighted in [chapter 5](#) in this volume, the main source of care and support for a significant share of older people is not formal care providers but rather relatives or friends acting as informal carers (Suanet et al., 2013). This is particularly relevant for lower-income groups (Rodrigues et al., 2018). A significant share of families' contributions to the costs of long-term care therefore takes the form of *time* rather than OOP payments. A number of studies have attempted to attribute a value to this time or *in-kind* contribution from families (see Ekman et al., 2021; Del Pozo-Rubio et al., 2020), concluding that the value of informal care is at least as high as public expenditure on long-term care, even in relatively high-spending countries. While attributing a value to time spent caring, these studies often overlook the material consequences of informal care provision – in other words, they fail to consider the

financial impact of care provision on families, even if informal carers may draw on specific benefits in a number of countries. In the [third section](#) of this chapter, we therefore provide estimates of the additional financial impact for families arising from informal caregiving by applying the concept of *impoverishment*. The concept refers to the onset of poverty as a consequence of informal caregiving. We also present figures for carers that are *further impoverished*, which captures those families that are already below the poverty line and whose distance to the poverty threshold increases after taking up caregiving – i.e. families that become even poorer as a consequence of caring. We further estimate the impact on carers' employment and income resulting from transitions into informal caregiving.

Finally, a [concluding section](#) summarises policy implications from the findings, drawing on the institutional differences between systems and what these might reveal in terms of their influence on the financial impact of long-term care on users and their families (including carers).

8.2 Evidence of the impact of OOP payments on the financial resources of care users and their families

OOP payments are meant to contribute to the fiscal sustainability of long-term care while keeping demand in check, or at least curbing frivolous demand (moral hazard). Moreover, they may contribute to enhancing fairness, by making sure the contributions to costs reflect people's ability to pay, and equity, by ensuring that people with fewer financial resources do not contribute to a disproportionate share of costs (Mayhew et al., [2010](#); Colombo et al., [2011](#)). However, both care needs and equity are concepts that suffer from the lack of a fundamental definition and measurability, so that thresholds and eligibility criteria in the context of long-term care always contain a discretionary aspect. The challenge is to find a balance between setting the amount of OOP payments too high, which would lead to a high lack of take-up by certain groups in spite of their care needs, and having free long-term care at the point of delivery, which might lead to an extent of demand that cannot be satisfied by the system (Ikegami & Campbell, [2002](#); Ilinca et al., [2017](#); see also [chapter 5](#) in this volume). However, as financing patterns of long-term care have developed in the context of different welfare regimes, related characteristics have shaped the extent and scope of OOP payments. In general, it could be assumed that the

more universalist a welfare regime, the more ‘socialised’ financing of long-term care would be (i.e. financing will be spread across society rather than concentrated on users). This would mean that in Nordic welfare regimes, where there has always been a rather universalist access approach to care services, public financing based on progressive taxes would contribute to funding the largest degree of care costs, with OOP payments playing only a limited role even for those with higher resources. Likewise, the more familialist a care regime (i.e. more reliant on the family for the satisfaction of needs) (Saraceno, 2016), the more liability would be expected to be placed on the nuclear family, based on the principles of subsidiarity (i.e. that the state should intervene only after family support is exhausted) and social assistance (i.e. needs and means testing). In an ideal example of a familialist care regime, the state would only contribute to care costs if family members were neither able to provide care nor to pay for external services. These features are likely to underpin the specific rules governing OOP payments in each country. As a first step, governments define criteria for access and eligibility for public or subsidised services, including setting the income or wealth threshold beyond which users are expected to pay fully for their costs of care. Most countries have built their long-term care systems around this logic rather than on eligibility and access criteria that are needs-based only, such as in universal health care systems. OOP payments are therefore used in practice as a key mechanism to steer access and eligibility under the assumption that persons in need should contribute their fair share to their costs. Funding of long-term care is thus generally based on the principle of subsidiarity, where the state only steps in as a last resort (Morel, 2007).

Taking a broad definition of OOP payments to include those payments that contribute to the full costs of care, three non-mutually exclusive types can be distinguished:

- income-related OOP payments
- asset-based OOP payments, and
- OOP payments required from partners, adult children or other family members and heirs.

This section presents information on these several types of payments, how they are defined and applied in various countries, and the evidence of their impact on the financial situation of individuals and their families. Throughout, the focus is on care at home, supplemented by

information on residential care. The information presented here refers mostly to OOP payments for public or subsidised long-term care, while the reader should refer to the eligibility chapter for a discussion on access to such long-term care services.

Income-related OOP payments

Income-related OOP payments are intended to ensure that the individual user pays a proportional amount of their income towards the costs of long-term care; the general aim is to ensure that people pay an amount that is not in excess of what they can afford, since the amount varies according to income. In residential care, income-related OOP payments generally consider the individual's income (pension plus any other cash benefits such as cash for care allowances – see [chapter 3](#) on eligibility) rather than that of the household. Rules regulating OOP payments for residential care usually allow residents to keep only a minimum amount for personal expenses (pocket money or personal allowance). These personal allowances can amount to about 3 per cent of median income after costs are covered in Croatia, 20 per cent of pension income in Austria, more than 25 per cent in Iceland or around 30 per cent of the national minimum income in Slovenia (Oliveira Hashiguchi & Llana-Nozal, 2020). The low amounts of these personal allowances reflect the fact that individuals in residential care already receive (and pay for) board and lodging. Sweden stands out as having a flat cap on OOP payments in addition to regulations that either exempt or substantially limit the amount that can be demanded from low-income individuals (Karlsson et al., 2007). Similarly, a very low flat-rate cap on income-related OOP payments is in place in the Netherlands and as a result financial barriers to accessing residential care are limited. However, unlike Sweden, eligibility for nursing homes in the Netherlands is based not only on assessed need but also on the lack of availability of informal care, rather than on the financial situation of the household (Hussem et al., 2016). This may explain why lower-income individuals use a proportionately higher amount of residential care services even after controlling for the concentration of needs among this group (Tenand et al., 2020).

OOP payments for subsidised home care are typically income-related (i.e. their amount varies with income) in OECD countries with exemptions in place for lower-income individuals, while for users from higher

income quintiles the requested OOP payments may approximate market prices. As with residential care, income considered for the calculation of OOP payments for home care remains basically restricted to the individual (pension as well as cash for care allowances in countries such as Spain, Austria, France and Italy). In addition, entitlement to subsidised home care services is usually capped in terms of service hours and/or total OOP payments that can be charged to users (see eligibility chapter in this volume). Hours or amounts above such cap are then charged at their full cost. For instance, in Austria clients are charged about 1 per cent of their income (calculated as pension and cash for care allowance, both to a defined threshold) per each hour of care service, with a maximum of 60 subsidised service hours per month. As a result, a service hour may be charged at between EUR 10 (low pension and median level of care allowance) and EUR 36 (high pension and high level of care allowance), with considerable variation between Austrian regions. In France the beneficiaries of the *Allocation personnalisée d'autonomie* (APA) are charged an hourly price that depends on both the provider price and a co-payment rate that increases with disposable income. For instance, for individuals with an income below EUR 739 per month (2014), the co-payment rate is zero, while it reaches 90 per cent for those with a monthly income above EUR 2,945. The average monthly OOP payment for home care was estimated to be over one fifth (c. EUR 300 in 2011) of the average pension (Roquebert & Tenand, 2017). Such amounts, plus the cumbersome bureaucratic application procedures they usually entail, may entice users to seek other (cheaper) privately paid solutions, including the employment of a live-in migrant carer (Italy, Austria, Germany and Spain) (Schmidt et al., 2016).

There is still a relative dearth of research on the impact of OOP payments on households in connection with both home and residential care (see Hancock et al., 2013; Fernández & Forder, 2010; Cullen, 2007). The few existing studies however attest that OOP payments remain at exceptionally high levels for the majority of users. In the United States only 15 per cent of older adults could fund extensive home care from their income, as these costs would be similar to a place in a nursing home (Johnson & Wang, 2019). In reality about 63 per cent of home care users in the United States are fully paying costs from their own income alone (Janus & Ermisch, 2015), attesting to the limited number of people qualifying for public support. This suggests

that a high share of potential users may not be able to get the (home) care they need. A recent mapping of different types of OOP payments in OECD countries by Oliveira Hashiguchi and Llena-Nozal (2020) has shown that a number of countries have moved away from strictly means-tested approaches to these payments for home care. Rules governing such payments also have an important impact on how these are distributed across income quintiles. For example, a simulation based on the English system for residential care concluded that increasing the personal expense allowance – the amount one is able to keep after paying for residential care – would likely benefit the lowest three income quintiles the most and the highest quintile the least (Hancock, 2000), thus showcasing the equity implications of different OOP payment designs. Similarly, it is possible to conjecture that flat caps on OOP payments for residential care would mostly benefit middle or even higher income individuals.

In a broader perspective, research by Moody et al. (2019) suggests that income-related payments for services may actually represent only a small fraction of all care-related expenditure. Referrals to support services for medical conditions or functional impairments that are not reimbursed by health insurance, and specific assistive devices or home modifications represent a sizeable share of private expenditure for long-term care. Additional services such as snow removal, gardening or safety measures may have to be purchased in the market too, with related costs fully paid. In other words, the total costs borne by users will reflect what is covered (or not) by social protection systems, and it will often be necessary for the household or even the wider family to step in to cover additional costs which are not adjusted in light of an individual's income.

Asset-related OOP payments

Income is not the only indicator of financial ability to pay, especially among older people who may have accumulated substantial assets along their life course (Colombo et al., 2011). Against this backdrop some long-term care systems include assets (e.g., savings, investments and property) when determining OOP payments and/or eligibility for social assistance schemes, particularly in residential care. Such asset-based OOP payments stipulate various thresholds for the amount of assets that users need to put towards long-term care before being entitled to social assistance. An example of how asset-based OOP

payments function is the Fair Deal scheme in place in Ireland. People moving into residential care must pay 80 per cent of their ‘assessable income’ (i.e. regular income minus allowable deductions such as health costs) and in addition, if they own assets or property, another 7.5% per year on the value of their assets above a threshold of EUR 32,000, for a maximum period of 3 years. This time limit – in effect a cap on the total asset-based OOP payments that people may expect to pay – attempts to ensure that certain assets such as agricultural land and family-owned businesses are not further eroded in case of long stays (Robinson & O’Shea, 2010). Such caps on the total amounts one may expect to pay are however not always in place in asset-based OOP payments. These types of payment may also be described as an early inheritance tax affecting families with a member in need of long-term care, with a marginal tax rate that may amount to almost 100 per cent. Families may try to circumvent the risk of total exhaustion of assets due to asset-based OOP payments through in vivo transfers (i.e. gifts of living parents to their children with the aim of becoming eligible for subsidies) or early depletion of savings (Hancock et al., 2013). Asset-based payment systems thus usually examine these in vivo transfers (e.g., amounts and elapsed time since those transfers were made) as they may be included when determining the amounts to be paid.

Asset-related OOP payments are more relevant in residential care funding, even if it has been shown that demand for residential care is relatively inelastic to prices (Grabovski & Gruber, 2007). The tightening, reduction or even waiver of asset-related OOP payments may influence individuals’ and their families’ decision making to some degree, but evidence on the significance of specific factors that influence housing decisions of older people is scarce (Roy et al., 2018). One such example however is provided by the abolishment of asset-based OOP payments for residential care in Austria at the beginning of 2018, which caused demand for residential care to increase by around 10–12 per cent in that same year (Firgo & Famira-Mühlberger, 2020), although by 2019 the rate of increase had returned to earlier levels (Statistics Austria, 2021). This example shows that due to tight household finances and perverse incentives from public regulations, families may give more importance to financial considerations than to needs and preferences.

As mentioned before, asset-based OOP payments may lead to the depletion of assets or limit savings during the life course due to the uncertainty around the actual amount that will have to be paid. To

limit this uncertainty, the Irish Fair Deal scheme described above effectively places a cap on total lifelong OOP payments, thus allowing users and their families to plan ahead or smooth their consumption along their life course. However, the fact that the state still takes a financial interest in the estate has led in practice to many residents opting to pay fully out of pocket, with ‘Fair Deal residents’ confined to those with no or low assets. As the fees for self-payers are usually higher than those negotiated by public authorities for Fair Deal residents, it is likely that there is a fair degree of cross-subsiding from richer residents to residents with fewer financial resources – in particular, private for-profit providers try to compensate for low tariffs set by public purchasers by charging higher fees from self-payers.

Studies on the distributional impact of asset-based OOP payments are also scarce, but findings from studies on residential care in England and Austria show that these fall more often on lower- and middle-income individuals (Hancock et al., 2013; Rodrigues et al., 2022). These individuals have a higher probability of moving into residential care (and longer lengths of stay) due to poor health, while at the same time having insufficient income to cover the costs of care. This is particularly the case if exemption thresholds are set at a low level (Muir, 2017; Hancock et al., 2007; Simmons et al., 2020). In Austria for example before the abolishment of the asset-based payments, many low-income residents held assets in excess of the defined exemption threshold (between EUR 4,000 and EUR 12,000) and were therefore liable for substantial asset-based OOP payments (Rodrigues et al., 2022). While such payments are usually defended on fairness or equity grounds, given that wealth rather than income may better represent older people’s financial situation (Rodrigues et al., 2018), evidence thus suggests that this type of charge may disproportionately fall on the least affluent individuals, for whom affordability of residential care will hinge on asset depletion.

The alteration or waiver of asset-based OOP payments can influence care decisions to some extent as seen in Austria’s temporary abolishment of asset-based OOP payments, which led to a spike in residential care demand. Nonetheless, evidence on the significance of such financial factors in influencing care decisions remains limited. These asset-based OOP payments, while aimed at ensuring fairness, have been shown to potentially burden lower- and middle-income individuals disproportionately as the exemption thresholds may not adequately

reflect individuals' financial capacities. This necessitates further examination to ascertain the equitable distribution and impact of asset-based OOP payments in long-term residential care funding.

OOP payments required from partners, adult children or other family members and heirs

Families, adult children or other family members may also be called upon to contribute to the OOP payments of their ageing relatives. Such requirements reflect the distribution of responsibilities between the individual, the family and the state. For instance, in the Nordic countries with a more individualistic welfare system, partners or other family members are not required to contribute to the costs of long-term care at all. By contrast in France, eligibility for social assistance to cover the costs of residential care hinges on a stringent means test with recourse to first and second order heirs, including grandchildren and in-laws who have to reach agreement on how to divide the charges among themselves. If no agreement can be reached, local authorities step in to recompense the care home provider but may reclaim the amount paid from the resident's estate after their death. In Germany too a number of requirements for OOP payments from next of kin were recently simplified but not abandoned: since January 2020 adult children can be required to contribute if their gross annual income exceeds EUR 100,000 (Bundesregierung, 2020). The impact of such regulations is unfortunately not well documented either in economic terms, including public and private transaction costs, or in relation to intra-familial conflicts, decision making and financial impacts beyond the service user.

To summarise the issue of OOPs payments as a whole, flat caps on income-related OOPs payment may mostly benefit middle-class or more affluent individuals, while increasing exemption thresholds or personal expense allowances (i.e. how much of their income users may keep after paying for care) may be more effective in reducing OOP payments for individuals with the least financial resources. Asset-based OOP payments seem attractive from a fairness standpoint but evidence suggests they are regressive and mostly financed through the savings of less affluent users, or they force users to become impoverished before qualifying for social assistance. A lifelong cap on the amounts paid would likely go a long way toward reducing uncertainty and possible depressive effects of these payments on savings.

8.3 Financial burden of OOP payments on home care users and their families

As described in the [previous section](#), OOP payments are required from home care users across Europe although long-term care systems tend to afford some level of financial protection to users. These range from a ceiling or cap on the monthly fees paid, as in Sweden, Denmark or the Netherlands, to subsidisation of services subject to a means test or a limit on the uptake of subsidised hours in countries such as Austria, France and Belgium (Spasova et al., 2018; Rodrigues & Nies, 2013; Rodrigues et al., 2020). In addition, cash for care benefits may be provided to help individuals choose and afford the costs of home care (e.g., in Austria, France, Italy and Spain). The amount of such benefits may however fall short of covering all the costs of long-term care, which may require individuals to contribute out of pocket for their home care.

In this section, we assess the financial impact of OOP payments for home care across Europe, based on data from SHARE (a representative survey of older adults across European countries), as well as how this impact is distributed across different income groups. More specifically, we provide estimates for OOP payments made and their distribution across income quartiles, before calculating several measures of ability to pay, such as average OOP payments as a percentage of income and the prevalence of catastrophic payments for home care services. The distribution of these indicators across income quartiles is also analysed. The type of home care services considered include those providing help with personal care (e.g., getting in and out of bed) and domestic tasks (e.g., cooking), meals on wheels and other activities such as medicine management.

To this end, we used information on OOP payments by all home care users aged 65 and above across a number of European countries, pooling observations from waves 5 (2013) and 6 (2015) of SHARE. Equivalised household income is used for all calculations in the analysis and is computed based on all income components at the household level, divided by the square root of the household size. We used income rather than wealth as a measure of the resources available to older people as i) OOP payments for home care are overwhelmingly income-related; ii) catastrophic payments are typically defined in relation to consumption expenses or household income and not wealth; and iii) income is a way to provide a measure that is

comparable to the analysis carried out subsequently for informal care, which uses the concept of ‘at risk of poverty’ that is typically measured in relation to income.

Average OOP payments for home care across the income distribution

Public support for the costs of long-term care is often prioritised for individuals with lower income based on the principle that they tend to have not only higher care needs but also a lower ability to pay than higher income individuals (Oliveira Hashiguchi & Llana-Nozal, 2020). As a result, one would expect more affluent individuals to contribute more in absolute terms (i.e. as a sum of all OOP payments) and as a percentage of the costs of their long-term care, if not a higher proportion of their income. The data confirm this, in that the two upper income quartiles pay the most out of pocket annually for home care in absolute terms in most countries in the sample, with the higher income quartiles tending to pay at least twice that of the lower income quartiles (Figure 8.1). Notable exceptions, among others, are Sweden and Denmark due to the low caps on OOP payments that are in place in both countries.

Absolute amounts however do not provide a complete picture of the financial impact of OOP payments on home care users. Affordability or ability to pay is relative to the income an individual has and therefore varies across the income distribution (Muir, 2017). In examining the proportion of income paid towards home care by quartile, we find that the lower income quartiles (i.e. first and second) pay a larger proportion of their income across all countries, ranging from 5.6% to 20.4%, reflecting the disproportionate impact that OOP payments for home care have on these groups due to their lower average income and lower ability to pay (Figure 8.2). In comparison the average OOP spending on health as a share of final household consumption¹ for the 27 EU member states was 3.3% in 2018 (OECD, 2020). This resonates with previous research, in that low-income individuals are often the most exposed to substantial OOP payments despite the mechanisms in place to direct public benefits to them (e.g., social assistance), while those with higher incomes tend to be able to afford the costs of long-term care

¹ The measure is different from the share of equivalised household income that we use in this chapter and comparing both metrics should be done with caution.

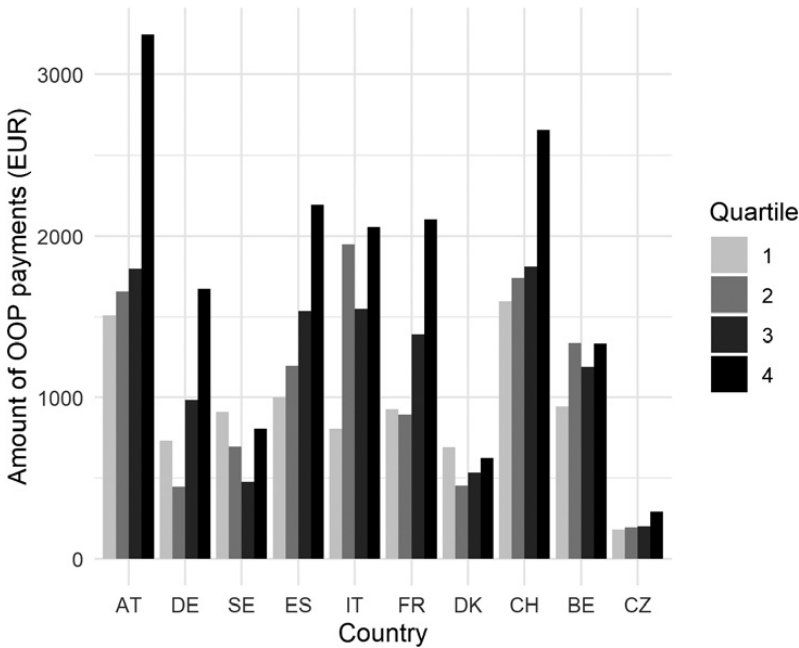


Figure 8.1. Average absolute annual amount of OOP payments (EUR) paid, by income quartile and country

Notes: All adults aged 65 and over using home care services. Countries: Austria (AT), Germany (DE), Sweden (SE), Spain (ES), Italy (IT), France (FR), Denmark (DK), Switzerland (CH), Belgium (BE) and Czech Republic (CZ). Equivalised household income (square root) adjusted for purchasing power. The first quartile represents individuals at the lowest end of the income distribution while the fourth represents those at the highest end. Weighted results.

Source: Own calculations using wave 5 (2013) and wave 6 (2015) of SHARE

on their own (Muir, 2017). This is especially the case given the lower level of income older adults tend to have in conjunction with the often high cost of home care services. In some cases, OOP payments can be so excessive as to push care users into poverty (Del Pozo-Rubio et al., 2020) with women, low-income groups and the very old being most at risk of financial ruin (Scheil-Adlung & Bonan, 2013).

Another way to assess how the average size of OOP payments and ability to pay are distributed across income is to calculate concentration indices (CIs) (see Box 8.1). The concentration of absolute amounts of

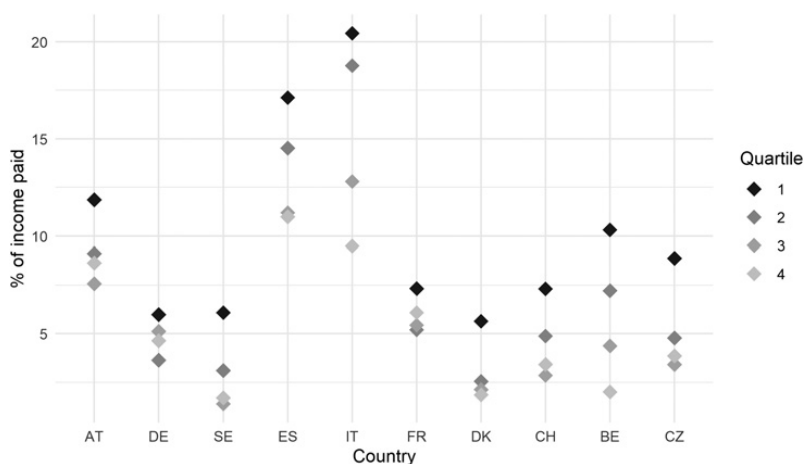


Figure 8.2. Percentage of income paid towards home care OOP payments, by income quartile and country

Notes: All adults aged 65 and over using home care services. Countries: Austria (AT), Germany (DE), Sweden (SE), Spain (ES), Italy (IT), France (FR), Denmark (DK), Switzerland (CH), Belgium (BE) and Czech Republic (CZ). Equivalised household income (square root). The first quartile represents individuals at the lowest end of the income distribution while the fourth represents those at the highest end. Weighted results.

Source: Own calculations using wave 5 (2013) and wave 6 (2015) of SHARE.

Box 8.1. Concentration indices

A concentration index (CI) is a measure of inequality where the concentration of one variable, for example OOP payments or use of home care, is measured across the distribution of another rank variable, often income or wealth. In our case, the CIs capture the concentration of OOP payments, the use of home care services and catastrophic payments across the income distribution. A positive value represents a distribution where payments/use are concentrated on richer individuals, while a negative value represents a distribution where payments/use are concentrated on individuals with lower financial resources.

OOP payments for home care among richer individuals is confirmed by the CIs displayed in [Table 8.1](#) (column 2), where for most countries the value of the CI is positive and for many it is also statistically significant.

Table 8.1. Concentration indices of distribution of home care use, OOP payments for home care and catastrophic payments by country

Country	Prevalence of home care users (percentage)	Home care use	Home care OOP payments (total amounts)	Catastrophic payments
Column		1	2	3
Austria	15.3	-0.053**	0.208**	-0.012*
Germany	12.9	-0.121***	0.157	-0.008
Sweden	8.7	-0.114***	-0.230***	-0.007**
Spain	12.1	0.004	0.275***	-0.006
Italy	8.8	-0.017	0.217***	-0.003
France	19.4	-0.120***	0.189*	-0.012**
Denmark	13.6	-0.217***	-0.365***	-0.017***
Switzerland	11.0	-0.104***	-0.022	-0.008
Belgium	24.0	-0.048**	0.074*	-0.021***
Czech Republic	9.0	-0.050***	0.002	-0.007**

Notes: * p-value<0.05, ** p-value<0.01, *** p-value<0.001. The p-value provides a measure of how likely it is that the difference from 0 is due to chance (example: if a p-value is <0.05, for a CI, it means that the probability of that CI being in reality equal to zero is less than 5%). Ranking variable: equivalised household income (square root). Weighted results.

Source: Own calculations using wave 5 (2013) and wave 6 (2015) of SHARE.

Notable exceptions to this are Sweden and Denmark where the absolute amounts of OOP payments are concentrated on people with the least financial resources, even if OOP payments represented a small share of these individuals’ income (even those in the first income quartile – see [Figure 8.2](#)). This is likely driven by two institutional features of the long-term care systems of these countries. Firstly, the relatively low cap on OOP payments in Denmark and Sweden limits the amounts paid, even by higher income users. Secondly, these systems prioritise provision of home care to lower-income users – as depicted by the CIs for home care use (column 1 in [Table 8.1](#)) – even after needs are accounted for (Rodrigues et al., [2018](#)), resulting in use being concentrated on

individuals with lower financial resources. These together pay a sizeable share of the overall amount of OOP payments, even if each individual pays only a small share of their income. Conversely, the very high concentration of these payments among the rich in Spain and Italy may reflect a relatively pro-rich distribution of the use of home care, although the estimate is not statistically significant.

8.4 Prevalence and distribution of catastrophic payments

Another measure of the impact of OOP payments on users' financial situation is the prevalence of catastrophic payments, a concept commonly used in the health care literature (Cylus et al., 2018), although still relatively novel in long-term care (see Del Pozo-Rubio & Jiménez-Rubio, 2019). We use the denominated *budget share method* in which OOP payments are considered catastrophic if they are above a certain threshold (or percentage) of the user's equivalised household income (Cylus et al., 2018) – in this case if they amount to at least 25 per cent of this income. This is also one of the thresholds used in the context of the United Nations' Sustainable Development Goals to assess access to universal health coverage. Given that some home care services may substitute for basic expenditure (e.g., meals on wheels for food and cleaning), this might be a more appropriate threshold for hardship than, for example, using 10 per cent of income. It provides in any case a lower bound for the prevalence of catastrophic expenditure given how significant 25 per cent of income is. The prevalence of catastrophic payments among the total population aged 65 and older is relatively low, ranging from 0.27% to 1.89% across countries (Figure 8.3a). However, the prevalence of catastrophic payments conditional on use of home care ranges between 2.5% and 19.6% of home care users across the countries considered, with lower-income individuals comprising the majority of these (Figure 8.3b). This means that once a person is in need of care, the risk of facing long-term care-related catastrophic expenditure can be quite high in Europe.

The impact of institutional context, namely the level of protection afforded by the state against costs for home care services, can be directly seen in the proportion of home care users experiencing catastrophic payments across the different countries. In the Nordic countries, where protection against OOP payments is generous with the state covering the majority of long-term care costs and where a low cap

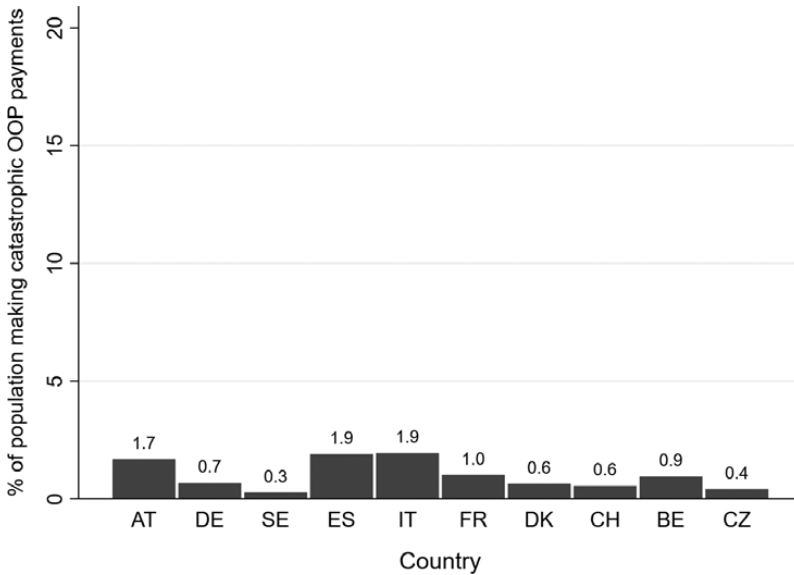


Figure 8.3a. Percentage of individuals experiencing catastrophic payments among those aged 65 and over

Notes: Catastrophic payments defined as 25% or higher of equivalised household income spent on OOP payments. Countries: Austria (AT), Germany (DE), Sweden (SE), Spain (ES), Italy (IT), France (FR), Denmark (DK), Switzerland (CH), Belgium (BE) and Czech Republic (CZ). Weighted results.

Source: Own calculations using wave 5 (2013) and wave 6 (2015) of SHARE

on OOP payments is also in place (Karlsson et al., 2012), only a minority of people are not insulated from catastrophic payments, although these are concentrated on the lowest-income quartile. At the other end of the spectrum, in countries with little or no such protection a substantial proportion of individuals paid 25 per cent or more of their income towards home care fees (e.g., Spain and Italy). This may also include individuals paying the full costs of care (i.e. buying services in the market) to circumvent poor availability of public services. As for the distribution of catastrophic payments, these are concentrated primarily on lower-income individuals in all countries (column 3 in Table 8.1), although not all of the CIs are statistically significant. The concentration of catastrophic payments is arguably higher among less well-off individuals in Belgium and Denmark, showing that even in

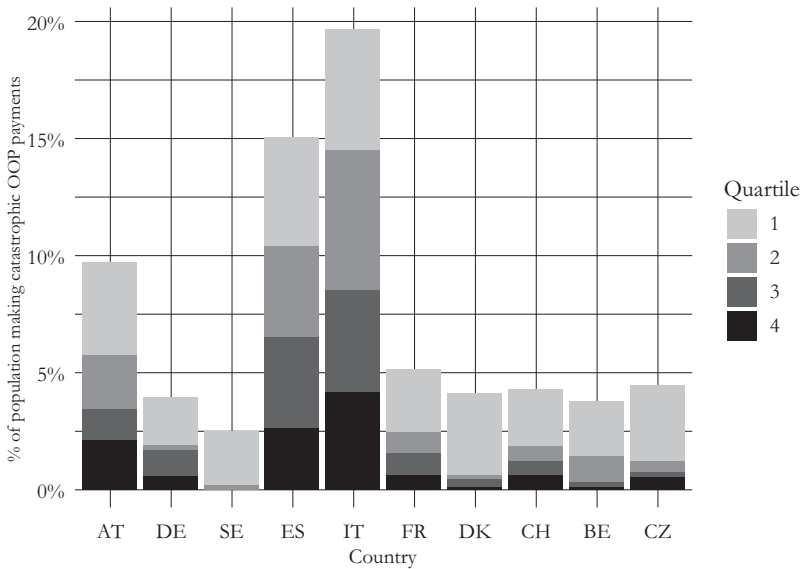


Figure 8.3b. Percentage of individuals experiencing catastrophic payments per quartile among those aged 65 and over using home care

Notes: Catastrophic payments defined as 25% or higher of equivalised household income spent on OOP payments. Countries: Austria (AT), Germany (DE), Sweden (SE), Spain (ES), Italy (IT), France (FR), Denmark (DK), Switzerland (CH), Belgium (BE) and Czech Republic (CZ). Weighted results.

Source: Own calculations using wave 5 (2013) & wave 6 (2015) of SHARE.

countries with generous long-term care systems lower-income individuals are at greater risk of catastrophic payments. This confirms the disproportionate impact that OOP payments have on lower-income individuals for whom costs of care can still be substantial despite means-tested social assistance (Muir, 2017). As shown in Table 8.1 and Figure 8.3b, Spain and Italy do not have such a concentration of catastrophic payments among the less well-off because OOP payments are also substantial for middle-income and even more affluent individuals.

From a policy standpoint, the findings indicate that despite means-tested eligibility rules and income-related OOP payments that increase with income, these payments still represent a sizeable share of the income of lower-income individuals. Low caps on income-related OOP payments could be an option as they seem to limit the prevalence of catastrophic

expenditure overall. However, OOP payments are still concentrated among those with low income even where such caps are present, because low-income households are more likely to utilise long-term care. There is also a clear interplay between accessibility of services and OOP payments: where supply of home care services is limited, OOP payments and the prevalence of catastrophic payments are high even for more affluent families. In such contexts, an improved supply of public or subsidised home care may bring about a reduction in these payments for families.

8.5 The financial impact of providing informal care on families

Caregiving generates a competing demand for time which may reduce the number of hours available for paid work. This is discussed more extensively in [chapter 10](#) with respect to the macroeconomic effects of long-term care needs on economic growth. Evidence on the impact of informal caregiving on employment seems to confirm this, although the effect is relatively small in size and heterogenous. Carers are on average 5–10 per cent less likely to be employed and they work less hours than non-caregivers (Lilly et al., 2007; Bauer & Sousa-Poza, 2015). These effects are concentrated among lower-income carers and especially on those providing intensive (i.e. longer hours) informal care. This reduction in labour supply may have a negative effect on earnings, although here the evidence is much less conclusive (Bauer & Sousa-Poza, 2015). In some countries, informal carers may receive social benefits that compensate for the loss of income, either provided directly to carers or as ‘routed wages’ passed on by the relatives they care for (Courtin et al., 2014). Nonetheless, the possibility of caregiving having a negative impact on carers’ financial situation is very real.

One way to assess this is therefore to estimate the impact of becoming an informal carer on employment and income, and consequently on risk of poverty. To this end, we used a sample of informal carers aged 50–64 years old from ten European countries drawn from SHARE. Taking advantage of the longitudinal characteristics of SHARE, we compared employment, equivalised household income and the risk of poverty² in the period immediately before and after starting to provide

² The poverty threshold for each country was anchored around the year 2011 and subsequently only adjusted for inflation for 2013 and 2015 (Eurostat, 2021a, 2021b). This approach enabled us to compare changes to the carers’ income with a constant level of real income, removing possible changes to the poverty

care for each informal caregiver, using waves 4 (2011), 5 (2013) and 6 (2015) of SHARE. Risk of poverty for each country is defined as having an equivalised household income below 60 per cent of the national median equivalised income (defined for a single person). In addition, we estimated how many carers became *impoverished* after starting to care and how many carers witnessed an increase in the gap between their income and the poverty threshold after taking up caregiving (*further impoverished*). Informal care is defined as someone providing personal care inside and outside the household or home help outside the household. This approach captures the short-term effect of informal caregiving and allows for some of the potential self-selection effect of individuals into caregiving to be accounted for³.

Effect of caregiving on employment and income

Data confirm that taking up caregiving leads to a reduction in labour market participation and earnings for a sizeable share of carers (Table 8.2). This reduction was mostly at the intensive margin as most carers that reported a downward change in labour supply reduced their working hours rather than dropping out of the labour market altogether. Across the sample of countries represented, exiting the labour market was reported by 8–10 per cent of carers. Only in Sweden and Switzerland was this percentage markedly lower, possibly denoting better opportunities to provide low-intensity informal care since affordable home care services are more readily available and users may thus combine informal care with care services instead of relying on full-time informal care alone (Bolin et al., 2008). Reductions in the number of hours were reported by close to one quarter of carers across our sample of countries. The relatively low percentage of carers that reduced labour at the intensive margin in Spain and Italy, as opposed to the higher percentages observed among the Nordic countries and Switzerland, reflects differences in the employment rates of would-be carers between countries (e.g., female employment rates,

threshold resulting from merely recompositing the income distribution in a given year or country (Atkinson et al., 2015).

³ Individuals may become informal carers because they are of low income or are out of the labour market in the first place, which would overestimate the effect of caregiving on such outcomes if observed only after caregiving has started. In other words, individuals may be impoverished when providing care because they were already of low income before taking up care and that was actually one of the reasons why they became carers.

Table 8.2. *Reductions in labour supply and equivalised household income after becoming a carer*

Country	Percentage of carers who stopped working	Percentage of carers who reduced their working hours	Percentage of carers who reported a reduction in income
Austria	8.6	22.2	46.2
Germany	9.0	21.4	46.4
Sweden	4.9 ^a	25.6	59.7
Spain	10.2	19.6	43.3
Italy	8.2	16.2	45.3
France	12.0	23.1	50.0
Denmark	9.1	26.6	49.4
Switzerland	6.4	33.9	39.5
Belgium	10.8	22.2	49.3
Czech Republic	9.5	21.7	48.3
Total	9.7	21.8	47.2

Notes: ^aLow sample size. Weighted results. Sample size refers to individuals that transitioned into caregiving roles between waves of SHARE. The ‘total’ refers to the overall figures for the countries considered.

Source: Source: Own calculations using wave 4 (2011), wave 5 (2013) and wave 6 (2015) of SHARE.

as women are the main group of carers in this age group) which already existed before taking up care. On average, carers that remained employed worked 8 hours less per week after starting informal care.

The reduction in labour supply, which affected about one third of carers altogether, contributed to a deterioration of their financial situation after the onset of caregiving (Table 8.2). For most countries included in the sample, between 40 and 50 per cent of carers reported a reduction in their equivalised household income immediately after

the onset of caregiving. This figure was even higher for Sweden, where close to 60 per cent of carers reported a deterioration of their financial situation. The magnitude of the income lost was also substantial: equivalised household income after taking up care was 35 per cent lower on average in comparison with the period before. It is worth pointing out however that increases in equivalised household income were also observed for some households. These increases in income mostly came from withdrawing savings (for 83.4% of carers whose income increased), some of which may have been intergenerational in vivo transfers received as a reward for care (Rodrigues et al., 2018). However only 5.2% of all carers reported such transfers after the onset of care⁴. Increasing labour supply of the spouse/partner (5.1%) or self (5.0%) and taking up of old-age pensions (3.9%) were other causes of increased income. Cohabitation, often referred to as being spurred by the care needs of older relatives⁵, was only reported by 0.8% of carers.

Effect of caregiving on risk of poverty

Despite a reduction in income observed overall, carers may still have sufficient income or, as just mentioned, they may be able to tap into savings to smooth consumption while caring. Yet at lower levels of income, even marginal declines in earnings can have an impoverishing effect, that is, they may cause people to fall below the poverty line. The impoverishment effect of caregiving is sizeable (Table 8.3, column 1), albeit with significant country differences. In Spain, Italy and the Czech Republic, between 11.4% and 12.0% of carers become newly impoverished after the onset of caregiving, while in Austria the impoverishing effect of informal caregiving is also relatively high at 8.5%. It is worth noting that this impoverishment effect seems the highest among countries that have cash for care benefits as the most prominent way to provide support for those in need of care. These are also countries with

⁴ SHARE asks interviewees whether they have received financial gifts or support of at least EUR 250 or an inheritance/bequest of at least EUR 5,000 in the previous 12 months. It is not clear whether these amounts include payments for care ('routed wages') or if these transfers are linked to care. Furthermore, the exact amount of these transfers is impossible to determine. This figure should therefore be interpreted with caution.

⁵ Depending on the individual incomes of household members, intergenerational cohabitation may result in a higher equivalised household income and further enable the routing of cash for care benefits to carers.

Table 8.3. *Impoverishment and poverty rates in connection with caregiving*

Country	Impoverished (%)	Poverty rate before caregiving (%)	Poverty rate after caregiving (%)
Column	1	2	3
Austria	8.5	23.1	21.5
Germany	5.8	13.5	13.9
Sweden	4.3 ^a	6.9 ^a	6.2 ^a
Spain	11.4	37.1	34.4
Italy	12.0	34.2	28.7
France	5.8	14.3	14.2
Denmark	5.5	4.9 ^a	6.4
Switzerland	5.1 ^a	5.6 ^a	5.6 ^a
Belgium	5.5	8.8	9.0
Czech Republic	12.0	32.5	26.0
Total	7.5	19.4	18.2

Notes: ^aLow sample size. Weighted results. Sample size refers to individuals that transitioned into caregiving roles between waves of SHARE. Poverty thresholds are anchored (2011) and subsequently updated for inflation only. Poverty thresholds used refer to 60 per cent of the national median equivalised income in the given country for a single person. The ‘total’ refers to the overall figures for the countries considered.

Source: Own calculations using wave 4 (2011), wave 5 (2013) and wave 6 (2015) of SHARE and Eurostat (2021a, 2021b) poverty thresholds and inflation rates.

a much more limited supply of formal home care (Austria excepted), which may hamper the possibility of combining care services with provision of low-intensity informal care while remaining employed (Rodrigues et al., 2013). In most of these countries, informal care is indeed of a more intensive nature (Bolin et al., 2008).

However, despite some households in all countries being newly impoverished after becoming caregivers (Table 8.3, column 1), the

overall effect of caregiving on the risk of poverty among caregivers varies substantially. We discuss this complicated phenomenon below.

First, it is important to note that poverty rates among would-be carers were highest in Spain, Italy, the Czech Republic and Austria even before they began to provide care (Table 8.3, column 2), despite the relatively high GDP per capita and relatively low poverty rates overall for some of these countries (Eurostat, 2021a). For example in Spain more than one third of informal carers were below the poverty line even before the onset of caregiving. In comparison, in Sweden, Denmark and Switzerland only between 4.9% and 6.9% of carers were in poverty before taking up care (although underlying sample sizes for these countries are small). This suggests important differences between countries in the types of individuals who provide informal care and highlights how in many countries it is those who are already impoverished who often take up caregiving. As a group, carers face economic difficulties that go beyond those arising from caregiving alone and a disproportionate share of carers were already struggling financially before taking up care. It indicates that people who already have lower incomes and may not be able to contribute to financing formal care services may be pushed into providing informal care.

Counterintuitively, in some of the countries with the highest overall rates of poverty among carers – Spain, Italy, the Czech Republic and to a lesser extent Austria – the rate of poverty among carers actually *reduces* after taking up care. This may well be a short-term effect explained by take-up of social benefits by previously unemployed people or only marginally employed carers who were previously living below the poverty line. Of note, these are all countries with sizeable cash for care benefits and so it may be that for some individuals, cash for care benefits help to lift them out of poverty. In the case of Austria, Germany or Italy, for example, there is no obligation to declare how cash for care benefits are spent, so it is not possible to identify specifically whether increases in income are coming from cash for care schemes. Cohabitation, which is often motivated as much by economic difficulties of carers as by filial duty to care for ageing parents (Gierveld et al., 2012), could be another possible motive for this, although changes in cohabitation seem to be marginal in our sample.

At the same time there are many households where the financial situation deteriorates after beginning to provide care. Indeed, Sweden, which has very low poverty rates among individuals before

taking up care, reported the highest share of informal carers that saw their income decrease because of care (Table 8.2). About 4.6% of carers in the SHARE sample overall became further impoverished – that is, were already impoverished before taking up care and their equivalised household income moved farther away from the poverty threshold after starting to care⁶.

The main policy message arising from these findings is the precarious financial situation in which many carers find themselves even before taking up care. For many this is exacerbated by the sizeable reductions in labour market participation observed immediately after starting to care. Income-maintenance policies for carers therefore seem like a key priority and among these, policies that would expand some access to services and thus allow carers to continue some paid work. Conversely, cash for care benefits, which are partially meant to provide such income support, seem to have an overall positive impact although many people seem not to benefit from them perhaps due to eligibility criteria. Countries where these are in place have, on the one hand, a high share of people who became impoverished after starting to care but on the other hand, they also have many carers lifted out of poverty after taking up care.

8.6 Policy implications and conclusions

The need for care is clearly associated with financial hardship for users and their carers in Europe. For users, this is connected with high OOP payments when accessing care and/or from the need to spend down their savings – in effect diminishing their socioeconomic standing – in order to qualify for long-term care services. Income-based OOP payments and means tests alone seem unable to protect users from catastrophic payments as shown by our findings. Data does not afford us definite conclusions, but this seems to stem from the following (non-exclusive) factors: i) potentially high eligibility thresholds to qualify for affordable long-term care in systems that still make access dependent on resources of users; ii) poor targeting of income-related OOP payments rules (e.g., OOP payments for home care mostly do not have personal expense allowance guarantees in place); and iii) limited

⁶ Limited sample sizes do not allow for a breakdown of further impoverishment by country.

availability of public or subsidised home care services, requiring families to seek alternatives at full market prices (Geerlings et al., 2005). The latter is relevant for countries with less developed long-term care systems outside of Europe. Although beyond the scope of this chapter, the limited protection afforded against high costs of care could also lead to unmet care needs, as older adults forgo services due to lack of funds. As unmet needs are unaccounted for in our analysis, it is likely that the unaffordability of home care is underestimated here.

Care needs of relatives also spell increased financial hardships for carers, namely through reduction in employment and income as a result of informal caregiving. The estimates presented in this chapter show that the effect can be quite substantial, although the resulting impoverishment of those that transition into informal care is somewhat limited. On the one hand, poverty rates among carers do not seem to be too affected by the onset of caregiving, perhaps as a result of the amounts provided in cash for care benefits (Huber et al., 2009). On the other hand, carers both before and after taking up care are at an increased risk of poverty relative to the wider population, especially in countries considered to be familialist (Saraceno, 2016). This finding nonetheless calls for policies that are able to ensure carers a living care wage that current social benefits are apparently unable to do. The correlation between caregiving and poverty has been highlighted before (Eurocarers, 2018), albeit with the qualification that many carers are already impoverished before taking up care. The figures reported here seem to confirm this. The existence of poverty prior to care among caregivers only reiterates that their vulnerable economic situation stems from life-course trajectories for which care is only a supplementary factor (Carmichael & Ercolani, 2016). Nonetheless, if informal care can be considered as an in-kind subsidisation of long-term care by families, it seems clear that this subsidy is disproportionately being paid by lower-income individuals.

Data reported in this chapter capture only the short-term or immediate impact of caregiving on the financial situation of informal carers. It is very plausible that as time evolves this represents the lower bound of this impact. For example, research has shown that the negative impact on wages from caregiving likely increases with time (Bittman et al., 2007), thus producing a scarring effect on earnings over the life course akin to that observed for unemployment in early youth (Genda et al., 2010).

Another example of the potential deferred impact of caregiving is how the loss of or diminished earnings may impact pension rights. As a review of care policies in Europe documented, pension rights associated with caregiving are still absent in a number of European countries (Courtin et al., 2014). Even if caregiving is temporary, it may have a detrimental effect on the health of caregivers (Bauer & Sousa-Poza, 2015) and thus hamper their chances of returning to the labour market or lead to early onset of long-term care needs for themselves. A number of carers in our sample reported an equivalised household income above the poverty line, or even an increase in their income, because of liquidation of savings – in a parallel with the spending down of assets to qualify for care from users. These savings may eventually be depleted and land those carers in poverty and/or be unavailable later on in the carers' life cycle to smooth consumption in their old age (e.g., when they find themselves in need of care). These longer-term effects of caring are particularly worrying for countries with less developed long-term care systems where informal carers are still often the only providers of care.

The findings presented here show the sizeable contribution that users and their families make towards long-term care costs. It exposes the reasoning that such contributions, especially from informal carers, may be seen as a free good and highlights the potential for paying catastrophic payments and/or falling into poverty as a result of needing long-term care that still permeates the experiences of older people and their carers in Europe. Closing this gap in social protection among the wealthiest countries in the world is another powerful case for investing in public long-term care systems.

8.7 References

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9

Does a strong long-term care system benefit societal wellbeing?

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9.1 Introduction

The purpose of this chapter is to demonstrate how a strong long-term care system can positively impact the wellbeing of society as a whole, beyond the individual older or person with disability receiving care. There has been some criticism of the current public funding of long-term care. It has been argued that the long-term care system is a selective system that benefits a limited segment of the population, even as the number of older people increases. Furthermore, because the primary recipients of long-term care are older people and people with disability, it is often perceived as a costly welfare system that burdens the current generation and society as a whole, rather than being invested in the public interest or the common good of society (Brunk, 1998; Nicholson, 2014). This chapter attempts to challenge this understanding and highlights the positive and proactive social impact that a strong long-term care system has on society as a whole and its members. The arguments in this chapter could provide another important justification for individual countries to actively invest in their long-term care systems.

Before explaining how a strong long-term care systems positively impacts social wellbeing, the characteristics of such a system as focused on in this chapter have to be described. These characteristics can be seen as prerequisites for a long-term care system to have a socially beneficial impact.

- First, it is a sustainable system that is publicly funded, universally accessible and affordable to all. In this regard, it is important that the long-term care system is integrated with the existing universal health care system in order to be sustainable.
- Second, it is an equitable system that responds to and meets the needs and demands of its users, while paying attention to supporting the needs of caregivers. In this regard, in order for a long-term care system to be equitable, it is important for it to focus on person-centred care

for individuals who benefit from the care rather than focusing on the service structure itself, and to promote the working environment of caregivers and give them due recognition.

- Third, although the state is ultimately responsible for building and implementing a long-term care system, a democratic system should be introduced, operated, evaluated and fed back on from the municipal to the national level by various stakeholders involved in the system, including care recipients, caregivers, institutions, communities, the market, civil society and the state. In order for a long-term care system to be democratic, it is crucial to have a cooperative community-based system that collaboratively involves various stakeholders – including both care recipients and providers – in the decision-making process and operation of the system.

This chapter examines the positive impact of a strong long-term care system on social wellbeing from three perspectives: social justice, social solidarity and social innovation. A strong long-term care system can contribute to mitigating persistent and entrenched care inequalities (social justice), foster social relationships and solidarity among citizens beyond direct care giving and receiving relationships (social solidarity), and enhance society's capacity to create new solutions to pressing social problems (social innovation).

9.2 Contribution of long-term care to social justice

A strong long-term care system can contribute to the promotion of social justice. Social justice consists of a set of norms and values that vary from culture to culture and context to context. A strict definition of social justice is not provided here. Instead, the concept of social justice will be approached by utilising Joan Tronto's (2013) discussion to help us understand social justice in the context of care-related issues.

According to Tronto one of the major injustices in society is the vicious cycle of care inequalities. This is a persistent cycle of inequalities, where care inequalities are linked to other inequalities in society – a vicious cycle where inequality begets inequality. In other words, economically disadvantaged people are generally less likely to have equal access to care, and when they lack equal access to care, they are more likely to be in a disadvantaged economic position. For example, children from socioeconomically disadvantaged families are less likely

to receive adequate care, and children from these families are more likely to have a lower socioeconomic status when they grow up than children who receive adequate care (Blossfeld et al., 2017).

Long-term care for older adults is no exception to this vicious cycle. As people age, become frail and lose the core functions and capabilities needed to maintain their daily lives, they will need some form of long-term care. If these needs are not met by informal care from family and friends, older people will need to purchase professional care services which can be quite expensive. Of course, the cost of long-term care will vary depending on the level of dependency and care needs of the individual. However, in the absence of public support, the cost can take up a significant portion of an older person's income. This creates a barrier to accessing care for those with fewer financial resources, and the expenses involved can result in their being unable to meet other needs, deepening inequalities in the process.

For example, recent data for twenty-six countries and subnational areas in the OECD and European Union show that the total cost of reported long-term care is, on average, between one-half and five times the median disposable income of individuals over retirement age (OECD, 2020; Hashiguchi & Llana-Nozal, 2020). For a low care need of 6.5 hours of care per week, the cost of long-term care would be equivalent to 60 per cent of the wages of a low-wage older person. For moderate care needs, requiring 22.5 hours of care per week, the cost of long-term care is more than twice the disposable income of someone in the lowest quintile (20 per cent) of the senior income distribution. In this case, only the wealthiest older people would be able to rely on income alone to cover their total care costs. Those with particularly high care needs require an average of 41.25 hours of care per week, and while it varies by country, long-term care costs are reported to be up to six times the median disposable income of retired individuals. In general, long-term care costs are a significant financial burden for older people who do not have sufficient savings.

More importantly, the vicious cycle of care inequalities that Tronto notes is not only linked to and reinforced by economic inequality, but also by inequality in other areas of society. Furthermore, this vicious cycle of inequalities extends beyond care recipients to the status of caregivers and their families. For instance, an economically vulnerable person is not only less likely to have access to care, but also less likely to receive quality care. According to WHO, LMICs not only lack

a universal health care system, but the quality of health care their citizens receive is often poor, which is one of leading causes of death in these countries. Each year, 15 per cent of all deaths in LMICs are attributable to poor quality of care (WHO, 2020).

Due to the high cost of long-term care, family members may provide informal care. This tends to reduce the family's quality of life and undermine the family economy. As many studies have shown, family caregivers experience a variety of mental, emotional, physical and economic burdens. Family caregivers speak of a range of depression and mental stresses, including worry about the health of the care recipient, psychological strain from the caregiving situation, as well as social isolation and feelings of inadequate recognition of their work by others (Coe & Houtven, 2009). They are also more likely to experience physical strain from caregiving, which can lead to the development of various chronic diseases such as back and neck injuries, high blood pressure and muscle pain (Zacharopoulou et al., 2015). This of course has knock-on effects in terms of need for health care and associated costs both to individuals and families and to health systems.

In addition, in many cases caregivers are more likely to quit their jobs or reduce their hours of paid work to provide care, leading to losses in the family economy (Nguyen & Connelly, 2014). For example, Choi and Ahn (2019) find that in the Republic of Korea, informal family care reduces family caregivers' probability of working by an average of 16 per cent and their annual hours worked by about 14 per cent. Even if they do not leave the labour market entirely, family caregivers may have to reduce their hours or take time off work more often due to care responsibilities and are more likely to endure disadvantages such as lower wages and slower promotions (Yamada & Shimizutani, 2015; Bauer & Sousa-Posa, 2015). In addition, family caregivers often have little time for socialising with friends, coworkers, family and relatives, which limits their social interactions and reduces the quality of those interactions (Amirkakanyan & Wolf, 2003). Existing research suggests that as many as two-thirds of family caregivers give up time for social interaction, personal development and leisure to fulfil their caregiving responsibilities (Cranswick & Dosman, 2008).

When family caregivers are adolescents or young adults, the financial challenges they and their families face and the burdens they place on their futures are even greater. As the majority of young caregivers are young people with limited earning capacity, they struggle to meet the

costs of living, household labour and health care while providing care (Brimblecombe et al., 2020). With the majority of their time and effort devoted to caregiving and their livelihoods, young caregivers lack the time and financial resources to prepare for and invest in their future. In Canada, the school absenteeism rate for young caregivers is as high as 10.8% (Stamatopoulos, 2018). Research from the United Kingdom also shows that 56 per cent of young caregivers at university say that family caregiving interferes with their academic performance and that they are unlikely to complete their studies (Sempik & Becker, 2014). This creates a vicious cycle in which young caregivers lack time to invest in their future and develop themselves during adolescence, which increases the likelihood that they will remain in poverty in the future.

A strong long-term care system, on the other hand, would provide universal and decent care for all older people with care needs. All older people, regardless of poverty, would have equal access to a certain level of quality care provided by the system. The effectiveness of the system could result in socioeconomically disadvantaged older people receiving more social protection. For example, data for OECD countries show that in countries with higher total public long-term care expenditure, older people tend to be at lower risk of poverty, as their long-term care needs are officially recognised and they receive public support (Hashiguchi & Llana-Nozal, 2020). The data above should be taken with caution, as not all public long-term care spending is used to provide care. But it seems relatively clear that public social protection systems in countries that spend a larger share of GDP on long-term care tend to reduce the expected risk of poverty associated with long-term care needs more than those with lower public expenditure (Hashiguchi & Llana-Nozal, 2020).

Many other studies also report how a strong publicly funded long-term care system has positive impacts that extend beyond the care recipient to caregivers and family members. Following the introduction of universal long-term care insurance in the Republic of Korea in 2008, a survey of older people, primary family caregivers and family members who used the system found that a high proportion reported that their functioning and psychological and emotional state had improved after using the system: for in-home services, 30.6% of primary caregivers reported that the older person's physical condition had improved, and 41.6% reported that the older person's psychological and emotional

state had improved. Many primary caregivers reported that their caregiving burden had decreased in terms of the physical burden (80.3% of respondents), psychological burden (81.2%), social burden (47.3%) and economic burden (39.1%). Many also reported that family relationships had improved after using the programme due to increased trust between the older person, the primary family caregiver and other family members: 32.2% of respondents reported improved relationships with other family members when their spouse was the primary caregiver, and 52.4% when their adult child was the primary caregiver in in-home services (Choi et al., 2011).

In sum, inequalities in care are linked to and reinforce not only socioeconomic inequalities for care recipients, but also socioeconomic and psychological, emotional, physical and temporal inequalities for caregivers and their families. A strong long-term care system, however, can have the effect of weakening this vicious circle of care inequalities. Beyond meeting the care needs of older people and people with disabilities, it can make an important contribution to social justice by arresting the vicious cycle of inequalities perpetuated in society.

9.3 Contribution of long-term care to social solidarity

Social solidarity is a difficult concept to define: some see it as collective action in pursuit of a common purpose and value, while others see it as a historical concept that was fundamental to the creation of the welfare state in Europe (Douwes et al., 2018; Weale, 1990). In practice, social solidarity manifests differently in different countries and societies. Despite this diversity of concepts and manifestations, at its core social solidarity is about relationships – about fostering relationships among citizens. These relationships are based on empathy and responsibility for other vulnerable citizens in need, and trust between interdependently connected citizens. A strong long-term care system can make an important contribution to fostering broader social solidarity based on empathy, responsibility and trust among citizens, beyond direct caregiving relationships.

First and foremost, care is a relationship (Ruddick, 1995). It is a relationship between a vulnerable care recipient and a caregiver who cares for that recipient. The health and wellbeing of the care recipient is directly dependent on the caregiver's role in providing biological and psychological care to them. In this sense, the relationship

between care recipient and caregiver is one of power asymmetry. However, in a good caregiving relationship this power asymmetry does not become hierarchical or dominant (Kittay, 1999). For example, in a typical caregiving relationship such as a parent-child relationship, the parent (caregiver) has an asymmetry of physical, mental and material power over the child (care recipient), but the parent does not dominate the child and enables the child to survive, grow and learn. In this respect, good care from the perspective of the care recipient can be seen as a state of empathy and responsiveness to one's situation and needs, as well as responsibility and trust for each other, rather than the perfect performance of any care function per se.

Therefore, a good care relationship is one in which there is empathy, responsibility and trust for each other. The caregiver must empathise with the vulnerability of the care recipient and take responsibility for meeting their needs. Conversely, the person receiving care must trust that the person providing care will fulfil their responsibilities in caring for them and will not abuse that power and responsibility. This empathy, responsibility and trust in a care relationship is primarily formed and maintained through interpersonal relationships in the personal sphere, such as parent-child relationships or relationships between friends. Importantly, however, the experiences of empathy, responsibility and trust that are nurtured in care relationships can be a significant resource for the strengthening and extension of social ties (Held, 2007).

For example, Kathleen Lynch proposes a category of care networks as 'circles of care' (Lynch, 2009). The circle of care shows that, just as primary and secondary care relationships are other-centred relationships of love and care, tertiary care relationships with others can also be other-centred relationships of solidarity. Primary care relationships are personal and intimate, such as parent-child relationships; secondary caregiving relationships are those involving the outside world, such as relatives, friends and coworkers; and tertiary caregiving relationships are those with others at the national and international levels that do not require a personal or intimate relationship. According to Lynch, while relationships in these three circles of care may have varying degrees of empathy, responsibility and trust, she argues that other-centred solidarity based on these three characteristics is possible even in tertiary care relationships. An example of this solidarity is when citizens participate in campaigns to improve welfare services for homeless people or migrants who do not seem to have a direct relationship with them.

Expanding the network of care relationships can be accomplished through the operation of the 'care imaginary' (Groves, 2014). This is the moral and emotional capacity to extend and transfer the feelings and experiences of giving and receiving care to others in similar situations. It is imaginary but derived from the universal experience of care that each person has had in their own particular life. Thus the care imaginary involves the moral capacity and attitude to feel a sense of bonding and solidarity with other members of society who are excluded, threatened and oppressed, based on relational experiences with vulnerable human beings (identified as my child, my parent and my neighbour), who have been the objects of my affection and attachment in my own life. Thus feelings of compassion for one's child, parent and neighbour (not traditionally considered as private) can be the driving force behind civic attitudes that can be communicated and extended socially. For example, the care imaginary, derived from the experience of giving and receiving care, leads one to understand oneself in relation to others not as an indifferent individual but as a being connected in the circles of care, which in turn leads to a sense of solidarity based on empathy, responsibility and trust for vulnerable others. In this case, a citizen with a sense of solidarity can advocate for welfare services that support an older stranger living alone, or demand changes to the welfare system to support a child with disability in the neighbourhood.

Social solidarity among citizens can be a trigger and guiding principle for public welfare systems, as is the case in Europe. At the same time however public welfare systems, including a long-term care system, can also contribute to strengthening social solidarity. If caregiving is institutionalised, that is, if caregiving goes beyond informal types of care relationships such as caring for one's family members and friends to state-wide institutionalisation such as a long-term care system, then empathy, responsibility and trust in care relationships can be further extended socially. Certainly, empathy, responsibility and trust are primarily formed and maintained through private relationships but, as ter Meulen (2017) significantly points out, when interpersonal solidarity can flourish when supported by social care based institutions, it can expand and flourish into social solidarity with the institutional support of a long-term care system.

Ultimately, social solidarity means that citizens care for, trust, support and depend on each other through an institutionalised network of care relationships. However, it can be very difficult to specifically

characterise the type of social solidarity based on a long-term care system as opposed to that caused by a long-term care system, or to compare and measure the degree of social solidarity (Rusu, 2012; Lomazzi, 2021). The characteristics of solidarity developed via long-term care can also be very diverse. The easiest and most representative form of social solidarity based on care relationships is where citizens become good neighbours, providing each other with various types of mutual resource. For example, running errands for a sick neighbour, climbing a ladder to change a neighbour's light bulb, picking up a neighbour's parcel, clearing snow, holding onto spare keys, watering a neighbour's flowers or taking care of a neighbour's pet are all various examples of being a good neighbour (The Care Collective, 2020).

Numerous examples of the network of care relationships being extended to good neighbour relationships can be observed, creating various forms of citizen networking. A care-based community leads to various collaborative associations and cooperatives involving residents, such as gardening communities, workshops and cooking classes (The Care Collective, 2020). In Japan, long-term care insurance was institutionalised in 2000 and the general community support system was established in 2005. The latter is a community-based care service system that provides medical care, nursing care, disease prevention, housing and livelihood support to older people so that they can live out their lives in their own communities. As part of the system, more than 4,600 government-run general community support centres have been established across the country. The purpose of the centres is to provide comprehensive and continuous support for older people, such as care services, living support and medical care. Thus local older people with long-term care needs and their families can easily connect with and receive help from nurses, social workers and care managers who provide professional welfare services, medical care and personal care. In this respect, the general community support centres play an active role in establishing and supporting a systematic care network for older people and residents to connected with each other (Ministry of Health, Labour and Welfare, 2019).

Another specific example of care networks spreading and promoting social solidarity is the *Yeomindongrak* ('Sharing enjoyment with ordinary people') community in the Republic of Korea (Kim & Shim, 2015; Jeon, 2020). This community appeared in 2008 in a small village in South Jeolla Province. At that time the village was ageing and underdeveloped,

with the population aged 65 and over accounting for nearly 40 per cent of the total. The *Yeomindongrak* community started with the establishment of a *Yeomindongrak* welfare centre for older people by three couples returning to the area with the purpose of offering revitalised community-based activities to support the daily life of older people living in the area and to improve their quality of life. The *Yeomindongrak* welfare centre offers various care activities for older people based on the long-term care insurance system that has been in operation in the Republic of Korea since 2008. For example, a typical day care service provides for older people with reduced mobility, while a rice cake factory and a bakery have been opened for the older people to run as an activity to meet the demand for work and to earn an income.

In addition to caring activities for older people, various community activities have been introduced. A typical example is the local quarantine and disinfection project. Due to Covid-19 the village needed to regularly disinfect not only public areas but also individual living spaces. With the support of the local government, the *Yeomindongrak* welfare centre carried out disinfection work down to the smallest detail in the area, including the yards and barns of the members' homes. These quarantine activities created an important opportunity to communicate with local members, understand the needs of the village and establish a communication link. Village welfare events are held for members, such as a *kimchi* sharing event, and residents take part in weekend safety activities in connection with local high schools. At the same time, community efforts to revive a local elementary school which was in danger of closing was an important activity that emphasised the importance of the local community for the residents.

All of these community activities and projects have been guided by the opinions of the residents and the needs of the community. The various projects carried out by the *Yeomindongrak* community have been made possible by the active participation of older people and local residents. In fact, local older people act as social service providers rather than solely as beneficiaries of social services. In addition, the *Yeomindongrak* community has strengthened social relationships by offering relationship-making activities for local residents who do not otherwise participate in community activities and by forming relationships with other local community welfare and community organisations. According to a representative of the *Yeomindongrak* community, care activities require expertise, but ordinary residents and

communities lack this, so relational competencies between citizens must be improved. The representative noted that creating a structure where members can help each other and engage in regular interactive activities with local specialised institutions can improve expertise. Since 2020 major community projects such as the welfare centre for older people (which offers a day care service), bakery and rice cake factory have been converted into social cooperatives in which all villagers participate as members.

To sum up, the relationships among citizens, which are at the heart of social solidarity, can be promoted and strengthened in a variety of ways. A long-term care system, as well as other social care systems, can contribute to creating and enhancing connections among citizens. In a society with well-organised care systems and institutions, there is more empathy, responsibility and trust for each other, which leads to the creation of various networks of relationships and associations that broaden and strengthen the network of mutual benefit. This in turn helps to strengthen the institutionalised care systems.

9.4 Contribution of long-term care to social innovation

Given the conceptual definition of social innovation as the creation of new solutions to social needs that are not being addressed in existing ways, a strong long-term care system has the potential to create new and better alternatives and practical solutions to the social needs at hand (The Young Foundation, 2012). Because long-term care is primarily targeted at older people and people with disabilities, and because of the high public costs of supporting a long-term care system, long-term care is often misunderstood as a system with narrow benefits and as a costly system that erodes the capacity of society. On the contrary, a strong long-term care system can promote overall social capacity by addressing previously unmet social needs in new and effective ways and is therefore rich in potential for positive social change. The potential of long-term care as a driver of social innovation to solve social problems and induce social change is discussed in this section.

When discussing the potential for social innovation in and through long-term care, several studies highlight the conditions that a strong long-term care system should fulfil (Schulmann et al., 2019; Leichsenring, 2013). First, the long-term care system should be participatory, inclusive and collaborative. This means that the long-term care

system should be operated and managed in such a way that decision making is based on collaboration and cooperation involving the various stakeholders and based on a democratic structure that is inclusive of stakeholders (Ayob et al., 2016). Long-term care service providers can be central governments, local governments, NGOs or cooperatives. However, in the operation, management and evaluation of the system, the positions and relationships of the various stakeholders (including care recipients, family members, informal caregivers, local communities, service providers, government agencies and related public officials) should not be excluded from the decision-making process. In a long-term care system, the state should not unilaterally provide care services to people; care recipients and caregivers must be able to contribute to service design and delivery by actively expressing their needs and participating in the system. Second, it is very important to have a community-based long-term care system. Social needs should be defined and met through discussion and consensus among various stakeholders in local situations depending on the demographic and socioeconomic characteristics of the region. Only then can the decision outcomes contribute to the community and society as a whole, rather than merely to specific individuals or groups, and contribute to positive social change (Phills et al., 2008).

The social innovation potential of inclusive and collaborative community-based long-term care is, among other things, the ability to be proactive and responsive to diverse and complex long-term care needs and to find new solutions. In other words, it attempts to generate a variety of new options and new possible combinations of kinds of service, forms of delivery, forms of governance, forms of resourcing and ways of evaluating for the needs faced. The long-term care needs of older people can be diverse, including not only medical treatment and restoration of health, but also self-reliance and independence, employment, relationship connections, social participation and psychological stability. In this regard, community-based long-term care with democratic participation and collaborative systems can be more responsive to the needs of older people.

Various research-based and practical projects that focus on the social innovation potential of long-term care have been launched worldwide (Davies & Boelman, 2016; Ghiga et al., 2018). An example is the InCARE project, the purpose of which is to design and develop innovative long-term care policies and services through community-based

participatory and integrated decision making (InCARE, 2023). The InCARE project is currently under the leadership of the European Centre for Social Welfare Policy, conducting research and implementing pilot policies that target the long-term care systems in Spain, Austria and North Macedonia. The focus of the InCARE project is the innovative potential of long-term care and it explores this potential through inclusive participation and collaborative decision making involving care users, their families, caregivers, communities and other stakeholders.

There are examples of socially innovative long-term care systems, such as the Tubbe model in Denmark. Many older people prefer to remain in their own homes and receive care there rather than in remote nursing homes or hospitals, but in some cases it is important to have intensive, specialised care in a hospital-like setting. The Tubbe model is an innovative model of assisted living that emerged as a result of reflection on how older people could receive extra care in a home-like setting. What is remarkable about this model is that residents move from a passive role of receiving care to actively demanding and fulfilling their care needs, directly participating in the nursing home's operational system, from choosing food to hiring the staff. The Tubbe model is recognised as providing opportunities for meaningful interaction for everyone involved in the care process, and both residents and staff report high levels of satisfaction (Healthcare Denmark, 2019).

Another similar example is *The Hogeweyk*, a dementia village in the Netherlands, which is often cited as an innovative model for older persons' care environments. *The Hogeweyk* is a 1950s-style 'village' designed to help older people with severe dementia, who have intact long-term memory, to live comfortably and familiarly with their childhood memories. The model is a paradigm shift away from established models of institutional care, improving the overall quality of life for older people with dementia and approaching long-term care from a prevention and inclusion perspective. Overall, the model has proven to be highly effective in assisted living and dementia care, with long-term care residents reporting improved health outcomes and reduced reliance on medication (Godwin, 2015).

While the Tubbe model in Denmark and the dementia village in the Netherlands are examples of innovative mechanisms within long-term care itself, there are other examples where long-term care has been used to solve social problems and drive broader social change. One example is the time bank experiment in health care services. A time bank is

a multilateral time exchange system that saves the amount of time spent helping others and uses that amount of time when receiving help from others. The model is spreading around the world, including the United Kingdom, the United States, the Republic of Korea and Japan, as an innovative way to provide public services (TimebanksKorea, 2023). An older person who knits a neighbour's newborn baby's hat gets credit for the time, which can be redeemed for a companion service for their weekend grocery shopping. All members of the programme, not just older people, interact with each other based on the principle of reciprocity. The Rushey Green Time Bank in the United Kingdom, a prime example of a time bank integrated into a health care service, has individual and nine institutional members. The case of the Rushey Green Time Bank has implications for social innovation because the programme has been evaluated as not only overcoming social prejudices against older people who were viewed as a social burden and unproductive, but also solving the problem of social isolation of older people through ongoing relationships with neighbours and encouraging their active participation in society. In addition, the programme has been judged to be effective in raising self-esteem and preventing disease among older people, and it is also estimated that it has had a positive effect on cost savings for the National Health Service in the United Kingdom (Česnuitytė et al., 2022; Rushey Green Time Bank, 2023).

Another innovative long-term care organisation that has found new ways to address pressing social problems is the Older Person's Cooperative Union (*Koreikyo* Union) in Japan. Since 2000 Japan has experienced the most significant population ageing in the world due to low fertility rates and high life expectancy. This has led to the emergence of a number of older persons' needs, including long-term care, jobs, life stability, self-development and opportunities for training. The *Koreikyo* Union is a nationwide cooperative organisation established in November 2001 by combining cooperatives in seventeen regions. All services are provided by the members, and they are managed via a member agreement system. Healthy people between the ages of 55 and 75 care for care dependent people over the age of 75. The *Koreikyo* Union helps older people to remain active, independent and well-engaged during their old age. It not only provides the services necessary to maintain a healthy social life, but also provides a platform for people to continue working even into old age. In addition to caring

for older people, which accounts for three-quarters of all services, the *Koreikyo* Union offers various commercial services such as parking management and building management, and hobbies and cultural activities needed in the community, centring on middle-aged and older people (Matthew, 2017; *Koreikyo* Union, 2023).

One last case to mention is the Seoul Supporting Centre for Workers in the Care of Older People. The centre is a leading example of social innovation that has led to a wide range of social changes, including improved treatment of care workers, improved social awareness of care and changes in care policies, triggered by the introduction of the long-term care system. Since the Republic of Korea introduced universal long-term care insurance in 2008, a large formal caregiving workforce has been created, called *Yoyangbohosa*. Today there are about 1.8 million licensed *Yoyangbohosa*, with about 440,000 currently working in the field. The implementation of long-term care insurance led to social demands for improved treatment and working conditions for *Yoyangbohosa*, which eventually led to the creation of a centre to officially support care workers in the local government. In 2013 there was one location in the city of Seoul; now there are eight in the Seoul area and thirteen nationwide. In addition to conducting research on the treatment of care workers and supporting their health and labour rights, the centre engages in challenging existing social prejudices against care work, leading campaigns to promote a culture of mutual respect and good care, and actively participating in the process of recommending, implementing and evaluating local government care policies. In addition, through public-private governance, the centre serves as a hub of care networks among care workers, older people, care organisations and family caregivers, and it also show potential as civic education centre in that it provides education and psychological support to those who are not direct stakeholders in long-term care insurance, such as informal family caregivers (Seoul Supporting Centre for Workers in the Care of Older People, 2023).

In brief, social innovation through long-term care can take many different forms. It can range from addressing the problem at hand by introducing new changes to the long-term care system itself, to addressing broader societal changes and issues triggered by or through the long-term care system. Whatever the form, what is clear is that long-term care can enhance social capacity and as a result act as an engine and catalyst for positive social change.

9.5 Conclusion

This chapter aims to show that the benefits of a strong long-term care system extend beyond the care recipients to positively impact the well-being of society as a whole. It has shown that a strong long-term care system can contribute to mitigating the vicious cycle of care inequalities in society, foster networking and social solidarity among citizens, and enhance society's capacity to address pressing social issues and promote broader social change.

While this chapter has looked at selected cases and examples, the social wellbeing gains from a long-term care system can vary widely across societies and national contexts. This is an area that will require further discussion and research. What is clear, however, is that investing in the long-term care system benefits more than just the individual older or person with a disability receiving care; it benefits the development and capacity of society as a whole, and so countries will need to continue to invest actively in long-term care systems to ensure that they are actually implemented and fully operational.

9.6 References

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10

A strong long-term care system is necessary for economic growth

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10.1 Introduction

A country's economic growth – the rate at which its income is increasing or shrinking – is a key concern for policy makers. A growing economy suggests that income per person and living standards are rising, and the country has more resources for investments that will increase future economic productivity and income growth. Proposals to expand government spending or change tax rates are almost always evaluated in terms of how they will contribute to the country's economy and especially the growth of the economy. In countries with rapidly ageing populations, economic growth is increasingly viewed by policy makers as essential if the country is going to have enough income to support continuing improvements in the standard of living. Thus, proposals to strengthen existing long-term care systems or create new programmes must consider how an ageing population might impact the country's economic growth.¹

Models of the determinants of economic growth indicate that a country's income grows when its labour supply grows or workers are more productive, or its supply of physical capital (such as equipment, manufacturing facilities, laboratories, transportation infrastructure) increases. Labour productivity increases when workers are more skilled, or if they can work with more or improved forms of capital, or if new knowledge or organisational

¹ The European Commission, the OECD, the IMF and the World Bank, as well as many country-specific government agencies and researchers, regularly issue papers about how the ageing of populations is likely to affect economic output, worker productivity and countries' ability to support government programmes. See, for example, several recent analyses: European Commission (2021), Kim and Dougherty (2020), Dubina et al. (2021).

changes enable workers to produce more with existing forms of capital.² The obvious concern for countries with ageing populations is that the models also imply that economic growth will slow as older workers retire unless there are other changes that increase worker productivity or the productivity of labour and capital taken together.³

This scenario often leads to the conclusion that countries with ageing populations cannot afford to finance a strong long-term care system. The presumption is that doing so would further slow economic growth by raising taxes or reducing public expenditure on investments that help economies grow – such as education or research that leads to production innovations. However, the conclusion does not allow for the possibility that other changes could occur to increase the supply of labour or worker productivity. Instead, debates about proposals to strengthen long-term care systems have largely focused on how workers and businesses have responded in the past to tax changes. But research on responses to tax changes typically cannot isolate the effects of particular changes in tax rates from the context of other simultaneous tax code changes (including to the tax base). Despite a lack of evidence, the assumption that economic growth will be slowed by higher taxes to finance long-term care has contributed substantially to an impasse in most high-income countries about whether to strengthen their long-term care systems as their populations age.

The Covid-19 pandemic provided a different perspective for how to think about the possible behavioural responses to implementing a stronger long-term care system and its impact on economic growth. In the United States, it is not clear why many previously employed people have remained out of the labour force since the onset of Covid-19, despite employers' strong

² The supplies of natural resources (e.g., land, water, minerals) are also factors that determine economic growth but we will treat that as constant in this context.

³ From an accounting point of view, a country's output (GPD) generally grows at a higher rate than the sum of the growth rate of labour and the growth rate of capital. The difference is attributed to technological changes that allow a country's labour and capital to work together more efficiently to produce the country's output. Thus, as a country's supply of labour grows more slowly or contracts due to an ageing workforce, technological changes are increasingly needed to raise productivity.

demand for labour (Autor, 2021).⁴ But women account for the overwhelming share of people who were employed prior to March 2020 and have remained out of the labour force since then (Mitchell et al., 2021; Tappe, 2021). Covid-19 had a larger and lingering negative impact, especially on women's labour force participation, than was expected at the end of 2020 (Aaronson & Alba, 2021; Lim & Zabek, 2021; Powell, 2021). Even the loss of unemployment benefits in some states and offers of higher wages did not entice them to apply for job openings and return to work. However, continuing waves of Covid-19 cases increased uncertainty about whether a person with family caregiving responsibilities could plan to go to work each day. Not knowing if Covid-19 would prevent home health care aides from showing up each day to care for older relatives or suddenly cause a child's school or childcare centre to close for a few days produces significant stress for people trying to work. The heightened uncertainty and stress gained salience as an explanation for why many women remained out of the labour force. This explanation implies that when workers do not have stable arrangements for their family responsibilities, their ability to work is hampered significantly.

The Covid-19 pandemic's negative impact on the ability of women to participate in the labour force provides credible evidence of what might happen to economic growth if a country does *not* strengthen its long-term care system. Unless a substantial share of women can participate in the labour force and replace older workers as they retire, countries with ageing populations will experience a slowing rate of growth in their labour supply and slower economic growth. On the other hand, if a strong long-term care system helps provide stability so more people are in the workforce, the gain in income growth may outweigh any negative labour supply impact of higher contributions or payroll taxes to finance the system.

⁴ In European countries, the drop in women's labour force participation in the two years after March 2020 was smaller than in the US largely because many countries created programmes to support employers' retention of workers during the pandemic and most workers returned to their jobs as more people were vaccinated (Ando et al., 2022). Even so, Covid-19 caused sudden disruptions to people's ability to work when home-health aides were exposed to Covid-19 or positive cases caused childcare centres or schools to close for a week.

This chapter explores how a country's economic growth might be strengthened by changes to long-term care systems, paying particular attention to providing stability for workers who have ageing relatives with needs for long-term care. Three themes emerge in the chapter:

- Countries' current long-term care systems impose an implicit tax on the labour supply of informal (unpaid) caregivers – the vast majority of whom are women. The loss of their labour supply and skills suggests a significant shortfall in a country's potential income and opportunities for economic growth compared to what could occur if informal caregivers were able to work. If more employers and industries offered flexible working conditions, informal caregivers could work in jobs for which they have a comparative advantage.
- Studies of the labour effects of unpaid caregiving and of programmes to support the labour force participation of women with young children offer some suggestions for how unpaid caregivers' labour decisions might be affected by programmes and policies intended to help with caring responsibilities (for example, subsidies for paid caregivers' wages or public early childhood education). The research does not provide an overwhelming consensus that a particular type of programme or policy change is most useful for unpaid family caregivers who also want to work. But it is clear that without more trained and licensed care professionals paid competitive wages, it will be difficult for unpaid caregivers to increase their labour supply.
- To increase productivity and economic growth, a long-term care system has to include a mix of support programmes and policy changes that encourage informal caregivers to participate in the labour force and to work in jobs that fully utilise their skills and abilities. A strong long-term care system has to recognise the variety of care needs of individuals if informal caregivers are going to be confident that their family member will be appropriately cared for while they are at work. A broader definition of what constitutes care services may be required – for example, several hours per week of assistance with grocery shopping or transportation to social activities may be sufficient help so informal caregivers can work. Paid caregivers' time also could be allocated among several people with such needs, increasing caregiver productivity. Simultaneously, more

employers creating flexible work options may be the most helpful way of enabling workers to continue in their jobs when they also look after a relative with care needs.

The [next section](#) briefly reviews what long-term care is and characteristics of a strong long-term care system. The [third section](#) reviews why a country's economy needs to grow and the key factors that economists generally agree are needed for economic growth. For countries with ageing populations, it is especially important that the labour supply and labour productivity continue to grow. The discussion draws on what is known about labour supply responses to changes in payroll and income taxes in different circumstances, and how changes in taxes on wealth have affected investment. There is little empirical evidence that government sponsored programmes (i.e. those financed by a mix of insurance contributions and/or taxes paid by everyone, which provides universal entitlement when a person meets the criteria for assistance) have hurt economic growth. The [fourth section](#) focuses on findings from research on the effects on women's labour supply of long-term care systems that require families to provide informal care to older relatives with care needs, and several policies and programmes intended to increase the labour supply and earnings of women after having or adopting a child. In both situations, opportunity costs are incurred by caregivers; and equally important, the research finds a negative impact on wages, which suggests an inefficient allocation of labour and missed opportunities for increasing productivity and economic growth. The [fifth section](#) uses these findings to argue for reframing the public discussion about the relationship between economic growth and a strong long-term care system. The absence of workers with job experience and capabilities from the labour force because they need to provide unpaid long-term care is a drag on a country's ability to reach its potential economic growth rate. A long-term care system can promote economic growth if it includes policies that reduce uncertainties tied to a relative's long-term care needs so caregivers can be employed in jobs for which they have a comparative advantage. The [last section](#) provides some concluding comments.

10.2 Background

Long-term care versus post-acute care

As described in the introduction to this volume, long-term care refers to a broad range of personal, social and medical services and support for people with or at risk of a significant loss of intrinsic capacity. Such services and support include assistance with tasks of daily life, where the need for such assistance is due to a physical, mental or emotional condition (Hado & Komisar, 2019).⁵ The fundamental objective of long-term care is to enable its recipients to maintain the greatest quality of life possible for the longest possible time. With an appropriate mix of long-term care services and support, the goal is for people to remain in their homes and minimise any need to move to a care home.

This definition does not include what in the United States 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.⁶ Services and support provided over a long period of time generally fall into two categories: *formal* care that is paid for by an individual and/or by a country’s long-term care system and *informal* care that is provided by a family member or friend who is not paid for providing the care.⁷

⁵ Tasks of daily life include personal care needs (e.g., bathing, dressing). In some instances the population with long-term care needs also includes people with difficulties handling routine tasks (e.g., everyday household chores, grocery shopping).

⁶ Medicare covers post-acute care but does not cover long-term care as we are defining it. In some OECD countries, long-term care is provided in what translates in English to skilled nursing facilities (SNFs). Germany, for example, refers to nursing homes as SNFs. In the United States, however, a SNF level of care is post-acute care. A majority of nursing homes in the United States have sections that provide SNF-level care, and the terms ‘nursing home’ and ‘SNF’ are often used interchangeably, creating further confusion.

⁷ Expenditure for formal long-term care in the US in fiscal year (FY) 2018 were estimated to be \$379 billion (Watts et al., 2020), a little more than 10% of total US health expenditure that year. This total does not include Medicare spending for post-acute care (estimated to be \$83.8 billion) or payments for long-term care to care workers who were paid privately by people. Importantly, the total also does not include the estimated value of informal care provided (at least \$470 to \$522 billion annually) (Reinhard et al., 2019; Chari et al., 2015).

Whereas for health care there is broad awareness of the wide range of needs and services used by different people, in discussions about long-term care there is a tendency to assume much more uniformity of needs and services. In reality, long-term care covers a range of situations, and recognising this variation is essential to assessing costs, delivery models and their impact on outcomes. At one extreme are people who need a few hours per week of help for activities like light housework, grocery shopping, preparing meals or being driven to medical appointments. At the other extreme are people who need ‘intense’ assistance with personal care such as bathing, using the toilet, feeding, walking and moving from a chair to a bed. Although some people with intense long-term care needs have to live in nursing homes because their care needs are beyond the ability of relatives to provide, many are able to continue living at home with a mix of formal and unpaid care. The latter situation happens most often when the person with long-term care needs lives with the family member providing the unpaid care.

Most countries rely on a large amount of unpaid, informal care being provided as a way to restrain the costs of their formal long-term care systems. While there are a few systems (such as in Nordic countries) that apply a needs-based entitlement approach rather than a primarily means-tested approach, most OECD countries’ long-term care systems (regardless of how they are organised) expect or require an individual with care needs and their family to be responsible for a substantial share of the long-term care services. Such systems require people to rely on informal care and/or to pay out of pocket⁸ for the costs of formal care up to some limit (with the limit depending on the person’s resources) (Colombo et al., 2011; Costa-Font & Courbage, 2012; Swartz, 2013a).⁹ Thus, in all OECD

⁸ Out of pocket (or private) payments include co-payments, user charges and deductibles.

⁹ In the United States, the primary payer of long-term care services is Medicaid – the federal-state health insurance programme for low-income people of all ages (Watts et al., 2020). Since 2013, more than half of what Medicaid spends for long-term care pays for long-term services and support provided to people in their homes or in community-based settings (known as HCBS) rather than care for residents of nursing homes. Most people who receive Medicaid-funded HCBS also depend on some amount of informal care from relatives. To be eligible for Medicaid coverage of long-term care, people must have very low income and assets (frequently by spending down their income and wealth to pay for medical and long-term care expenses).

countries the vast majority of people who have long-term care needs receive unpaid care provided by family and friends. Although this outcome is preferred by many people, it is important to note that the burden of providing the care is borne primarily by women. Estimates for EU countries indicate that up to 80 per cent of care is accounted for by informally provided support and 70 percent of this is provided by women (WHO, 2022). In the United States, women account for 62 per cent of people providing unpaid care for family members 65 years of age and older (Spillman et al., 2020; National Academies of Science, Engineering, and Medicine, 2016). Hence, the burden of requiring family members to provide unpaid care is analogous to a tax on women. We will return to this point below.

Characteristics of strong long-term care systems

This chapter builds on the discussion in previous chapters of the characteristics defining a strong long-term care system, with an emphasis on two particular features. First, a strong long-term care system is publicly funded, via either taxation or social insurance. It covers everyone with needs for costly long-term care irrespective of their level of income or assets, and is financed by individual insurance contributions or taxes based on payroll and general revenues. Second, a strong long-term care system emphasises assisting both the person with long-term care needs and the person providing unpaid care (WHO, 2022). Programmes and policies that provide employment stability for caregivers when relatives with long-term care needs have a medical appointment or in case of emergencies are an important component of a strong long-term care system. The particular set of such supportive programmes and policies will differ among countries, and many may come from employers. Covid-19 caused more employers to realise that flexibility in work schedules provides the support many workers need to deal with family responsibilities. As Goldin (2021) points out, the caring sector and the wider economy are interdependent. How countries and employers support workers providing informal care for family members with long-term care needs has an impact on economic productivity and growth (European Commission, 2020).

10.3 Why countries need economic growth

Maintaining or increasing a country's income growth (economic growth) is needed for countries to sustain rising personal incomes and maintain or expand government-funded programmes. Economic growth signals that the total income (GDP) from the goods and services produced by the country is increasing at a steady or rising annual rate.¹⁰

As noted briefly in the introduction, simple models of economic growth illustrate that a combination of labour, physical capital (e.g., manufacturing buildings and equipment, office buildings, laboratories) and technological change drive the growth of a country's economy. The key insights from this model of growth are that a country's economy will grow if the capital stock and/or the size of the labour force grow or the quality of labour improves, and if technological changes increase the productivity of either capital or labour or both. Investments in capital depend on companies and some people's willingness to supply a portion of their earnings to improve and grow the capital stock. Improvements in capital equipment often come from technological change – innovations that change the processes used in producing goods and services so the combination of capital and labour is more efficient and output increases. Some innovations result in new products or higher quality products that consumers are willing to buy, thereby also leading to growth in GDP. Importantly, GDP grows when more people are working or the quality of labour rises as a result of improvements in education and skills (i.e. investments in human capital). A more skilled workforce can take advantage of technological changes that improve the productivity of labour (the amount of goods and services produced per worker).

An ageing population can adversely affect the supply of labour in two ways. One is that as people over age 65 reduce their labour force participation, the country's supply of labour will grow more slowly or even contract.¹¹ The slowing growth of the working population is

¹⁰ An increase could result from a steady annual rate of growth (say 3 per cent), or from a one-off jump in GDP (perhaps due to greater efficiency in electric power storage) that doesn't change the rate of growth but does provide the country with more income. Increasing income also could be the result of a combination of the two.

¹¹ Japan, for example, by one estimate could experience a reduction of 4.5 million people in its labour force by 2030, a 6.6% decline over its 2021 labour force (Duell et al., 2018).

a problem because rising life expectancy means the older population is growing faster than the working population, increasing the dependency ratio of older non-workers to working adults. This will cause a decline in per capita income. The second problem with an ageing population is that in general, worker productivity changes over a person's lifetime, often increasing in younger years as experience accumulates and then declining in later years as physical ailments increase or an ability to learn new skills declines (Aiyar et al., 2016). The impact of ageing on a country's labour productivity is nuanced; it depends on the mix of industries and occupations in a country, the age structure of the workforces in the different industries, as well as spill-over effects on firms from being located in areas with an ageing labour force (Daniele et al., 2019; Maestas, Mullen, and Powell, 2023). Thus, the concern with an ageing workforce is that labour productivity may decline, leading to slower economic growth and a decline in per capita income (Maestas et al., 2023; Aiyar et al., 2016; Daniele et al., 2019). One estimate of the combined effects of a slowing growth in the supply of labour and an ageing workforce on productivity growth in OECD countries between 2006 and 2014 indicates that had the workforce not been ageing, the cumulative per capita GDP growth would have been 1.5 percentage points higher on average than it was; the actual rate was 2.3 per cent (Daniele et al., 2019).

The need to grow (or at least maintain) income per capita in the face of an ageing population is real. Health care expenditure is higher for older people than those younger than 65 years of age, and with greater life expectancy, a country's public spending on health care and pensions will rise as the population ages.¹² Economic growth is essential if countries are to meet the expected growth in the costs of their older

¹² An ageing population per se is a factor but it is not a key driver of the growth in health care spending; the primary drivers are new (generally more costly) technologies and medicines and greater intensity of use of medical services (Reinhardt, 2003; Smith et al., 2009; Sorenson et al., 2013; MedPAC, 2022). But as a simple arithmetic exercise, a society with a growing share of its population who are older will increase its public spending on health care (Niu & Topoleski, 2014). In the United States, in 2014 (the latest year where spending is available by age groups) per person health care spending for people 65 and older was USD 19,098, compared to USD 7,153 per 18–64 year-old people and USD 3,749 per child (CMS, December 2021). As the number of people aged 65 and older increases, health care spending will increase unless per person costs for older people are substantially reduced.

population and be able to continue spending public monies on programmes such as national defence, education, health and social welfare programmes as well as have people confident that their standard of living will not decline.

Thus, to foster economic growth, countries with ageing populations have to create conditions that promote greater employment of adults of all ages, and incentives for investments in human and physical capital and technological change.¹³ Creating such conditions for labour implies that a combination of tax policies and social programmes is needed to motivate more people to work (increase the labour force), and induce people to work in jobs and pursue careers for which their skills are well-suited so labour productivity also increases. Similarly, tax policies affecting businesses and individuals need to promote investments in capital and new technologies that increase labour productivity and generate new goods and services that increase GDP.

Despite the growth models' clear implications that incentives are needed to encourage more people to participate in the labour force and to increase productivity, creating or strengthening a long-term care system is often viewed as likely to hurt economic growth because higher taxes would be needed to finance it.¹⁴ Popular opinion holds that raising taxes on labour causes people to work less, and raising taxes on unearned income (i.e. income from investments rather than income earned through labour) causes investors to invest elsewhere. Simple economic models of worker decisions to supply labour indicate that when the costs of working, such as transportation and childcare, exceed after-tax wages, workers drop out of the labour force or find jobs with lower costs of working. In this context, additional taxes are a disincentive for people to work more unless they feel that the taxes pay for programmes that help them (Bozio et al., 2019). Simple models of the effects of taxes on unearned income (such as capital gains from investments) similarly suggest that higher tax rates reduce the rate of return on investments, thereby discouraging people from investing in

¹³ The European Council's Lisbon Strategy of 2000 aimed to reverse the low productivity and anaemic economic growth in the European Union of the 1990s; the strategy's goals included increasing employment by 2010, especially among women (a target of 60% labour force participation rate (LFPR)) and people 55 to 64 years of age (a target of at least 50% LFPR) (European Parliament, 2010).

¹⁴ In the United States, opponents of increasing Medicare's coverage of long-term care have long argued that economic growth will suffer because taxes will be raised to finance it. See Feder (2015).

new buildings and equipment (capital) or ventures that might produce technological change (Mankiw et al., 2009; Burman & Slemrod, 2020). Opponents of increasing taxes on unearned income or corporate earnings argue that they will hurt economic growth (Hodge & Hickman, 2018).

The belief that raising taxes will hurt economic growth persists despite the lack of strong empirical evidence of how people's employment and investment behaviours respond to different specific taxes and social programmes. Using more sophisticated methods to estimate behavioural responses to taxes, a large body of empirical economics research has attempted to understand how changes in specific taxes have affected labour supply decisions and investment decisions. However, much of this research has analysed effects of *reductions* in individual and corporate income tax rates rather than tax increases dedicated to pay for social programmes. Furthermore, most analyses of the effects of specific taxes have not examined how economic growth was affected by the tax change. Instead, analyses of how tax changes impacted economic growth have largely been conducted in the context of major tax reform legislation that involved reductions in individual and corporate income tax rates and an expansion of the tax base (e.g., Gale & Samwick, 2017). The result for our purposes is an absence of strong empirical evidence about either the labour supply or economic growth effects of specific tax increases dedicated to particular programmes. Indeed, Lindert (2004a, 2004b) has argued that there is no evidence that social welfare states (i.e. countries with large publicly funded programmes) funded with 'careful' taxes (tilted towards labour rather than capital) have slower economic growth than countries with less generous social programmes.

Thus, countries with ageing populations need to pivot away from assuming that economic growth will be hurt by strengthening their long-term care systems. Framing the issue as a choice between raising taxes and promoting economic growth completely ignores the extent to which most countries' current long-term care systems place an implicit tax on people who have to reduce their labour supply in order to provide unpaid care to relatives with long-term care needs. Importantly, the burden of this ignored tax falls predominantly on women, who account for a little less than half of most OECD countries' labour force. Paying attention to this burden is crucial for thinking about how to maintain the future economic growth of countries with

ageing populations. Increasing or at least maintaining a country's economic growth rate depends on increasing the supply of labour and the quality of labour. When a large number of possible workers are not participating in the labour force or are not pursuing careers that match their abilities (which would increase labour productivity), it is an indication that the economy is not growing at its potential rate of growth.

10.4 Policies that increase and decrease women's labour supply

Given our focus on how a strong long-term care system might impact economic growth and the lack of empirical evidence about how tax increases to support other programmes have affected people's supply of labour, we turn to examining the effects of tax-financed social programmes that were at least partially intended to increase the labour supply of women.¹⁵ Over the past three decades, a large body of empirical research has investigated various effects of Western European countries' childcare and family support policies on women's earnings, labour supply and, occasionally, career choices. Another body of research conducted over the same time period has focused on how providing informal long-term care services has affected women's labour force participation, hours of work and types of jobs or careers. Both areas of research face a common problem: the decision to provide informal care (or care for one's own child) and the decision to participate in the labour force (and how many hours per week to work) are each correlated with other, often unobservable, factors – such as concern about social consequences if one does not conform to gender norms (Bertrand, 2020). The correlations with other factors make it difficult to know whether people choose not to work (or reduce their hours of work) because they have to provide informal care (or childcare), or they choose to provide informal care or childcare because their employment options may be limited. It is difficult to assign causality to one decision or the other. The outcomes are said to be endogenous

¹⁵ It is important to note that many of these policies had dual purposes, including increasing the number of children in order to slow or reverse the ageing of countries' populations and addressing the 'child (or motherhood) penalty' – the negative effects of having children on wages and earnings over a decade or longer.

because they are simultaneously determined. Similarly, countries' implementation of various social programmes to support women working is endogenous with contemporaneous changes in social attitudes about women's roles in the labour force and caring for children and older relatives. Thus, it is important to pay attention to the empirical methods used to estimate effects when drawing conclusions about the directions of causality.

Long-term care systems' requirement that families provide informal care

As noted earlier, most countries' long-term care systems depend heavily on the provision of informal care by family and friends (Swartz & Feder, 2021; Feder & Swartz, 2021; Costa-Font & Courbage, 2012; Villalobos Dintrans, 2021). This dependency imposes an implicit tax burden on such caregivers' ability to work and pursue careers that match their productive capabilities. Surveys of people with long-term care needs or of older people who are informal caregivers consistently show that women are far more likely than men to provide unpaid care for older family members (AARP, 2020; ONS, 2019; NASEM, 2016).

In the United States and a majority of OECD countries, the heavy reliance on informal long-term care arises from the way access to publicly financed formal care services is structured. Often, eligibility for these services is linked to individual or household income, involves considerable co-payments by users, and does not fully cover the costs of long-term care unless a person has very low or no income and/or assets. Some countries also place financial responsibility for parents' long-term care costs on their adult offspring. The final social safety net in most OECD countries is residential care, but only for people with sufficiently pronounced care needs to qualify for such care. For those who need less intensive support, informal care compensates for the lack of services in the community and for their lack of affordability. In these cases, the alternative would not be to move to a nursing home, but rather to receive no care.

Three problems make it difficult to estimate the effects of providing informal care on labour market outcomes of interest (the decision to participate in the labour force, the number of hours to work given that the person is working for pay, and wages earned). The first problem, as just noted, is that decisions about providing informal care and

participating in the labour force (and how many hours to work per week) are endogenous. If the endogeneity is not controlled for, the causal effect of providing informal care on labour market outcomes has been shown to be overestimated (Ettner, 1995, 1996; Heitmueller, 2007). A second problem relates to unobservable differences in people's preferences for providing informal care for parents and working. A third problem is that surveys focused on ageing issues often do not gather detailed information about the paid employment of family caregivers (e.g., hours of work, income) and hours of informal care provided, as well as how much the caregiver was working before starting to provide unpaid care. Researchers have addressed the problems of endogeneity and unobservable differences in preferences with different empirical methods and by focusing on different groups of caregivers.

Earlier research based on cross-section data that attempted to account for the endogeneity of caregiving and labour force participation decisions relied on instrumental variable methods¹⁶ (Ettner, 1995, 1996; Heitmueller, 2007; Bolin et al., 2008). Estimates from these studies are somewhat dated in that they rely on data primarily collected in the 1980s and 1990s.¹⁷ More recent studies have been able to exploit

¹⁶ Instrumental variable (IV) methods try to provide a consistent estimate of the causal impact of an endogenous variable on an outcome of interest – in this case, the impact of having a relative who needs long-term care on that person's labour force participation. If another variable can be observed that is likely to be correlated with the decision to provide care, and is not likely to be correlated with the decision to participate in the labour force, it could be used as an instrumental variable. In this case, the IV method involves estimating the decision to provide care as a function, for example, of the health status of an aged parent. The *predicted* value of the decision to provide care would then be used as an explanatory variable in a separate estimation of the decision to work. However, if the instrumental variable is only weakly correlated with the endogenous variable of interest (the decision to provide care), the estimated effect will be inconsistent and biased – making any estimate of the causal impact suspect. In general, it is difficult to find instrumental variables that are more than weakly correlated with the endogenous variable of interest and yield plausible estimates of a causal effect.

¹⁷ Since 2000, most countries' long-term care policies have shifted to providing more home-based long-term care services so people with long-term care needs can stay in their homes. Moreover, these data are from people who most likely would have been born between 1920 and 1940 – and the women especially had very different labour market expectations throughout their lives compared to women born during the baby boom years or since. Fahle and McGarry (2018) have results that confirm caregiving differences among women in their fifties and sixties who were born in different cohorts.

the longitudinal nature of data in the Health and Retirement Study (HRS), the British Household Panel Study (BHPS) or SHARE to control for the endogenous relationship when estimating the effect of providing informal care on labour market outcomes (Heitmueller & Inglis 2007; Johnson & Lo Sasso, 2006; Casado-Marin et al., 2011; Van Houtven et al., 2013; Fahle & McGarry, 2018). These studies differ in terms of their focus on recipients of care (parents or parents-in-law, spouses), the type and intensity of care provided, and details about the caregivers' characteristics (e.g., age, education, years in the labour force). Nonetheless, the studies' findings are mostly consistent. First, the share of women providing informal care to parents or parents-in-law is substantial – about a third of women provide such care before they reach 65 years of age (Johnson & Lo Sasso, 2006; Fahle & McGarry, 2018). Second, providing informal care has a significant, negative effect on the probability of women working. Estimates range from about 8 per cent (on a mean of 41 per cent of women working) by Fahle and McGarry (2018) and 6 per cent by Heitmueller (2007), to 20.5 per cent and up to 26 per cent for caregivers providing intense care (defined as more than 28 hours of care per week and more than 20 hours per week, respectively) in research by Casado-Marin et al. (2011) and Heitmueller (2007). Van Houtven et al. (2013) estimate that caregiving of any type has no significant impact on the probability of working for women or men.¹⁸ But when they examine the effect on self-reported retirement status, they estimate that caregiving of any type increases the probability of being retired by 2.4 percentage points for women – an increase in mean retirement status of 6.7 per cent. Thus, while there is general agreement that providing care services increases the probability that women who had been working will stop participating in the labour force, the magnitude of the effect seems to depend on details about the caregivers and the intensity of care being provided.

There also is general agreement that caregiving reduces women's hours of work, conditional on working, but there is less agreement about the size of the impact. Fahle and McGarry (2018) find a relatively small effect – a 1.3 hour (4 per cent) decrease in hours worked in an average work week

¹⁸ Their explanation for this finding is that they control for 'permanent' unobserved differences (heterogeneity) with fixed effects and suggest that by doing this, there is no evidence of endogeneity between caregiving and participating in the labour force (the extensive margin of labour supply) (Van Houtven et al., 2013).

of 34 hours. Van Houtven et al (2013) obtain different results depending on whether they treat caregiving as exogenous or endogenous, and whether the hours of care are intense (defined as at least 1,000 hours over a two year period). When caregiving is treated as exogenous, they find no causal effect on work hours but when it is treated as endogenous, their results change: caregiving of any type reduces women's work hours by 3 hours per week while intense caregiving reduces work hours by 9 to 13 hours per week. This result and the finding by Casado-Marin et al. (2011), that providing more than 28 hours of care per week causes Spanish middle-aged women to not participate in the labour force, highlight the need to account for the intensity of care being provided in any estimates of caregiving's impact on labour force outcomes. It also is noteworthy that younger women (in more recent cohorts) are providing more hours of care to parents or parents-in-law than women in older cohorts, probably because of increased longevity of the parents of younger women (Fahle & McGarry, 2018).

Only a few studies have examined the effect of caregiving on wages of working caregivers because most surveys do not collect wage and earnings information. But well-done estimates based on data from the United States and the United Kingdom are consistent and indicate a significant wage penalty for the caregiver. For women, the estimates range from a reduction on average of 3 or 3.1 per cent in hourly wages (Heitmueller & Inglis, 2007; and Van Houtven et al., 2013, respectively) to almost 9 per cent (Carmichael & Charles, 2003). The only estimates of a significant effect on men's wages are from Carmichael and Charles (2003), who surmise that the negative effect is primarily for men with relatively low earnings, which may also be indicative of limited job options.

Altogether, the effect of caregiving (especially intense caregiving) on labour force participation, hours of work and wages indicate that caregivers incur substantial opportunity costs.¹⁹ When people drop out of the labour force, in addition to a loss of income they stop accumulating pensions and savings for their retirement years, and in the United States they also may lose access to employer-sponsored

¹⁹ Researchers' estimates of family caregivers' forgone earnings in the United States and the United Kingdom are more than twice official government estimates of spending on formal long-term care services (Chari et al., 2015; Buckner & Yeandle, 2015; Reinhard et al., 2019). The estimates also underestimate the opportunity costs because they do not include earnings forgone by choosing to work in lower-paying jobs in order to provide care.

health insurance.²⁰ The compounded negative effects of caregiving on hours of work together with lower wages suggest even greater opportunity costs in terms of total lost income from working (and any future retirement fund accumulations tied to earnings). The decline in wages for women may reflect decisions to change jobs (even with the same employer) that do not fully match with the women's skills and experience as a way to reduce stress at work or have more flexible work hours. A few studies have analysed the effects of caregiving on caregivers' own health, expanding the set of opportunity costs that informal care requirements impose on caregivers (Coe & Van Houtven 2009; AARP, 2020). Harmful effects to caregivers' health have substantial implications for the productivity of people who also participate in the labour force: productivity is likely to suffer due to mental fatigue or physical injuries and intermittent absences from work.

It is important to recognise that these opportunity costs are the direct result of an implicit tax on caregivers' ability to participate in the labour force that is built into most countries' long-term care systems. To control the costs of paid care visible in government budgets, long-term care systems depend on family to supply unpaid care. This implicit tax is based on a social norm about women's labour – a norm at odds with the need to increase labour force participation rates of women in order to counteract the slowing growth in countries' labour supply as the populations age. It is also inconsistent with policies at least partially intended to increase the labour supply of young women when they have young children. In the context of long-term care, new evidence underlines the implications of this idiosyncratic relationship between work and care. When public policies push women to work longer in older age (as with increases to the state pension age), they reduce the amount of informal care they provide, especially if they have demanding jobs, and there is no compensation for this forgone care by other care providers (Carrino et al., 2023).

Parental leave policies and childcare programmes

The impetus for empirical research about the effects of child-oriented and family support programmes on women's labour supply stems from efforts

²⁰ In the United States, they also may lose accumulating at least 40 quarters (3 months per quarter) or 10 years total of payroll tax contributions needed for Social Security and Medicare eligibility.

to understand if (and how) such programmes might reduce persistent differences in labour force participation and earnings by gender. In particular, there is an interest in going beyond explanations of discrimination against women to try to understand why women may choose different employment paths than men.²¹ Findings from the research have implications for how a strong long-term care system might be designed so that economic growth is also maintained or increased.

Having or adopting children has been seen as creating a child or motherhood penalty on the labour market outcomes of women relative to men (Bertrand et al., 2010; Kleven et al., 2019; Bertrand, 2020). Most high-income countries (with the United States being a notable exception) have implemented social policies and programmes intended to alleviate the costs of caring for young children so that women can participate in the labour force. The policies and programmes vary across countries but generally they involve parental leave rights, public expenditure on early childhood care and education and, to a lesser extent, flexibility in when the workday starts and ends. Countries' parental leave structures vary in terms of maximum length of time for the leave and the percentage of the leave-taking parent's income that is paid during the leave. Public expenditure on early childhood care and education varies in terms of whether they are direct payments to childcare agencies or schools, or subsidies to parents who can choose private childcare providers, and whether the subsidies are tax credits for the parents or payments to the childcare providers. Countries also differ in the extent to which they may emphasise one or more of the policies in their support of women working. It would be a mistake to analyse any one policy as if it exists independently of other policies in the same country (including those that may seemingly not be related).²²

²¹ See Bertrand (2020) and Goldin (2021) for excellent discussions about efforts to understand and identify the impacts of changing social norms, gender norms and stereotypes on gender differences in employment outcomes.

²² For example, during the 1990s, Spain implemented subsidised full-time childcare for children 3 years of age. The enrolment rate in public childcare for 3 year-olds rose from 8.5% in 1990 to 67.1% in 2002, but the increase in labour supply by mothers was modest. A primary contributing factor to the growth in enrolment of 3-year-olds is that the local school must take 3-year-old children who live in the neighbourhood but if the school has reached its capacity for 6-year-olds (the age of mandatory school enrolment), the school does not have to enrol any more 6-year-olds. Thus, if parents want their child to attend the local public school, they can ensure that outcome by enrolling their children at age 3 (Nollenberger & Rodriguez-Planas, 2015).

These policies can affect many outcomes (children's educational attainment, for example) but our interest is in the estimated effects of these policies on women's labour force participation. It is beyond the scope of this chapter to review in detail the studies that have attempted to identify the causal effects of such policies.²³ Nonetheless, we can draw some conclusions from studies that focused on specific countries and took advantage of within-country variation in the implementation timing of programmes and policies (see, for example, Lefebvre et al., 2009; Cascio et al., 2015; Asai, 2015; Bettendorf et al., 2015; Geyer et al., 2015; Givord & Marbot, 2015; Nollenberger & Rodríguez-Planas, 2015; Kleven et al., 2019).

Two general conclusions related to labour force participation can be drawn from these studies. First, parental leave of as much as a year after the birth or adoption of a child increases women's participation in the labour force but the effect is small. Crucially, when childcare facilities or private nanny care are not widely available, it appears that parental leave policies have little to no significant effect on women's labour supply or earnings. Second, publicly funded spending on childcare and universal early education – particularly if such spending involves creating more childcare facilities and raising the salaries of providers and teachers – increases the labour force participation of women with children one year of age and older. These conclusions are highly relevant for efforts to increase the labour supply of informal caregivers. They imply that without a long-term care programme to substantially raise wages for home health care aides and increase the supply of trained and licensed aides, informal caregivers are unlikely to increase their supply of labour.

Moreover, although the estimated effects of the childcare and early childhood education policies on women's earnings are inconclusive,²⁴ the analyses lend weight to the argument that many women are employed in

²³ Olivetti and Petrongolo (2017) provide an excellent review of the research done before 2018 on the effects on women's labour supply of high-income countries' parental leave rights, public expenditure on early childhood care and education, and flexibility in the start and end time of the workday. The paper helpfully distinguishes between cross-country analyses of similar support policies and studies using micro-level data from different countries that examine specific policies' effects on women's labour supply and earnings outcomes.

²⁴ Several studies suggest that childcare and early childhood education policies may have positive employment and earnings effects especially for less skilled women (Olivetti & Petrongolo, 2017). The absence of conclusive evidence that

jobs where their skills are not fully utilised. This is significant as more women are obtaining more education and skills, and pursuing careers previously thought to be suitable only for men. Labour productivity growth depends on having workers with more education and skills, and the loss of skilled women from the workforce in the future because of needing to provide informal care to older relatives will make maintaining economic growth all the more difficult.

Importantly, the finding that the labour force participation rates of mothers with young children increased when public funding for child-care and early education increased belies the argument that raising taxes will reduce the labour supply and thereby hurt economic growth.

10.5 Policies to support caregivers and promote economic growth

Taken together, these research studies show that there is a significant amount of forgone productivity and national income (as well as personal income) due to a substantial share of working age people providing unpaid care when they would otherwise be employed or working more hours, or employed in jobs that better matched their aptitudes and skills. A country's ability to achieve higher economic growth is constrained by the loss of caregivers' labour supply and the misallocation of their skills and aptitudes to jobs when they are employed.

The clear implication is that the public discourse around the pros and cons of establishing a strong national long-term care system needs to be reframed. Framing the issue as 'how can we afford it, especially if raising taxes slows economic growth?' is a red herring. The pertinent issue is that ageing populations cause a country's labour supply and productivity to decline as older workers retire – and the shrinkage will hurt economic growth. When workers have to reduce their labour supply in order to provide informal care, the loss of their work effort compounds the decline in a country's labour supply and productivity.

family support policies reduce the child penalty effect on mothers' earnings may be due to several factors. It is difficult to measure and control for the diversity in women's (and men's) attitudes towards caring for young children and participating in the labour force. Some of the variability in attitudes appears to be related to gender stereotypes and the internalisation of gender norms into preferences (Bertrand, 2020). The absence of quality early childcare and education providers in several of the studies also makes it difficult to know which family support policies had any effects on women's earnings.

Thus, a strong long-term care system that enables informal caregivers to participate in the labour force and work in jobs where their skills are most productive will help prevent the slowing of economic growth.

Reframing the rationale for a strong long-term care system in this way also requires recognising that several interrelated policies will need to be paired with long-term care policies in order to encourage unpaid caregivers to increase their labour supply. Simply creating a national social insurance or taxation-funded programme for long-term care will not by itself achieve this goal. A recent study of how the introduction of Japan's national long-term care insurance programme impacted trends in women's labour force participation and the country's economic growth provides a cautionary note for expecting a rapid labour supply increase in response to implementing a long-term care programme (Ando et al., 2021).²⁵ Japan implemented a national insurance programme for long-term care in 2000, motivated in part by hopes that it would increase women's supply of labour (Campbell et al., 2010). The study found that middle-aged women did not enter the labour force in significant numbers ten years after the introduction of the national long-term care programme.²⁶ But as Ando et al. (2021) point out, the Japanese long-term care insurance programme provides in-kind services, enabling people with care needs to live at home, including many who had been living in nursing homes – and this comes with a catch. Most programme recipients still require some amount of informal care at home, making it difficult for women to work. In the fifteen years after the introduction of the long-term care insurance programme, the share of older people receiving the long-term care benefits at home grew from 4.4% to 12.4%. It also is possible that many middle-aged women did not choose to participate in the labour force after the introduction of the long-term care programme because they had been out of the labour force for some time. It is noteworthy that Japan's rate of economic

²⁵ It is difficult to estimate the causal impact of introducing a national long-term care social insurance programme on labour force outcomes because everyone who resides in a country is affected by the programme; a control group of people who were not affected by the programme does not exist. Ando et al. (2021) addresses this problem by creating a synthetic control group using data from eighteen other OECD countries.

²⁶ Similarly, efforts in several countries to expand the labour supply of women with young children by offering subsidies or tax credits to offset the costs of childcare did not have the intended effect because sufficient numbers of quality childcare centres were not available (Lefebvre et al., 2009; Olivetti & Petrongolo, 2017).

growth did not slow after the introduction of the tax-financed long-term care insurance programme (Ando et al., 2021).

To increase informal caregivers' willingness to participate more in the labour force, implementation of the long-term care programme will need to be paired with two related policy efforts: one directed at increasing the supply of paid home health care aides, and the other at finding ways to allocate the aides more efficiently. Increasing the supply of trained and licensed home-based caregivers is essential if workers with caregiving responsibilities for loved ones are to be willing to shift some of the burden of providing informal care. It can be an emotionally difficult decision to relinquish some caregiving tasks to a person who is not related to the relative with care needs. Knowing that a home health care aide has been through a certified training programme and passed a licensing exam helps ease that decision.²⁷ This is especially the case for caregivers who are providing intense amounts of care (more than 20 hours per week) and whose labour supply is most affected by caregiving (Heitmueller, 2007; Casado-Marin et al., 2011; Van Houtven et al., 2013; Fahle & McGarry, 2018). If family caregivers can remain in jobs or choose careers that better match their skills because there are licensed, trained aides who can provide some of the caregivers' tasks, the country's workforce will be more productive. Chapter 6 in this volume provides further discussion of the links between investment into the care workforce and the quality of the long-term care system as a whole.

Even if the long-term care system offers significant wage increases for home-based aides, the supply of trained and licensed aides will not substantially increase immediately. Educational programmes and standardised licensing exams will need to be developed to ensure minimum competency of home health care providers. But if management and organisational changes within home health care agencies could occur more rapidly, that would increase the productivity of the existing supply of home health care workers. In particular, health care workers' time among people with care needs could be allocated more efficiently than it often is. Many older people who need some informal care do not require a full-time (8 hours per day) aide. They just need help with chores (laundry, grocery shopping) or being driven to

²⁷ In most countries, home health care providers receive very little formal training or preparation for assisting older people who need different types of care.

medical appointments and social activities once or twice a week. (They and their relatives also might strongly prefer that any other care needs be provided by relatives.²⁸) Given the low number of hours per week of assistance needed by a large share of people with care needs, it should be possible to more efficiently organise the time of home health care workers so their productivity increases. Especially in more densely populated areas, perhaps two to three people who live not far from each other could have their needs met by one health care worker each week. Together with agency supervisors, family caregivers could be tasked with providing oversight to ensure that quality of care remained high.

The private sector has a strong interest in finding ways to lessen the decline in the labour supply caused by older workers' retirements. Creating more opportunities for workers to have flexible work schedules and working conditions does not always require government regulations or incentives for businesses. The Covid-19 pandemic shifted long-standing employer attitudes against flexible work schedules for salaried workers so they are now widespread; and flexible work schedules have become more common among firms with lower-wage workers (for example, in retail or hospitality) – firms that previously would have considered flexible schedules to be detrimental to productivity and profits. While workers in the United Kingdom and other European countries are entitled to take job-protected leave to provide care to older relatives with long-term care needs or parental leave, that is not yet the case in the United States.²⁹ The combination of regulations and incentives for businesses to have flexible working conditions remains an important means of moderating the impact of a decline in the labour supply caused by an ageing population.

A cautionary note also is important: if the long-term care system simply causes workers in other occupations (retail sales or food preparation, for example) to shift to working as health care aides, perhaps because home health care aides' wages are raised, the total supply of

²⁸ At the same time, the relatives who provide the unpaid care and are working would be better able to spend time with the care recipient if some of these activities were provided by the long-term care programme (Rapp & Swartz, 2021).

²⁹ Social pressure to institute such leave was particularly strong in the United States in 2021 and almost caused Congress to pass a minimum leave requirement in a budget bill.

labour will not increase. Astute policy makers and business leaders will realise that workers who shift to home health care jobs will have come from the existing workforce and their businesses. To grow the labour supply beyond what a strengthened long-term care system will do, countries with ageing populations need public and private sector strategies that entice people who are not in the labour force or are unemployed to choose to work. Many people who stopped working because they needed to care for a relative may remain out of the labour force because they feel they have lost prior skills. Private and public sector training programmes, including apprenticeships, could provide a way for people to regain or learn new skills. Furthermore, there remains significant reluctance (if not discrimination) among employers to hire workers, especially women, after longer employment breaks. A wider set of active labour market policies are needed to ensure that those with longer career breaks are supported to rejoin the labour market. A mix of such initiatives together with a strong long-term care system will be needed to enable more people to re-enter the labour force, thereby slowing the decline in the labour supply and helping to maintain economic growth.

10.6 Concluding comments

The public discussion about establishing a strong long-term care system needs to be reframed. For too long, debates about long-term care have stalled over the argument that economic growth would be slowed by the need to raise taxes to fund a social insurance long-term care system. The discussion needs to move beyond this view and acknowledge that most countries' current long-term care systems include an implicit tax on the labour supply of family caregivers. When family caregivers (mostly women) reduce their labour supply so they can care for ageing relatives with long-term care needs, economic growth is less than it potentially would be if the caregivers continued to work or chose careers where their productive abilities were fully utilised. The negative effects on economic growth caused by long-term care systems' implicit tax on the labour supply of family caregivers need to be recognised in debates about strengthening long-term care systems.

The need for reframing the discussion is becoming more urgent with more of the baby boomers ageing past 65 years every year. The increased longevity of more people (despite the disproportionate effects

of Covid-19 on older people) is already impacting the labour supply outcomes of prime-age workers. A recent study examining the impact of providing unpaid care on women's labour supply found that younger cohorts of women are providing more care during their mid-life years (fifties and sixties, prime working ages) than was true of older cohorts when they were the same ages (Fahle & McGarry, 2018).

Establishing a strong long-term care system is unlikely to immediately yield either an increase in the labour supply of prime-age women or to observed changes in established patterns of younger people's choices of jobs and careers.³⁰ But these changes will occur if a long-term care system increases wages paid to home health care providers, fosters training programmes to improve the skills and career status of such providers, and creates more efficient ways of having providers care for several people each week. Improving the status of home health care providers will attract more people to supply assistance for people with moderate care needs and thereby make it feasible for women to work and still provide other informal care help for older relatives. Moreover, if the long-term care system makes it possible for women to be in careers or take jobs that are better matches for their skills, labour productivity will rise along with the supply of labour – furthering economic growth.

If the history of the United States Medicare programme³¹ is a guide (see [chapter 5](#) of this volume), there also are likely to be positive effects for the economy of establishing a strong long-term care system. Medicare had a major role in fostering the development of new pharmaceuticals, medical device inventions and innovations in managing the treatment of diseases and conditions, boosting the health care industry's contribution to economic growth in the United States (Swartz, 2013b). A strengthened long-term care system would similarly no doubt lead to innovations and inventions that help people with care needs or make it easier for caregivers to provide quality care, increasing manufacturing production and economic growth.

³⁰ Social norms and gender stereotype expectations do not change quickly, but there are hints already that some of the social norms and gendered stereotype expectations about women as better caregivers than men are changing (Bertrand, 2020; Goldin, 2021).

³¹ Health insurance for almost all people 65 years of age and older, and people younger than 65 with qualifying disabilities. Further details on the long-term care programmes in the United States are provided in [chapter 5](#).

Terrible as the Covid-19 pandemic has been, it has provided strong evidence that economic growth is slower when substantial numbers of people with skills and experience leave the workforce because of uncertainty about family responsibilities. Avoiding that scenario as countries' populations age has to become paramount in policy makers' deliberations about revising their long-term care systems. A stronger long-term care system that addresses the sources of uncertainty experienced by a growing number of prime-age workers with ageing relatives will benefit older people with long-term care needs and their unpaid family caregivers. Equally important, it will contribute to economic growth.

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11 Conclusion

Towards universal, high-quality long-term care: changing the narrative

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11.1 Growing momentum for long-term care on the global development and social policy agenda

The 2020s have seen growing recognition of the need to invest in long-term care systems, with considerable momentum for long-term care reforms building at both global and regional level. The United Nations Decade of Healthy Ageing (adopted in December 2020) identifies investment in long-term care as one of four global priority action areas, unequivocally stating that ‘every country should have a system to meet the needs of older people for long-term care’ (WHO, 2020: 19). The launch of the European Care Strategy in September 2022 and the ensuing adoption by the European Council of a recommendation on long-term care in December 2022 (European Council, 2023) represent, to date, the most ambitious and comprehensive set of regional initiatives and policy commitments to ensure all those who need and who provide care are protected, supported and facilitated to use quality, affordable and accessible care services. In the same year, the adoption of the Buenos Aires Commitment¹ at the Regional Conference on Women in Latin America and the Caribbean charted a path towards a care society, placing gender equality and sustainability at the core of a transformative recovery plan. Most recently, the UN Department of Economic and Social Affairs dedicated the 2023 World Economic Report to drawing attention to inequality, intergenerational equity and the global crisis of care, concluding that ‘effective systems of old-age support will continue to be needed, as will the intergenerational solidarity required to sustain them’ (UNDESA, 2023:iv).

¹ Further details available here: <https://conferenciamujer.cepal.org/15/en/documents/buenos-aires-commitment>

Spurred by the disproportionate effect of the Covid-19 pandemic on older people and its devastating consequences in long-term care settings and facilities, long-term care has climbed higher than ever before on the policy agenda of countries at all stages of economic development. Severe disruptions to rehabilitative, palliative and long-term care were documented early in the pandemic at global level and persisted throughout the global health emergency phase (WHO, 2023a), adding strain to already pressured long-term care delivery structures. As is extensively documented throughout this volume, the need for transformative reforms in long-term care systems has long predated the pandemic, and the many cracks in care systems which made them vulnerable to the shock of the pandemic have themselves grown to crisis proportions. The rapidly growing demand for care (chapter 2), the accelerated erosion of informal care resources (chapter 8) and persistent shortages of adequately qualified care workers (chapter 4), anachronistic financing mechanisms and limited financial protection (chapters 5 and 8), pervasive fragmentation and unwieldy governance (chapter 4), and poor quality management (chapter 6) have all contributed to a growing prevalence of unmet care needs and have exacerbated equity concerns.

Even as the evidence has steadily grown that long-term care systems, in their traditional structures and underpinnings, are not fit for purpose and that care models will need to be transformed, policy responses have, by and large, not risen to the exigency of the challenges ahead. What is holding back more decisive and more impactful policy responses? And more importantly, what can be done to overcome the policy inertia?

The knowledge base summarised in this volume points to a combination of systemic, societal and economic factors which hinder ambitious long-term care reforms – but equally, it offers a series of evidence-based recommendations for addressing each of these factors and guiding meaningful investment in long-term care delivery. More pernicious still are the lack of clarity of purpose, a public and policy discourse which have overwhelmingly focused on problems rather than on solutions, and a plethora of myths and misconceptions about long-term care systems that must be decisively challenged. In closing this volume, we discuss each in turn, restating in short the case for investment and offering a pathway for the transformation of long-term care systems.

11.2 Changing the narrative on long-term care

A right to care

The UN Decade of Healthy Ageing (2020), the Buenos Aires Commitment (2022), the European Care Strategy (2022) and numerous other international, national and regional commitments and frameworks for action propose a rights-based approach to long-term care service and system development. Explicitly recognised as a social right in the European Pillar of Social Rights (Principle 18), a right to care is also a corollary of the rights to health, dignity and non-discrimination (European Commission, 2017).

When interpreted as an individual right, long-term care must be recognised not only as an essential pillar of social protection systems, but also as an integral part of the universal health coverage agenda. To aid governments and policy makers responsible for planning and implementing long-term care service provision at the national or sub-national level, WHO has developed the ‘Package of long-term care interventions for universal health coverage’ (WHO, forthcoming). This provides a list of basic long-term care interventions that are essential for all countries to consider, prioritise and provide, in line with their commitments to establish and expand formal long-term care systems. The core interventions are grouped under four categories: preventive and promotive care; rehabilitative and assistive care; palliative and end-of-life care; and caregiver support services. Two key facilitating factors are also identified as essential to high-quality care delivery: person-centred and integrated care processes, and a fit-for-purpose care workforce with the knowledge, skills and competencies to provide safe and quality interventions.

To deliver on this vision of care, the public and policy discourse must evolve from an exclusive grounding in social solidarity and welfare policy measures towards an explicit recognition of the rights of people to care for others, to be cared for and to exercise self-care. At the same time, there is a need to move away from fatalistic attitudes and short-termism. The challenges facing policy makers who wish to transform long-term care systems are daunting, but this should not constitute an argument for delaying meaningful change.

A more positive and constructive policy debate can start by confronting head-on and moving past commonly held but false beliefs about the

scope for policy intervention in long-term care systems. Based on the evidence presented throughout this volume, five myths of long-term care can be dispelled and replaced with more constructive and evidence-based narratives.

As the population ages, will long-term care costs bankrupt welfare systems?

The myth: Population ageing is frequently described in negative and alarming tones, which focus almost exclusively on the potential downsides and challenges: the grey or silver tsunami, the exploding dependency ratio, the ageing time bomb, the demographic crisis, the burden of ageing, and others. This reflects the commonly held belief that as the population ages, and the proportion of older individuals grows with respect to the working age population, it becomes impossible for public welfare programs to keep up with the exponential increase in costs at the same time as its revenue-generating power diminishes.

The evidence: Indeed, the process of population ageing has long been under way and will continue to deepen (UNDESA, 2019). What is more, we are observing a progressive ageing of the older population itself, as life expectancy continues to increase (the fastest growing age group globally is the oldest old – i.e. 80 years of age or older). It is also true that with increasing age, care needs become more prevalent. We can, therefore, expect a higher share of GDP will need to be allocated for the funding of health and long-term care systems in the future, in addition to other programmes that largely benefit older people (please refer to [chapter 2](#) for a detailed analysis). But the best evidence we have available does not support the conclusion that ageing populations will lead to a rapid and overwhelming increase in health and long-term care costs. Compared to technological innovation and price growth, the effect of population ageing as a cost driver for health expenditure is both modest and gradual (Cylus et al., 2019). Where long-term care services are concerned, a considerable relative increase in spending seems unavoidable but coming from a very low current base, this will not amount to an unsustainable cost pressure. What is more, available projections are highly sensitive to the underlying assumptions. In the EU member states, the demographic effect alone can be expected to lead to a 74 per cent increase in long-term care expenditure (as a percentage of GDP) by 2070, while expenditure

would more than triple (204 per cent increase) if expenditure patterns and coverage levels were to converge across the EU member states. However, in a scenario where people grow older in better health, so that half of the years of life gained to the horizon of 2070 are spent in good health, the projected expenditure increase can be contained to 64 per cent over current investment (European Commission, 2021).

Taken together, this evidence does not suggest that there is little to no scope for policy interventions in the face of inevitable welfare system collapse, but rather the opposite. Both total expenditure on long-term care and care outcomes in the future will overwhelmingly depend on how quickly policy makers react and how they decide to invest the resources available. The long-term care landscape of the future will be determined by the policy choices made today on volume and coverage of care services, investment in cost-effective technological and social innovation, integration of health and long-term care, and diversifying service provision to facilitate prevention, early intervention and better choices at the end of life². Opportunities to reduce the risks of needing care throughout the life course through primary, secondary and tertiary prevention are well documented (Bennett et al., 2022; Fors et al., 2022; WHO, 2021; Ilinca & Suzuki, 2021) but they require coordinated interventions across health, long-term care, education, housing and social protection systems and must be grounded in a commitment to equity. Similarly, the potential of innovative care models and the increased use of technology hold the promise of cost containment without sacrificing the quality or quantity of care, if appropriate investments and incentives are put in place (chapter 4).

Changing the narrative: Delaying both meaningful reforms and the reorganisation of care models in line with demographic, social and technological trends is placing the sustainability of welfare systems at risk and reducing wellbeing at societal level. The longer countries delay, the greater the challenges will eventually be.

² The interested reader is referred to the Economics of Healthy and Active Ageing series, published by the European Observatory on Health Systems and Policies for a structured overview of the evidence available and the policy options that can be derived from it. Available at: <https://eurohealthobservatory.who.int/themes/observatory-programmes/health-and-economy/economics-of-ageing>

Is long-term care a sunk cost which limits economic growth?

The myth: Expenditure on long-term care is often described as a sunk cost (i.e. it does not contribute to productive activity and capital accumulation), which diverts considerable resources from more productive sectors of economic activity and limits potential for growth and development. The more long-term care needs increase, the larger the distortionary effect on labour markets. Care is time and labour intensive, and the more people need care the greater the number of caregivers who need to reduce their work hours or leave the labour market altogether. This leads to loss of productive capacity and economic output.

The evidence: The conclusion of this type of argumentation is indeed worrisome, but it does not necessarily follow from the stated premises. Rather, the evidence available points to key levers of intervention that are not considered at all in this over-simplified approach. As discussed at length in [chapter 10](#), an over-reliance on informal caregiving can and does lead to losses in productivity, keeping considerable numbers of caregivers (mostly women) outside the labour market. But this can be addressed through interventions that promote reconciliation of work and caregiving obligations and through investment in formal long-term care delivery, by workers whose skills are better matched to care tasks, who are adequately trained and who provide care in contexts and settings which allow for much higher levels of productivity. Similarly, while labour intensive, there are no a priori reasons why a formal long-term care sector cannot prove to be innovative, productive, gender transformative and cost-effective. In fact, if pervasive issues linked to poor working conditions, low remuneration, work instability and lack of access to training (Eurofound, [2020](#); The Social Employers, [2022](#)) are appropriately addressed, there is every reason to assume rapid growth in the sector.

Changing the narrative: Investments in the long-term care workforce, innovation, working conditions and competitiveness in the care sector have the potential to trigger flourishing care economies.

Will investment in long-term care crowd out resources for health?

The myth: Due to their overlaps and complementary nature, health and long-term care systems are frequently presented as competing for the

same pool of resources, including financial, human and technological capital. This concern is more pressing in situations where budget constraints or competing priorities arise within health and long-term care systems. If resources are diverted towards expanding long-term care infrastructure and services there will be a corresponding reduction in available resources for investment in improving health care facilities, personnel and equipment.

The evidence: Such argumentation completely ignores that health and long-term care systems are not only complementary but inter-dependent in their functioning and outcomes. [Chapter 7](#) surveys the evidence available on the ways in which strong long-term care systems benefit, rather than weaken, health care systems through reducing demand for more intensive and more costly health services. While not always consistent in its results due to high variability in the quality and availability of data, the weight of available evidence favours the case for investment in better quality and more responsive long-term care services. When imbalances between health and long-term care capacity are pronounced, inefficiencies or even gridlocks in health care can arise – unable to discharge the bed-blockers³ who cannot be directed towards more appropriate care settings due to capacity gaps, hospitals are unable to admit patients who could benefit more from the specialised services they offer. The case of England is telling but by no means singular. The Care Quality Commission’s [2022](#) annual assessment of health and social care delivery found more than half of all hospital discharges had to be delayed due to insufficient capacity in social service and community-based care structures, contributing to record increases in emergency department waiting times and health care delays that put patients at significant risk (Care Quality Commission, [2022](#)).

To ensure that resources are allocated efficiently and effectively governments must build capacity for integrated planning approaches that consider both long-term care and health care needs, service delivery and system organisation. Preventing and compensating for

³ The term ‘bed blocker’ is used in the health care literature to describe a patient who, due to various reasons, has a delayed hospital discharge, leading to an inefficiency in hospital bed utilisation. The term has come to carry a negative connotation, but in no way implies blame on the hospitalised individual for their prolonged stay. Rather, it is used as shorthand for suggesting an ineffective management of care resources.

permanent or transient losses of intrinsic capacity are key to maintaining functional ability over time and rely on a series of actions and services across health and long-term care systems (WHO, 2021), which can only be achieved through access to a continuum of care services. Prioritisation and efficiency considerations in such an integrated planning approach must consider care outcomes beyond short-term indicators of efficiency and focus on maximising quality of life, wellbeing and broad societal impact of available resources.

Changing the narrative: Integrated planning and investment in health and long-term care systems will improve system performance and lead to better health and care outcomes at individual and population level.

Does investment in long-term care benefit only older people in receipt of care services? And does it increase intergenerational inequality?

The myth: Considering the limited fiscal space most countries are facing, it has been argued that public spending on long-term care services crowds out investments in infrastructure, in education, in innovation and in economic sectors that contribute more directly to economic development. Such decisions have considerable implications for intergenerational equity, if a disproportionate share of public resources can be seen as benefitting older generations to the detriment of younger age groups.

The evidence: First and foremost, it is misleading to conclude investment in health and long-term care, if used primarily by older population groups, is less of an investment in productive human capital. Older people, when healthy and adequately supported, contribute in myriad ways to our societies, both within and outside labour markets (Greer et al., 2022). These voluntary, informal and formal contributions accrue at societal level, benefit all age groups and enhance both social cohesion and economic development.

Regarding the balance of intergenerational justice in public welfare spending, the evidence at hand points to increases in public spending for older population groups as demographic ageing progresses. However, there remains significant scope of action for policy interventions and shaping public welfare spending despite demographic trends. While most OECD countries spend more on social programmes that benefit

older age groups (primarily pensions, but also disability benefits and long-term care) than on programmes that benefit primarily younger population groups (e.g., education, active labour market policies, unemployment benefits) this is not strongly correlated with the ageing of their population nor is it a uniform and unquestionable pattern (Vanhuyse, 2013). It suffices to look at examples of countries with similar demographic patterns who have adopted very different policy choices, to conclude that political will and governance cultures determine the shape of welfare policies to a much larger extent than demographics (OECD, 2020).

Nor is it clear that by *not* investing in long-term care systems, governments will be more likely to use whatever resources would be saved in order to address intra and intergenerational equity issues. On the contrary, analyses of the impact on families of underdeveloped social protection schemes for long-term care and the over-reliance on informal care resources (chapter 8) show the detrimental effects on labour supply, income and risk of poverty for caregivers. More worrisome still, it is particularly individuals from lower socioeconomic groups who are likely to be informal caregivers in the first place and see their opportunities for social mobility limited as a result. Large OOP payments for long-term care, even in countries with well-developed care systems, place many families (but especially those in disadvantaged financial situations) at considerable risk of catastrophic payments and of falling into poverty due to care needs. Therefore, the lack of public investment in long-term care systems is more likely to deepen inequalities across the life course (Ilinca et al., 2017) and to act as a vehicle for the intergenerational transmission of inequalities (for example, through the erosion of family assets and the obligation for children to cover costs of care for their ageing parents), which is detrimental to society (chapter 9).

Changing the narrative: Greater consideration of the poverty-exacerbating effects of long-term care for households, particularly those on the lowest incomes, in the design of long-term care systems would improve equity in access and reduce both intra and intergenerational inequalities

Why should the state intervene in long-term care? Wouldn't private markets organise care more efficiently?

The myth: The state's responsibility for long-term care has historically been and continues to be primarily to provide a minimum safety net.

The state should provide basic care for individuals of limited means and with no access to informal care resources, who would otherwise have to go without needed care. Likewise, market mechanisms can ensure care services are produced and provided in an open, competitive market, leading to greater efficiency, innovation and flexibility to respond to diverse user needs. There are numerous experiences with inefficient and costly direct provision of care by public authorities, burdensome bureaucracy and inability to contain costs, while facing difficulties in mobilising sufficient resources for innovation and investment.

The evidence: The debate on whether older people with long-term care needs are better served if governments play a greater role in providing vs contracting care services is complex (Rodrigues et al., 2014). In practice, recent decades have seen an increase in reliance on market mechanisms for the delivery of long-term care services, including in countries where a traditionally strong public sector has increasingly transformed from a provider to a purchaser and contractor of long-term care. As a result, the weight of the policy debate has shifted towards how contracting and public procurement mechanisms can be strategically used to achieve specific policy goals alongside an efficient and transparent allocation of resources.

But while the role of the state in the direct provision of long-term care can be considered as limited and declining, the same argument cannot be made for its role in regulating private provision and financing long-term care (Costa-Font & Raut, 2022). A purely private unregulated market for care would be unaffordable to most, unavailable to many and often of poor quality. The case for the need to develop public financing for long-term care is built in detail in chapter 5, highlighting how the affordability of care can only be ensured through social protection systems that pool resources across the population. Experiments with private health insurance have proven that well-documented market failures (extensively studied also in the case of health insurance) and rapidly rising costs cannot be avoided without significant regulation (if not compulsion) and considerable subsidies. As there clearly is a role for the state in financing long-term care, the more appropriate question is the extent of the coverage a state should provide and how it can best set eligibility for publicly funded programs. The evidence accumulated in countries with well-established long-term care systems strongly suggests that broader coverage and higher access to care lead to better

health outcomes and higher wellbeing, and offer opportunities for addressing socioeconomic inequalities in health and access to care (chapter 3).

Further issues of equity in access are also exacerbated by over-reliance on private provision, with limited oversight and regulation. As private providers seek more affluent markets, the geographical distribution of private (especially for-profit) care services in Europe is biased towards urban areas, while rural communities remain severely underserved (Government of Biscay & Age Platform Europe, 2022). The role of public regulation and incentives for quality development in long-term care provision is surveyed in [chapter 4](#), with growing evidence for the role of system-level strategies (e.g., public reporting of quality information, pay-for-performance schemes) and of interventions to diversify care provision and improve the competencies of the care workforce, contributing to higher quality and choice. Promoting quality in long-term care involves a complex set of tasks for regulators (including, but not limited to, legislation development, accreditation and quality assurance mechanisms, needs assessment and social planning, development of monitoring and enforcement frameworks, reporting). Their consistent application over a territory is impractical, if not impossible, to replicate through self-organisation of providers.

Finally, in democratic societies, the question of the involvement of the state in long-term care, as in any aspect of social life, should reflect the preferences of the population it represents. While the evidence on user preferences on long-term care policies and planning remains limited at best, available data from Europe (collected in 2007 and 2021) confirm strong support for increasing the role of the state in the financing and organisation of long-term care, while support for placing financial responsibility for care with the family is declining (Ilinca & Simmons, 2022). A large majority of surveyed individuals, across age categories, believe public long-term care programmes should cover all care costs or a standard package of care services, indicating the societal value of long-term care is well recognised within and across generations.

Changing the narrative: There is a significant role for the state in the financing, regulation, contracting and monitoring of long-term care services, regardless of whether services are provided in competitive (quasi)-markets by public and/or private providers.

11.3 Conclusion: The value of care and the cost of inaction

Care and caregiving are a universally shared human experience, with profound rooting in and consequences for families, communities and societies. In the broadest sense, care is needed and is provided by every person at least at some point during their life course and therefore affects everyone's wellbeing, participation and opportunities to flourish. More intensive and sustained care spells, associated with declines in intrinsic capacity and functional ability which are the object of this volume, are less frequent and tend to concentrate towards the later stages of life. They are nonetheless common: two out of every three older people are likely to need care and support at some point during their lives. For those who need it, access to appropriate long-term care is essential to maintain quality of life, dignity and social participation, in line with their human rights (WHO, 2022). Whether provided formally or informally, care is a productive activity and an essential contributor and facilitator of human flourishing, economic growth and development.

Viewed through the lens of societal value and by documenting its numerous contributions, the present volume amounts to a case for investment in equitable, affordable and high-quality long-term care. While data gaps limit precision and preclude detailed analyses in large parts of the world (primarily in the Majority World) the evidence at our disposal is sufficient to inform clear policy directions and to sound an alarm over the considerable costs of inaction and delay.

The failure to invest in the development of social protection for long-term care will place increasing numbers of older people and their families at risk of impoverishment and deepening socioeconomic inequalities, limiting potential for economic growth and increasing pressure on social safety nets. Investment in transformative care policies is estimated to lead to net benefits outweighing the costs of implementation for countries at all stages of economic development, and delaying such investments comes with significant opportunity costs (De Henau, 2022).

By imposing stringent eligibility rules for public long-term care services governments may contain expenditure in the short term, but not without wider costs. Restricting access to long-term care will mean that countries fail to take advantage of opportunities to prevent, stabilise and delay functional decline. This short-sighted approach leads to

higher care needs and correspondingly higher expenditure over the medium and long term. Far from freeing up resources for investment in health care and other economic sectors, weak care systems contribute to the accelerated erosion of human capital, depriving communities not only of the valuable contributions of older population groups but also limiting the social and economic potential of their caregivers.

The systematic undervaluing of care and care work, which effectively means millions of formal and informal caregivers subsidise health and long-term care systems through their underpaid or unpaid work, may keep public sector budgetary allocations for human resources in care artificially low. But their direct and indirect costs to economies and societies are incalculable. At the same time, the continued tolerance of gendered roles in care and the undervaluing of women's work is poised to impede any meaningful progress on gender equity and equal opportunities for women and girls (ILO, 2018).

The reluctance to invest in ensuring decent working conditions and decent pay in the care sector places many millions of care workers at risk of poverty and can be directly linked to unsustainable shortages of personnel. This in turn can be linked with important spillover effects for local economies, which can benefit from stability in a sector with considerable growth potential.

All in all, investment in care systems is an economic and social imperative and a precondition for transforming economies to deliver on the outcomes that most matter: wellbeing, quality of life and health for all. Rather than single-mindedly pursuing growth and expecting wellbeing to follow as a necessary by-product, economic systems and cross-sectoral policies must transform and adapt to place wellbeing (at individual, societal and ecological level) at the core of economic activity (WHO, 2023b; WHO, 2023c). This will require a change in mindset among policy makers, and we hope that this volume helps contribute to that shift.

11.4 References

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