

LONG-TERM CARE REFORMS IN OECD COUNTRIES



Edited by
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IN OECD COUNTRIES**
Successes and failures

Edited by Cristiano Gori, José-Luis Fernández
and Raphael Wittenberg



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ONE

Introduction

José-Luis Fernández and Cristiano Gori

Long-term care (LTC) is a key policy priority for governments internationally. Most countries are faced with demographic and/or socioeconomic changes that are resulting in a significant growth in the need for LTC services. The impact of this higher demand on LTC systems is compounded by long-run increases in service unit costs and by reductions in the availability of unpaid care, which still provides the lion's share of the support for people with LTC needs. In addition, the rising political voice of key LTC consumer groups and the mounting pressure on public service budgets mean that LTC is likely to remain at the forefront of the political agenda across OECD nations for the foreseeable future.

Since the 1990s, LTC policies have undergone significant transformations across many countries. In some instances, these changes have been the outcome of major explicit policy goals. In others, new systems have come about through the accumulation of incremental changes. As a result, LTC policy reforms in the last decades across OECD countries offer a rich body of experience that should inform the design of future strategies for improving equity and efficiency in LTC. The main purpose of this book is precisely that: to analyse the range of solutions adopted internationally about how to organise, regulate and fund LTC services in the face of the growing needs of our ageing societies.

Scope of the book

It is important to clarify the boundaries of the analysis in this book given the national variability in the range of services and care needs associated with the LTC system. In this book, we adopt a definition used recently by the OECD, namely, 'care for people needing support in many facets of

living over a prolonged period of time... typically... help with so-called activities of daily living (ADL), such as bathing, dressing, and getting in and out of bed, which are often performed by family, friends and lower-skilled caregivers or nurses' (Colombo et al, 2011, p 39). Whereas many LTC-related policies are introduced without reference to the dependent person's age, there are important differences in the need-related characteristics of care recipients in different age groups, for instance, in terms of their income and wealth, employment status, informal support and health profiles. In certain countries, these differences have led to a separation of the policy-making process between policies about 'disability' and policies about 'aged care'. We concentrate our analysis on the impact of public LTC policies on older people (defined here as those aged 65 and over).

Rather than providing a detailed international survey of LTC reforms, the aim of this book is to draw key lessons from salient policy reforms across all OECD countries. By 'reforms' we mean here both major changes introduced with an explicit policy goal to alter significantly changes in the design of LTC systems, and incremental transformations that actually redefine the system even in the absence of specific changes in legislation. Several chapters include evidence about a large sample of countries, but in a number of them, the analysis is centred on those countries showing the greatest reform activity and where more evidence exists about its impact. This means that a number of the chapters concentrate on various Western European countries, the US, Australia and Japan. With respect to the timeframe considered, the book focuses on recent policy reforms, reaching in certain sections as far back as the early 1990s, if doing so helps the analysis to consider central reforms to the argument considered.

LTC systems have complex legal and structural arrangements. Their features and performance are interconnected with other elements of the welfare system and reflect historical, cultural and environmental factors. It is not the intention for the analysis in this book to derive unquestionable judgements about the success of policy interventions or to attempt to develop infallible recipes for LTC policy reform. Instead, we aim to review the main policy strategies adopted in different contexts for tackling key LTC policy challenges, and to synthesise as transparently as possible the lessons that can be derived in order to inform future policy developments.

Each of the central chapters in the book examines a particular LTC policy area in this spirit.

All the core chapters, apart from Chapter Two, which examines the recent demographic and social determinants of changes in levels of LTC demand, follow a broad common structure around the three key objectives of the book: (a) to highlight the main LTC policy models and reforms adopted internationally; (b) to provide a critical assessment of their successes and limitations in light of the literature and other evidence available; and (c) to draw key recommendations for future policies.

Analytical approach

Even if relatively under-developed compared with areas such as health, pensions or social assistance, the international comparative literature on LTC systems has grown substantially in recent years. Overall, contributions to this literature to date can be divided into four main groups, according to their analytical approach: system mapping, sociology of care, institutional change and public policy approach, which is adopted in this book. The majority of existing publications belong to the first two groups.

Publications adopting the system mapping approach provide detailed accounts of existing LTC systems in different countries, the number of users, expenditure, institutional arrangements, service configuration and so on (see, for instance, Riedel and Kraus, 2011; Rodrigues et al, 2012). These projects fulfil the need for better information about LTC arrangements in various countries, their differences and similarities, and are often promoted by international institutions (such as the European Commission).

The sociology of care literature has concentrated on comparing the response of the Western welfare systems to the changing care needs of the most vulnerable sections of society, often considering jointly the care needs of dependent older people and children. This stream of the literature examines in particular the nature of the interrelationship between key groups in society such as the state, family care networks and private markets. Examples of key contributions to this literature include Le Bihan et al (2013), Pfau-Effinger and Rostgaard (2011) and Leon (2014).

Led by political scientists, the institutional change literature compares the causes of the transformations – in different countries – in the institutions responsible for LTC policy and delivery in response to the new risks faced

by citizens in the post-industrialisation era, and in particular, the rising care needs of dependent older people. Studies in this area have examined the social and economic drivers of change, and the role played in shaping observed changes by social and political actors and by institutional mechanisms (see, for example, Hieda, 2012; Ranci and Pavolini, 2013).

This book adopts a public policy analysis approach, by which we mean that the analysis examines the impact that the measures taken by the different public actors involved in the funding, regulation and commissioning of LTC have on dependent older people with different needs and their carers. Previous contributions to this strand of the literature include OECD (2005) and Colombo et al (2011). The key objective of our analysis is therefore to assess the effects of recent significant reforms on older people and carers in different national contexts. This task is pursued drawing from a range of disciplines including economics, political science, sociology, gerontology and social policy.

Inevitably, the analysis in the book is somewhat undermined by limitations in the comparability of the evidence available across countries. When possible, efforts have been made to standardise data across countries, sometimes at the price of limiting the number of countries and length of period considered. Finally, the breadth of the policy areas examined has inevitably constrained somewhat the space dedicated to each in the book, and thus the amount of detail reported in each of the chapters. References are provided across all chapters to highlighting additional sources of evidence

Outline of the book

The remainder of the book is divided into four sections, each devoted to a key LTC area: funding, models of care, carers and institutional actors. A final concluding chapter summarises the main policy lessons emerging from the evidence analysed, and speculates about future LTC policy directions.

Chapter Two, by Raphael Wittenberg, examines key trends in the drivers of demand for care and support for older people across OECD countries. Wittenberg discusses demographic changes, the prevalence of disability, the availability of informal care and their link to present and future demand for formal care. This chapter sets the scene for the rest of the funding section, and for the book overall. In Chapter Three, José-Luis Fernández and

Pamela Nadash examine recent developments in the funding of LTC services. In particular, they consider reforms aimed at developing new partnerships between individuals and the state for the funding of LTC.

A second set of chapters discusses the issue of models of care in LTC, a particularly multifaceted topic. In Chapters Four and Five, John Campbell et al and Cristiano Gori et al look at how public LTC resources are targeted in different OECD countries. The analysis examines the coverage of publicly funded care, its intensity, and the range of options adopted in the allocation of resources. In Chapter Six, Joanna Marczak and Gerald Wistow focus on patterns of service commissioning, and examine the degree of separation between purchaser and provider functions and recent trends towards marketisation in LTC. Barbara Da Roit, Blanche Le Bihan and August Österle analyse in Chapter Seven the different models of consumer-directed care, ranging from unconstrained cash schemes to the use of voucher schemes for approved carers and service types. Finally, Juliette Malley, Birgit Trukeschitz and Lisa Trigg examine in Chapter Eight policy strategies for promoting service quality in LTC – from directive approaches to the dissemination of information about provider quality, from incentive schemes to top-down managerial approaches.

The section on carers includes Chapters Nine and Ten, and considers both formal (paid for) carers and so-called ‘informal’ carers, family and friends providing support without a pecuniary compensation. In Chapter Nine, Francesca Colombo and Tim Muir examine the policies to address the need for a skilled LTC workforce, looking at the different options to improve recruitment, retention and productivity. In Chapter Ten Ulrike Schneider, Gerdt Sundström, Lennarth Johannson and María A. Tortosa analyse policies to support informal carers.

The last section in the book considers the interaction between the different institutional actors involved in the organisation and governance of LTC systems. Laurel Hixon looks in Chapter Eleven at the relationship between social and health care services for people with LTC needs, and discusses models of coordination, their promise and limitations. In Chapter Twelve, Hildegard Theobald and Elizabeth Ozanne discuss the interplay between central and local levels of government in the LTC area, and look at the implications of different models of interaction.

Finally, in Chapter Thirteen, Cristiano Gori, José-Luis Fernández and Raphael Wittenberg provide an overview of the key messages and policy

recommendations in the book, and speculate about likely future trends in LTC policy-making across OECD countries.

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Part One

Funding

TWO

Demand for care and support for older people

Raphael Wittenberg¹

Introduction

This chapter considers the drivers of demand for care and support for older people and trends in those drivers in developed countries. It concentrates especially on trends in disability, as the key indicator of need for care and support, and trends in household composition, as an indicator of the availability of unpaid care by family members. This chapter sets the scene for discussions in later chapters.

Understanding the drivers of demand is crucial in the context of policy concerns about the future affordability of care and support for older people. Projections of likely future demand are required to ensure that policy decisions are based on evidence, and projections in turn require clarity about the factors that can be expected to have an impact on demand and the likely trends in those factors.

Care and support – often referred to as social care or long-term care (LTC) – aim to help people with personal care and domestic care tasks. The July 2012 White Paper on care and support in England, for example, defines social care as ‘care and support [which] enables people to do the everyday things that most of us take for granted: things like getting out of bed, dressed and into work; cooking meals; seeing friends; caring for our families; and being part of our communities’ (HM Government, 2012, p 13). The Organisation for Economic Co-operation and Development (OECD) has similarly defined long-term care as ‘a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL), such as bathing, dressing, eating, getting in

and out of bed or chair, moving around and using the bathroom' (OECD, 2011, p 14).

Unpaid carers, also referred to as informal carers, provide the majority of care and support for older people. These comprise in particular spouses/partners and adult children/children-in-law of the person needing care, but may include other relatives, friends or neighbours. Since unpaid carers provide so much care and support, relatively small changes in the availability of unpaid care may have relatively large impacts on demand for formal care services.

LTC services include residential care in care homes, day care, a range of home-based care services, professional support services such as social work and occupational therapy and aids and adaptations. They include support for unpaid carers as well as services for those with care needs. The precise boundary between LTC/social care and acute health care varies between countries, as does the terminology, with international literature generally referring to 'long-term care' rather than 'social care' or 'care and support'.

There has been a long-standing policy in most if not all OECD countries towards home-based care rather than residential care, as older people generally prefer to remain in their own homes as long as possible. There is also a developing policy in many OECD countries towards consumer-directed care, known in the UK as 'personalisation'. This may involve accounts or vouchers, such as personal budgets in the UK, which care users may draw on to fund care. Or it may involve cash payments in lieu of care services, such as cash payments under the German long-term care insurance scheme. Recipients may be required to use these accounts or payments for purposes related to their assessed care needs under a care plan, or may be free to use them as they please, including to employ family carers. These changes in the balance between residential and home-based care and in the balance between services and vouchers or cash payments may have an impact on demand, especially if people needing care have strong preferences.

LTC services are by their nature highly labour-intensive. The costs of care are mainly staff costs, especially in the case of non-residential services. The workforce consists in most if not all countries of a minority of highly qualified social workers, nurses or other professionals and a majority of carers who tend to have limited, if any, specialist qualifications. Much of the workforce is low-paid, part-time and mobile between jobs. In some countries there is considerable reliance on immigrant workers. This means that the unit

costs of care such as the cost of an hour's home care are likely to rise in line with average earnings of relatively low-skilled, low-paid workers.

The extent to which there is a market for care services varies between countries. Some countries, such as Denmark, have a tradition of mainly publicly funded provision. Other countries, such as the UK, have a mixed economy of provision, with mainly independent sector for-profit and not-for-profit provision. Where countries seek to move towards a more mixed economy of care, with a greater role for the for-profit or not-for-profit independent sector, this may have an impact on the range of services available to users and their prices.

There is also a variety of financing mechanisms for LTC services. The systems that OECD countries have adopted to fund care fall broadly into four categories, as follows:

- social insurance, as in Germany;
- taxation and means-tested user charges, such as in the US and the UK (except Scotland);
- taxation without means-tested charges, as in Austria, Denmark and Scotland; and
- social insurance and taxation, such as in Japan.

These differences between countries in terms of funding and provision of LTC tend to reflect different cultures and traditions within the broader welfare state. They need to be recognised when considering factors affecting the demand for LTC, especially where countries reform or consider reforming their financing system.

Factors influencing demand and supply of care and support

The demand for most goods and services is generally considered to be a function of their prices, the prices of close substitutes or complements, people's incomes and people's tastes or preferences. The latter may, in turn, be influenced by a range of personal characteristics such as the person's age, gender, ethnicity or education.

The demand for care and support is clearly a derived demand. People want care and support as a means to the enhanced independence and wellbeing that they can promote: they are sought as the means to the ultimate goal of improved outcomes. This implies that the person seeking care and

support perceives a need for care. The person may be unable to perform personal care or domestic tasks without help or may experience considerable difficulty performing them without help. This may be the result of physical or sensory disability, cognitive impairment, mental health conditions or learning difficulties or, especially for people in late old age, a combination of physical and cognitive impairments resulting from a combination of long-term health conditions.

Demand for care and support should be distinguished from need. It takes account of the person's willingness and ability to purchase care and support. If, for example, a person has considerable difficulty conducting personal care tasks but does not want help to perform them, the person could be regarded as having a need for care but not a demand. There is clearly scope for debate about how to define need for care – health care need is often defined in terms of ability to benefit from treatment. On a similar approach, a person could be regarded as needing care and support if they have difficulty with personal care or domestic tasks and could benefit from help with those tasks, that is, if they could achieve better outcomes in terms of wellbeing as a result of receiving help. Demand would then arise if the person not only needed care and support, but also wanted to receive care and was, if required, able and willing to pay for it (Wittenberg et al, 1998).

These considerations suggest that demand for care and support can be regarded as a function of the following: disability that is likely to be associated with physical and mental health; price of care; income and wealth; and preferences that may vary by age, gender, ethnicity and other characteristics.

Three forms of care need to be distinguished in terms of costs to the care recipient: unpaid care by family and friends, publicly funded care services, and privately purchased care services. Unpaid care generally involves no direct cost to the care recipient, although there may be some reciprocation, possibly in terms of a bequest, but this does involve costs to the carer. The second may also involve no cost to the care recipient where care is free at point of use, but does involve a cost where publicly funded care is subject to user charges. The third clearly involves a cost to the care recipient or their family on their behalf.

To understand the factors likely to influence demand for each of these forms of care, it is important to understand the relationship between them. There are several issues to consider. For unpaid care, it is difficult to posit demand for unpaid care in the absence of potential supply. Since most unpaid

help with personal care tasks for older people is provided by spouses/partners or adult daughters or sons, there cannot, in practice, be demand for unpaid care unless the person has a partner or adult child (or, more rarely, other close relative or friend) willing and able to provide care.

Demand for publicly funded care services is likely to be influenced by whether or not the person receives unpaid care, in addition to the factors discussed above. People needing care may have strong preferences between unpaid and formal care. Some may prefer care by close family and seek formal care only if their family cannot provide all the care they need. They may feel that receipt of formal services involves stigma, perhaps especially in countries such as the US and England, where publicly funded care is subject to a means test and intended as a safety-net. Other people may prefer to avoid being or feeling that they are becoming a ‘burden’ on their families, and prefer to receive formal care services.

There has been considerable research interest in the issue of whether unpaid care and formal care are substitutes or complements. Some studies have found that formal services tend not to ‘crowd out’ unpaid care, but may lead unpaid carers to provide different forms of support. Others have found that provision of formal care does tend to lead to a reduction in unpaid care. The evidence suggests that the relationship between unpaid and formal care varies with the type of service, that is, residential care or home-based care, and with the direction of the relationship (Pickard, 2012). Increased provision of unpaid care reduces the use of long-stay residential care, but increases in formal home-based services have little impact on the provision of unpaid care (Pickard, 2012).

The relationship between unpaid and formal care also depends on countries’ policies on eligibility for publicly funded care as well as on the preferences of carers and care recipients. In some countries, including England, eligibility for social care is affected by whether or not the person receives informal care, that is, the system is ‘carer-sighted’. In other countries, including Denmark, the eligibility criteria take no account of unpaid care, that is, the system is ‘carer-blind’ (Eleftheriades and Wittenberg, 2013).

The German long-term care social insurance system does not take direct account of unpaid care when determining eligibility for benefits. It gives beneficiaries a choice between cash or services (or a combination of the two), but the cash benefit is worth only slightly more than half the value of the care package. In France, the availability of unpaid care does not influence into

which of the six need categories – *Groupes ISO Ressources* (GIR) – a client falls, but the availability of unpaid support from the client’s family and social network *is* considered in determining the size and content of the care plan, subject to the funding ceiling for the GIR category. The Dutch eligibility framework distinguishes between the ‘usual care’ provided by others living in the same house as the client, and support provided by other family members, friends and neighbours living elsewhere. Publicly funded support should not replace ‘usual care’, which includes all domestic tasks and personal care for the first three months of a client’s support needs, unless there is a risk of burnout for the carer (Eleftheriades and Wittenberg, 2013).

Demand for privately funded care can be expected to depend not only on the availability of unpaid care, but also on eligibility for publicly funded care. People who are eligible to receive as much free or subsidised care as they require of the quality they require would not seek to purchase care privately. Private purchase is likely where people are not able to receive sufficient unpaid and/or publicly funded care of the quality they want to meet their perceived needs.

In summary, demand for formal care and support services can be expected to depend on a range of factors including: needs in terms of disability, prices of services, income and wealth, availability of unpaid care, the funding system for public programmes and personal preferences. After a section on population ageing, the following sections concentrate on disability and on household composition and unpaid care as key drivers of the demand for care services.

Population ageing

All OECD countries are experiencing ageing populations: this is due to rising life expectancy and, in many countries, to baby boom cohorts starting to reach old age. The proportion of the population who are aged 65 and over, however, varies between countries, as does the projected growth in the proportion aged 65. The variation is even greater for the current and future proportion aged 80+. It is this oldest old group whose numbers are especially important for social care, since social care in later life is so heavily concentrated on this group.

Eurostat projects that people aged 65 and over will become a much larger proportion of the overall European Union (EU) population over the coming decades, rising from 18 per cent of the population in 2013 to 28 per cent in

2060. The proportion aged 80 and over will increase even more rapidly, from 5 per cent in 2013 to 12 per cent in 2060. Across the EU the numbers aged 65 and over are expected to rise by 59.1 per cent between 2013 and 2060, and the numbers aged 80 and over by 138.4 per cent over this period. Projections for a number of countries are set out in Table 2.1 below.

Trends in disability

The need for social care is related not to age per se, but to disability. While prevalence of disability rises with age, it is by no means the case that the majority of older people are disabled to the extent that they require social care. In Britain, for example, around 22 per cent of the population aged 65 and over cannot perform personal care tasks without help. This rises from around 10 per cent for those aged 65 to 69 to over 50 per cent for those aged 85 and over.

Table 2.1: Projected number of people aged 65 and over (millions)

Country	2013	2040	2060
France	11.7	18.4	18.8
Germany	17.1	24.3	22.9
Italy	12.8	19.2	19.9
Poland	5.6	9.1	11.0
Spain	8.3	13.8	13.9
UK	11.1	17.3	19.9

Source: European Commission (2014)

The most important driver of a need for LTC in old age and at younger ages is clearly disability. A crucial issue is how to define disability for the purpose of studying need for care. The International Classification of Functioning, Disability and Health (ICF) defines disability as an umbrella term for impairments, activity limitations and participation restrictions. Under this definition disability refers to ‘the negative aspects of the interaction between individuals with a health condition (such as cerebral palsy, Down syndrome, depression) and personal and environmental factors (such as negative attitudes, inaccessible transportation and public buildings, and limited social support)’ (WHO, 2011, p 4).

The World Health Organization (WHO) reports that the number of people with disabilities is growing (WHO, 2011). They attribute this growth is to

population ageing (older people have a higher risk of disability) and to the global increase in chronic health conditions associated with disability, such as diabetes, cardiovascular diseases and mental illness. They comment that patterns of disability in a particular country are influenced by trends in health conditions and trends in environmental and other factors – such as road traffic accidents, natural disasters, conflict, diet and substance abuse (WHO, 2011).

What matters in the context of need for care is people's experience of needing help and support, and additionally in the context of demand for publicly funded care, the disability-related criteria used to determine eligibility for publicly funded care. The former may differ between societies depending on cultural factors, and the latter certainly differs between countries, or in some countries, between regions or municipalities within countries.

Disability is frequently defined for LTC purposes in terms of ability to perform personal care tasks, or activities of daily living (ADLs), such as bathing, dressing, feeding and using the toilet. Domestic care tasks, or instrumental activities of daily living (IADLs), such as shopping and cooking, may also be considered. In Germany, for example, eligibility for benefits under the German long-term care social insurance scheme is determined in relation to ability to perform ADLs. This does not mean, however, that ability to perform ADLs and IADLs is the only factor generating need for LTC. In particular, cognitive impairment is also very relevant.

It is important in discussing disability rates and trends in disability to recognise a number of key points. First, while there are standard indices of disability, such as the Katz and Barthell measures, the list of ADLs and IADLs used to determine disability status differs in practice, both between eligibility criteria for care in different countries and between surveys used in different countries. Second, there is a variety of practice concerning how disability is assessed in terms of degree of disability: the trigger for eligibility for services or for inclusion among the disabled subgroup in a survey may vary from difficulty conducting an ADL task without help to complete inability to conduct the ADL task. Third, since ADL limitations in surveys are self-reported, changes between countries, or over time within the same country, may reflect differences in attitudes about what constitutes difficulty conducting a task and/or differences in reporting rather than 'real' underlying differences.

The proportion of the population who are severely disabled varies between OECD countries. The OECD studied trends in 12 countries in severe disability (or dependency), defined where possible as one or more limitations in basic ADLs (such as eating, washing/bathing, dressing and getting in and out of bed). This was on the basis that limitations in such activities tend to be closely related to demand for LTC (Lafortune and Balestat, 2007). Findings for several countries are shown in Table 2.2 below, but comparison between countries, in terms of rates of disability rather than trends in rates, is not appropriate because of differences in definitions of severe disability and methods of data collection.

A crucial issue for projecting future demand for social care for older people is whether the prevalence of severe disability will fall as mortality rates in old age fall, or rise as more severely disabled people survive to late old age or remain broadly constant. This issue of the compression or expansion of disability is the subject of much continuing debate. If disability rates fall, this might mitigate the demographic pressures from an ageing population, but if they rise, this would increase the overall upward pressure on demand for social care in later life.

Table 2.2: Proportion of population aged 65+ reporting severe disability

Country	Year	Proportion	Definition of disability
Australia	2003	22.0	At least one profound or severe limitation in core activities
Canada	2003	10.0	Need for assistance for at least one ADL
France	2002/03	15.8	Reporting major difficulty or needing help for some ADLs
Japan	2004	10.8	At least one ADL limitation
Sweden	2004	11.0	Requiring assistance in at least one ADL
UK	2001/02	22.5	Difficulty or requiring assistance in at least one ADL
US	2004/05	16.6	At least one ADL limitation

Note: Comparison between countries is not appropriate because of differences in definitions of severe disability and methods of data collection.

Source: Lafortune and Balestat (2007)

Fries (1980) postulated that increased total life expectancy would be accompanied by a shorter period with morbidity, that is, a compression of morbidity. He believed that there would be an increase in the age of onset of

chronic disease greater than the increase in longevity. Gruenberg (1977), however, argued that the decline in mortality rates from chronic diseases would be accompanied by increased prevalence of such diseases. He believed that falling mortality rates would mean higher survival rates for people with health conditions. Manton (1982) suggested that there would be a dynamic equilibrium. He maintained that decreasing mortality rates would be accompanied by increased morbidity rates, but that the proportion of life with severe morbidity would not increase.

It is important to recognise that the question about compression or expansion need not have a single answer. There could be different trends for prevalence of self-reported poor health, specific chronic conditions, limiting long-standing illness or severe disability in terms of conducting personal care tasks. In the context of our study, what matters are trends in the incidence and prevalence of conditions likely to require long term care services. It is also useful to distinguish between absolute and relative compression or expansion of morbidity. Absolute compression (expansion) occurs when the number of years with morbidity decreases (increases). Relative compression (expansion) occurs when the proportion of life with morbidity decreases (increases).

The OECD study concluded that the 12 countries they studied could be divided into four groups in terms of trends in disability over recent years:

- evidence of decline in disability rates among older people in Denmark, Finland, Italy, the Netherlands and US;
- evidence of rise in disability rates in Belgium, Japan and Sweden;
- evidence of stable disability rates in Australia and Canada;
- conflicting evidence from different surveys in France and the UK.

These findings need to be treated with some caution, since the definitions of severe disability differ between different countries' surveys, and since trends may reflect changes in reporting severe disability without any real changes in underlying health conditions. The OECD conclude that, despite these caveats, 'it would not seem prudent for policy-makers to count on future reductions in the prevalence of severe disability among elderly people to offset the rising demand for long-term care that will result from population ageing' (Lafortune and Balestat, 2007, p 4).

Chatterji et al (2015) found that 10 studies in their recent review contained evidence to support compression of disability, five contained evidence to support expansion of disability, four contained evidence supporting

equilibrium and five had inconclusive results. Studies in most high-income countries, but not all, generally suggested that most indices of ADLs are improving. An analysis by Chatterji et al (2015) of three large longitudinal surveys of older adults in the US and several EU countries with harmonised assessment of ADL and IADL limitations showed varied patterns. Although consecutive cohorts seem to have experienced declines in ADL limitations, limitations in IADLs did not improve.

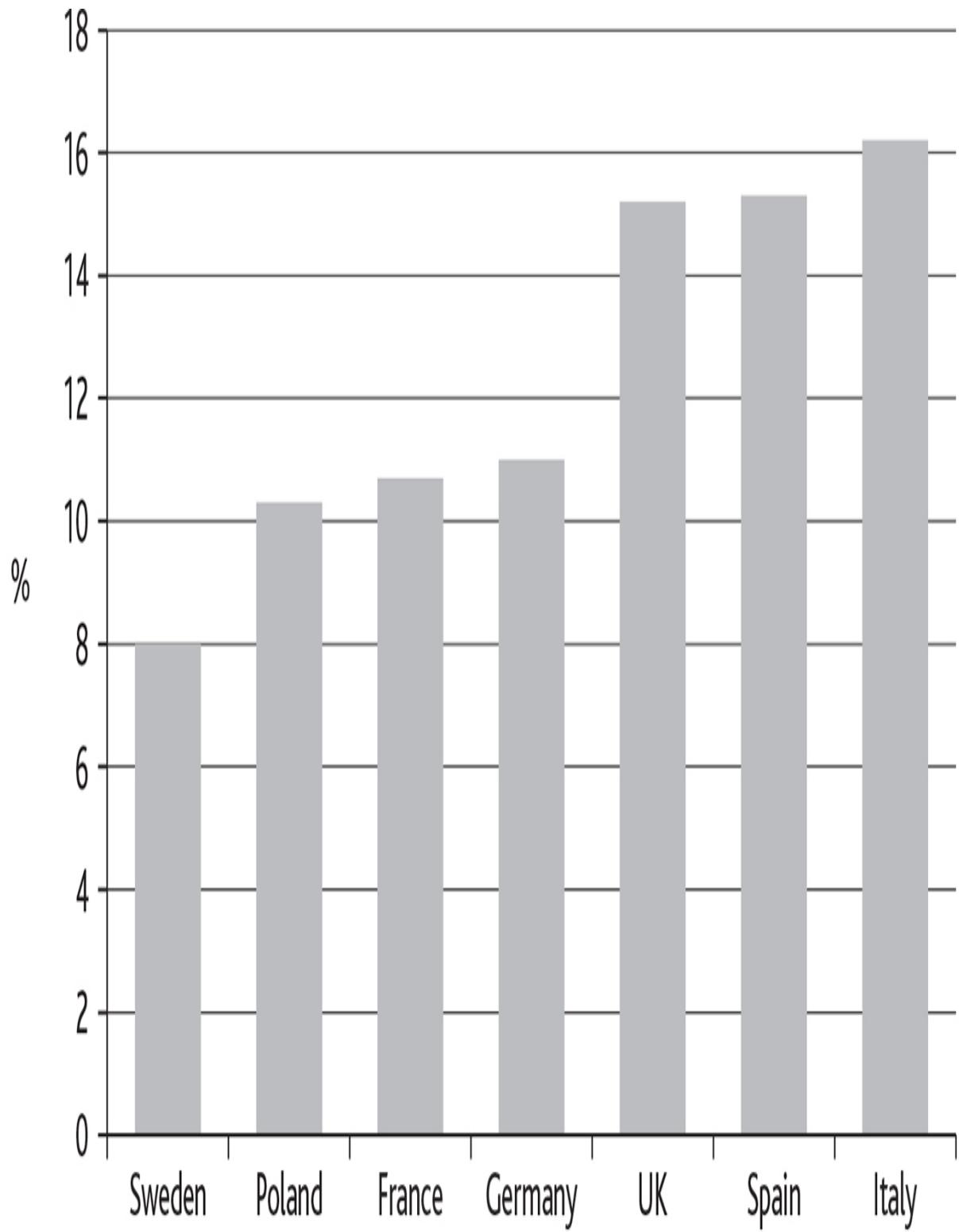
Trends in household composition and unpaid care

The future availability of unpaid informal care will be crucial to future demand for formal care services, as discussed earlier in this chapter. Unpaid carers provide the majority of LTC, and over 10 per cent of the adult population across OECD countries provide unpaid care, mainly for family members, but sometimes for friends or neighbours. This proportion varies between countries (see Figure 2.1) and exceeds 15 per cent for Italy, Spain and the UK (OECD, 2011).

Several questions arise in this context. Will future cohorts of disabled older people be as likely to have a surviving spouse/partner and/or children to provide care for them? Will they be happy to receive personal care from their close family or will they prefer formal services? Will their close family be as willing as current cohorts of carers to provide unpaid care? And if so, will they be as able to do so? Analyses and research have concentrated mainly but not entirely on the first and last of these questions.

During the later decades of the last century, many countries experienced an increase in the proportion of older people living alone and a decrease in the proportion of older people living with their children. In Japan, which has had a tradition of multigenerational households, the proportion of older people living with their children decreased from 87 per cent in 1960 to 70 per cent in 1980 and 47 per cent in 2005 (Japan National Institute of Population and Social Security Research, 2008). Over this same period the proportions living with their spouse only, living alone or living in institutional care rose sharply, to reach 33 per cent living with a spouse, 15 per cent living alone and 5 per cent living in an institution in 2005. Reasons are believed to include not only greater geographical mobility, but also rising real incomes enabling older people to afford to live independently of their families. This means that widowhood has left substantial proportions of older people living alone.

Figure 2.1: Proportion of the population reporting to be informal carers providing help with activities of daily living (ADLs)



Source: OECD (2011)

Many OECD countries prepare projections of their populations by marital status. These are valuable indications of the potential future availability of care by spouses, although a limitation is that projections that relate only to legal marital status will become less useful as cohabitation becomes more common among future cohorts of older people. The rise in cohabitation rates has led the Office for National Statistics (ONS) to produce projections of cohabitation as well as of legal marital status for England and Wales. Their latest projections show a reduction in the proportion of older women who will be widows and a rise in the proportion who will be married. This results from the projected decrease in the difference between male and female life expectancy, suggesting that a rising proportion of women may receive care from their husbands/partners, providing, of course, that the husband/partner is himself in good enough health to provide care.

The Assessing Needs of Care in European Populations (ANCIEN) project produced projections to 2040 and 2060 for four countries – Germany, Netherlands, Poland and Spain – of the supply of regular personal care by people aged 50 and over to their spouse/partner aged 65 and over (Pickard and King, 2011). They project that the supply of unpaid care to spouses/partners will rise between 2010 and 2040 by 29.5 per cent in Germany, 51.5 per cent in the Netherlands, 22.8 per cent in Poland and 56 per cent in Spain. This projected rise is from a low base in the Netherlands relative to the other countries. The projections are on the basis that the propensity of people by age and gender to provide regular personal care to their spouse/partner remains constant.

The ANCIEN project also produced projections for the same four countries of the supply of regular personal care by adult children (aged 50 and over) to older people (aged 65 and over) other than spouses/partners (Pickard and King, 2011). This would include parents-in-law, step-parents, grandparents, aunts and uncles, but in practice is likely to be parents in most cases. They project that the supply of such unpaid care will fall between 2010 and 2040 by 6.3 per cent in Germany and 4.6 per cent in the Netherlands, but rise between 2010 and 2040 by 45 per cent in Spain and 8.6 per cent in Poland. This is, again, from a low base in the Netherlands compared with the other countries. The projections are on the basis that the propensity of people by age, gender and marital status to provide regular personal care to older people remains constant.

A vital question is whether sons and daughters, especially daughters who tend to provide more care than sons, will be able to provide care for their

elderly parents in the future. It has been widely argued that rising female labour market participation will reduce the availability of unpaid care from daughters (see, for example, Fujisawa and Colombo, 2009). The female employment rate across the OECD increased from an average of 47 per cent in 1960 to 62 per cent in 2005 (OECD Statistics, 2008).

The European Commission expects the participation rate for older men (age 55-64) to rise from 62.8 per cent in 2013 to 73.0 per cent in 2060, and for older women from 46.5 per cent in 2013 to 67.4 per cent in 2060 (European Commission, 2014). These projections for the whole EU mask considerable variation between countries. While little change is expected in Nordic countries such as Sweden, for example, where participation rates among older people are already high, rates are expected to rise dramatically in Southern and Central European countries such as Spain and Hungary.

Supply issues and their impact on demand

A discussion of factors influencing demand for care and support needs to pay attention to supply as well as demand issues. The amount of services actually used and their prices depends on the interaction between demand and supply. The supply of unpaid care, which depends, as discussed above, mainly on the availability, ability and willingness of spouses/partners and adult children to supply such care, clearly affects demand for formal care services. The supply of publicly funded care depends on decisions by central and/or local government on how many resources to make available for care and support, which, in turn, are likely to be heavily influenced by societal attitudes towards the welfare state generally and the relative importance of care and support more specifically. Relatively more generous public funding is likely to encourage demand, while relatively less generous public funding is likely to encourage greater reliance on private resources, through private purchase of care and support for those able to afford it, or greater use of unpaid informal care for those with potential family carers.

The supply of services more generally, whether for public sector or private purchase, can be expected to be a function of price (Wittenberg et al, 1988). This highlights the importance of the arrangements for setting prices for care services, which vary between countries. In England, individual local authorities negotiate prices with individual independent sector care providers in a market for care services. Providers, with or without local authority contracts, can also sell services directly to users who purchase care with their

own resources or with direct payments, that is, with cash in lieu of publicly funded services. Where local authorities or insurance funds are the main purchasers of care services, they can have considerable market power. At the same time, providers may be able to obtain higher prices from individual users than from local authorities, resulting in a form of price discrimination, which appears common in the residential care market in England.

The prices of care services are heavily influenced by the wages of care staff, since care services are highly labour-intensive. It has been estimated that some 80 per cent of the costs of care services comprise labour costs, 10 per cent capital costs and 10 per cent other costs such as fuel and food (Heigham, 2005). The balance varies between home care, where the labour costs dominate, and residential care, where capital costs are more significant. In the long term, however, changes in capital costs of property may also reflect changes in average earnings in the economy.

Care staff tend to be low skilled and to earn lower wages than the average wage in the economy, even if often higher than the average for low-skilled professions. In Japan, the UK and the US, care staff typically earn between 50 and 70 per cent of the average wage, while in Canada and Denmark, they earn only slightly below the average wage (Fujisawa and Colombo, 2009). Turnover rates and vacancy rates for care staff are often substantial, with an adverse impact on the quality of care.

Projections of future costs of care and support tend to assume, at least as a central assumption, that the unit costs of care, such as the cost of an hour's home care, will in future rise in line with average earnings. This raises two questions. Will the wages of care staff rise in line with average earnings in the economy? And will there be any scope for efficiencies such that unit costs will rise more slowly than the wages of care staff?

There are two possible views on whether the wages of care staff will rise faster or more slowly than wages in the wider economy. One view is that, as labour demand continues to shift further toward requiring a higher proportion of skilled staff, there will be fewer employment opportunities for low-skilled staff. This would put downward pressure on wages for carers. Another view, however, is that, as demand for care services and care staff rises, there will be increasing shortages of people with an aptitude to work in the care sector. This would put upward pressure on wages for carers. It is difficult to be certain which of these scenarios will prevail.

The scope to improve the efficiency of care services may seem limited since the usual ways of driving efficiency improvements are of limited

applicability. There is little scope to substitute capital for labour, since caring involves almost by definition personal interaction between carer and care-recipient. There is also little scope to substitute less skilled for more skilled staff since in many countries the caring workforce is principally low skilled. There may, nevertheless, be some opportunities to seek improved efficiency. The use of information and communication technologies (ICT) has been suggested (Fujisawa and Colombo, 2009), both in terms of telecare to empower people needing care and in terms of IT systems to help organise care staff's time more effectively.

Preferences of older people and their families

The demand for care depends, like the demand for other goods and services, on the preferences of users. Two issues are especially important in the context of future demand for care and support. First, will future cohorts have different preferences between types of care, especially between formal and unpaid care? And second, will future cohorts expect higher quality care than current cohorts?

Analysis of data from the Survey of Health, Ageing and Retirement (SHARE) collected in 2006-07 in 11 European countries found that one-third (34 per cent) of people aged 50 and over believed that older parents should co-reside with their children when they become frail. This proportion varied from over 50 per cent in the Czech Republic, Italy and Spain, to under 10 per cent in the Netherlands and Sweden. In some countries, including Italy and Spain, children have a duty to care for, or fund the care of, their parents. Similarly, a special Eurobarometer survey conducted in 2007 asked respondents to consider what would be the best option for an elderly father or mother who lives alone and could no longer manage to live without regular help because of their physical or mental health condition. Less than 25 per cent of people in Denmark and Sweden, but over 50 per cent in Germany and Spain, responded that unpaid care by their children would be best (Eurobarometer, 2007).

There are significant cultural differences between countries in expectations about provision of care to parents. If attitudes in countries where there is strong support for unpaid care shifted toward those of countries with lower support for unpaid care, there would clearly be an impact on demand for formal services in the latter group of countries. Since unpaid carers provide the majority of care, this impact could be substantial.

Future cohorts of older people are generally expected to expect higher quality of care than current cohorts. Their expectations may reflect the higher living standards that they have enjoyed during their working lives and their incomes in retirement. Society more widely seems likely to be unwilling to accept the shortcomings in standards of care that have occurred, especially in care homes, in several countries in recent years.

Almost three out of five (59 per cent) respondents to a special Eurobarometer survey conducted in 2007 felt that professional carers of older people were highly committed and doing an excellent job (Eurobarometer, 2007). This varied considerably across countries: for example, the proportion was around 80 per cent in Malta and the Scandinavian countries, but less than 50 per cent in Greece and Spain. At the same time, 55 per cent of survey respondents felt that many dependent older people were becoming victims of abuse from those supposed to look after them (relatives and professional carers). This, too, varied considerably between countries, from over 66 per cent in some Southern European countries to 34 per cent or less in some Scandinavian countries. This suggests that there is likely to be pressure, in some countries at least, to raise the quality of care.

The quality of care and support relies on the skills, knowledge, experience and aptitude of formal and unpaid carers. To raise the skills of carers and to improve the retention of care staff may require more training for carers and higher wages and non-wage benefits. Such measures would add to the costs of care in the future, but may prove essential to promote the quality of care society will expect for their older and younger disabled populations.

Conclusion

There is growing concern across developed and developing countries about the future affordability of LTC as the number of older people rises. Yet it is not age per se, but disability that drives the need for care: underlying need is principally a function of disability, in particular, the inability to conduct personal care tasks without help. There is an ongoing debate about whether as life expectancy rises the period of life with disability will rise, fall or remain broadly constant. Different countries have experienced different trends and may continue to experience different trends in the future.

Demand for LTC as expressed in seeking formal services depends on a number of other factors in addition to disability. Most important is whether or not the disabled older person has close relatives or friends able and willing to

provide unpaid care. This may act as a substitute for formal care, and some countries effectively treat it as a substitute by providing less publicly funded care for people with access to unpaid care than for those without unpaid care. This means that future trends in the availability of unpaid care and policies towards unpaid carers are crucial for considering future demand for formal care. (Unpaid care is discussed later, in Chapter Twelve.)

Demand for publicly funded care depends on the country's eligibility criteria for access to public support. In countries that operate a means test, such that public funding is a safety-net for poorer people, incomes and wealth are clearly relevant, as is the level of user charges. In both these countries and countries where care is free at point of use, effective demand for publicly funded care depends on the needs threshold for eligibility for public support.

Expectations and preferences are also very important. Some societies have a greater expectation than others that children will provide care for their parents when they become disabled. Whether there will be convergence between countries in attitudes and expectations on this issue seems uncertain. Also uncertain is how far future cohorts of older people will expect higher quality of care than the current cohort of disabled older people. This, too, could prove an important influence on future demand for and expenditure on LTC services.

Notes

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THREE

The long-term care financing problem

José-Luis Fernández and Pamela Nadash

Introduction

Every developed nation aims to provide assistance to people with long-term care (LTC) needs. Motivations for supporting such programmes combine recognition of how vulnerable they are with a strong sense of social obligation, particularly towards the older people who comprise the majority of LTC recipients. And yet, the increasing number of people living to older and older ages, along with advances in medicine that ensure that even those with profound impairments live long lives, creates increasing pressure on LTC systems and the funding that supports them. On average across the OECD, it is expected that public LTC expenditures will increase, as a proportion of GDP, from 0.8 per cent in 2010 to 1.6 per cent in 2060 (de la Maisonneuve and Martins, 2013). In conjunction with the more widely recognised crisis in the funding of health services and retirement savings, the growing expense of LTC places pressure on public budgets and reduces funding available for other government services – in some cases, exacerbating political and intergenerational tensions.

Funding arrangements are obviously key to all aspects of performance of LTC systems. This is so not just because of their direct impact on the sharing of the financial burden of care between the state and individuals, but also because by changing the ‘price’ of care faced by service recipients (and often their family) at the point of use, they lead to changes in the patterns of consumption of formal care, therefore affecting the balance between informal and formal care and levels of unmet need.

It is therefore not surprising that many of the most significant LTC reforms in recent years have implied changes in the design of national funding systems. In many instances, funding arrangements have been used to determine directly the care package that is offered by the state. In

entitlement systems, in particular, algorithms are used to define the levels of resources available to individuals with different need-related characteristics, as well as with different combinations of income and wealth. Although in some cases these systems allow for flexibility in the allocation to individuals (for instance, in France or Germany they define maximum levels of support for given categories of individuals), in cash-based social security systems such as the Austrian model, funding systems actually dictate the exact level of support that is provided by the state, and how needs are taken into account to define eligibility.

At the aggregate level, the proportion of GDP consumed by LTC spending represents a significant issue for governments. Figure 3.1 shows the most recent estimates of spending on LTC across OECD countries, both private and public, as a proportion of GDP. Comparisons across countries are, of course, notoriously difficult to make accurately: the bundle of services included as LTC, as well as other factors, such as the extent of undocumented spending on LTC created by grey markets for care, for example, as well as how other programmes (particularly health or social services programmes) in each country are structured and affect estimates of LTC spending. Despite these limitations, Figure 3.1 shows that LTC costs are significant across a large proportion of OECD countries, and exceed 1 per cent of GDP for 18 of the 25 countries shown.

Whatever the aggregate level of spending, each country makes different choices about how its LTC funds are collected and allocated. Politics is, famously, about who gets what and why. In LTC, the ‘who’ reflects choices about the distribution of the benefits – does everyone benefit, or selected populations only? Are there differences in how different populations are treated? Nearly all states share the goal of protecting the most vulnerable with a minimum safety-net, which is often locally administered. In addition, many states, particularly those that value social solidarity, operate universal programmes that benefit all citizens with support needs, to a lesser or greater extent. How they do so varies dramatically, however, with some states providing income-related benefits while others provide flat-rate benefits to all, while still others provide direct services. As a result of these differences, Figure 3.1 also shows important variations in the balance between private and state contributions to the cost of LTC services, reflecting a combination of differences in cultural attitudes to gender roles, intergenerational transfers and the balance of responsibilities between the

state and private individuals. A reflection of these attitudes, the ‘what’, concerns the pool of resources available and how much a particular society wants or is able to invest in LTC – and how that money is raised. Countries may collect funds from general revenue, from a payroll tax, from employers, or via other means. Thus we can see patterns in the range of methods used to fund the programmes, populations covered and the types of coverage provided. However, all states are concerned about the increasing cost of and need for care, and managing costs means managing these different elements of programme design. This chapter looks at how states are adapting to the reality of increasing need and rising costs.

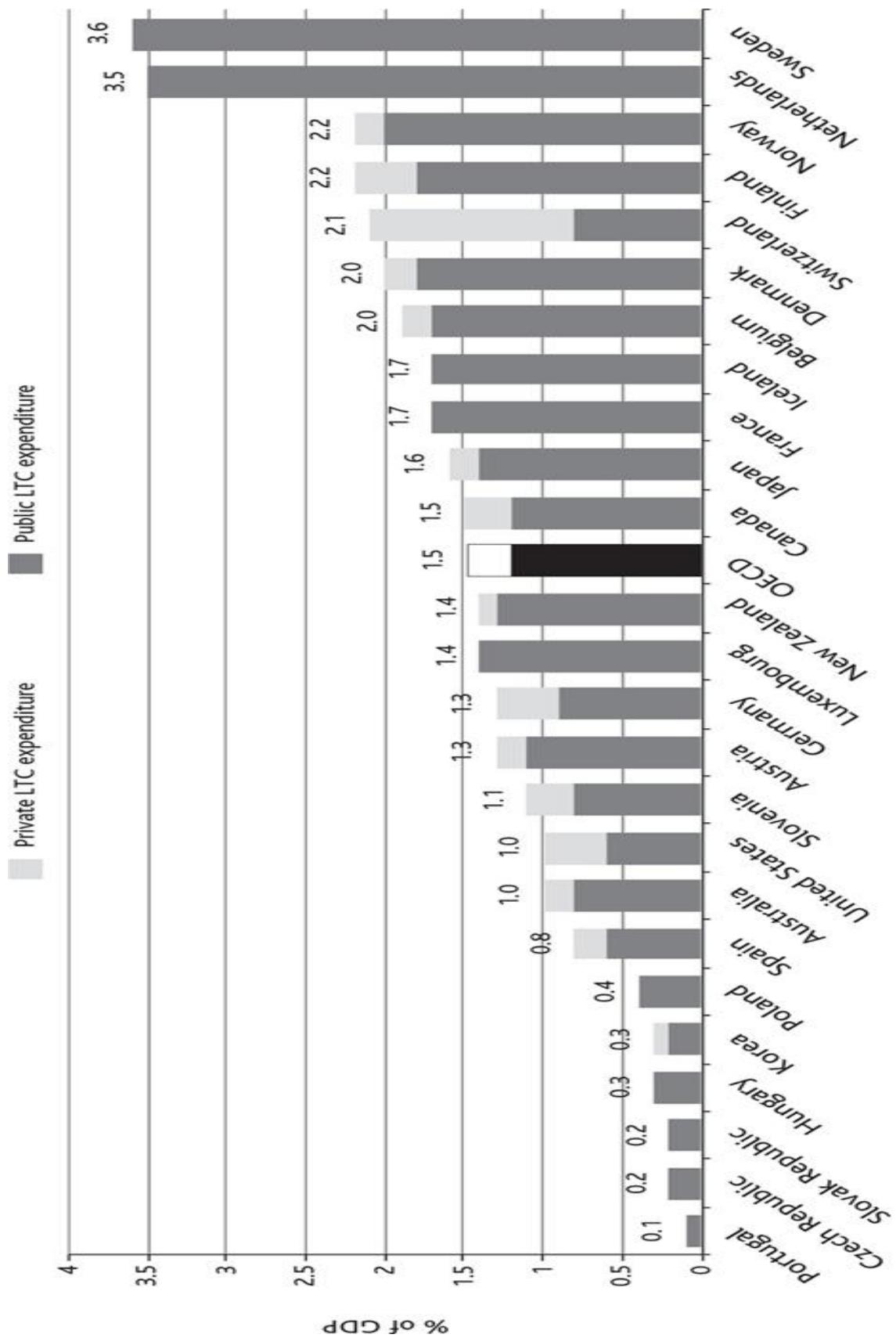
The winding policy reform road

Whereas concerns regarding the so-called ‘ageing tsunami’ have now been voiced for over 30 years (see, for instance, Torrey, 1982), its implications for public finances in general and LTC funding policies in particular have changed over time.

During the 1990s, a number of high-profile changes in funding arrangements across OECD countries aimed to broaden the contributions of the state to LTC costs, in particular, in terms of the universalisation of access to some level of financial cover. One of the first and most prominent examples of the growing involvement of the state in LTC financing was the German reform, which brought about the implementation of a pay-as-you-go social insurance system in 1995, with a headline premium rate of 1.95 per cent of income for working-age adults (shared equally between employers and employees). Pensioners, students and unemployed people paid lower rates. The introduction of the German LTC social insurance system recognised LTC needs as a ‘social risk’ that ought to be covered collectively and in such a way as to minimise individuals’ reliance on social assistance (social security benefits) in order to meet social care costs. Overall, the German social insurance system has been built around, and depends on, the care contributions of informal caregivers, with strong cultural (and legal) expectations that the bulk of the support should be provided by family members. This reliance on caregivers was reflected in the 0.25 per cent extra insurance contributions required of childless individuals (who are less likely to receive informal support), and on the reduction in the value of the benefits when taken in cash rather than

services, an option chosen by a large majority of cases and typically used to compensate family members for the care they provide.

Figure 3.1: Private and public long-term care expenditure across OECD countries (% GDP, 2008)



Source: OECD health data 2010

Following suit, Japan introduced a compulsory public long-term care insurance (LTCI) system (*Kaigo Hoken*) in April 2000. It put in place a mandatory system covering the whole population from 40 years and older. The scheme mixed contributions from general taxation (both nationally and locally) and also from specific age-related premiums: roughly one-half of revenues would originate from taxation, one-third from premiums from people aged between 40-64 (at a rate of 1 per cent of their income), and one-sixth from people over 65 (according to a fixed tariff of premium rates).

Recipients of the Japanese insurance system were required to make a 10 per cent co-payment (reduced on a means-tested basis for lower-income people). The scheme has been primarily designed to cover the care needs of those aged 65 and over; for adults aged 40-64 the system only covered LTC needs arising from age-related disease (such as early onset dementia, osteoporosis and Parkinson's disease). The insurance benefits were designed to cover the total costs of care and were high by international standards (see Chapter Four in this volume for a fuller discussion of the relative intensity of state support across national systems). They vary according to the person's assessed need being classified into seven levels (five care support, and two preventative). Assessment is carer-blind, its design philosophy being that it should help to substitute for informal care rather than complement informal caring, as in Germany. Unlike in many other countries, there is no cash option, and benefits must be taken as formal services in kind.

At the onset of the scheme, accommodation costs in care homes were covered but, in 2005, reforms aimed at controlling the overall costs of the scheme changed the basis of support for these costs from a (full) entitlement basis to a means-tested basis. The 2005 reforms also re-defined (and reduced) levels of support for lower-needs groups. Before 2005, low-need people received care services whereas now they receive (cheaper) preventative services.

As in Germany, the introduction in 2002 in France of the *allocation personnalisée d'autonomie* (APA) was justified in the view that the risk of developing LTC needs should be addressed collectively as a 'societal risk'. The APA was funded through general taxation but implemented at a regional level. Access to the system was universal, as with the German and Japanese systems, but the amount of support people received was set to depend on their financial means as well as their level of assessed need. In this way people were entitled to state support ranging from 90 to 10 per cent of the assessed care costs depending on the income and assets of the service user.

Overall, many service users were responsible for a large proportion of their care charges.

The APA system restricted eligibility to people over 60 years of age. It was defined on the basis of a specific assessment scale (the Autonomie Gérontologie Groupes Iso-Ressources [AGGIR]) with five levels of need reflecting an individual's capacity to perform activities of daily living (ADLs) and their mental health state. Although service users enjoy considerable freedom in their choice of support services, APA resources cannot be received as a direct payment or used to pay a spouse. In residential care, individuals are responsible for their accommodation costs, supported by means-tested social assistance if they lack sufficient funds.

In addition to the support provided through the APA, the French system offers incentives for individuals to pay for care privately, with people able to partially count these expenditures to offset their income tax liabilities. These are particularly effective for higher-income people, who by definition receive the lowest levels of state support through the APA. With the aim of encouraging the employment of personal and domestic staff in the home, families can deduct from their income taxes half the cost of employing declared workers, up to £10,200 per year (this excludes support purchased through the APA). In residential care, the costs of long-term nursing or residential care are eligible for a tax allowance of 25 per cent, up to £2,100. Furthermore, insurance pay-outs are not taxable and are excluded from the income assessment of the APA means test.

Other systems followed in the steps of Germany, France and Japan. In 2006 Spain, for example, introduced the *Ley de la Dependencia* that aimed to set, on the basis of a common needs assessment algorithm, minimum levels of financial support for people with LTC needs across all Spanish regions. However, the implementation of the new system has been hampered by problems in the collection of data to judge eligibility for state support, and most importantly, by the advent of the financial crisis soon after its implementation. As a result, the drive towards austerity in public spending has slowed down the roll-out of the national care system, with individuals other than those with the highest levels of need becoming excluded from the scheme, and levels of coverage significantly curtailed relative to the original proposals.

Even prior to the international financial crisis of 2007, and in contrast with the efforts to broaden state financial support described above, some Nordic European countries have started to reduce support in their traditionally

comprehensive state-funded LTC systems. This process, which represented a degree of convergence in levels of support across European countries at least, was achieved through measures such as increases in user charges (particularly in Finland), toughening of care eligibility criteria, and greater emphasis on the use of market-like allocation mechanisms such as the use of vouchers (Colombo et al, 2011; Vaarama, 2012).

In more recent years, the combined effect on public expenditures of increasing demographic pressures, the financial crisis, and the associated austerity measures has led to a change in the direction of many national LTC funding policy reforms. As a result, many governments are slowing down, stopping, and in some cases reversing the process of universalisation of LTC state support. Instead, the policy emphasis is being placed on developing funding policies that contribute to increasing efficiency in the care system, by ensuring the targeting of available resources on the neediest, and by incentivising private financial contributions in the context of a growing need for ‘individual responsibility’. We review below some of the most notable policy trends seeking to develop new forms of partnerships between the state and private individuals, including a focus on covering catastrophic costs (rather than the ongoing cost of care) and recent expansions in private coverage.

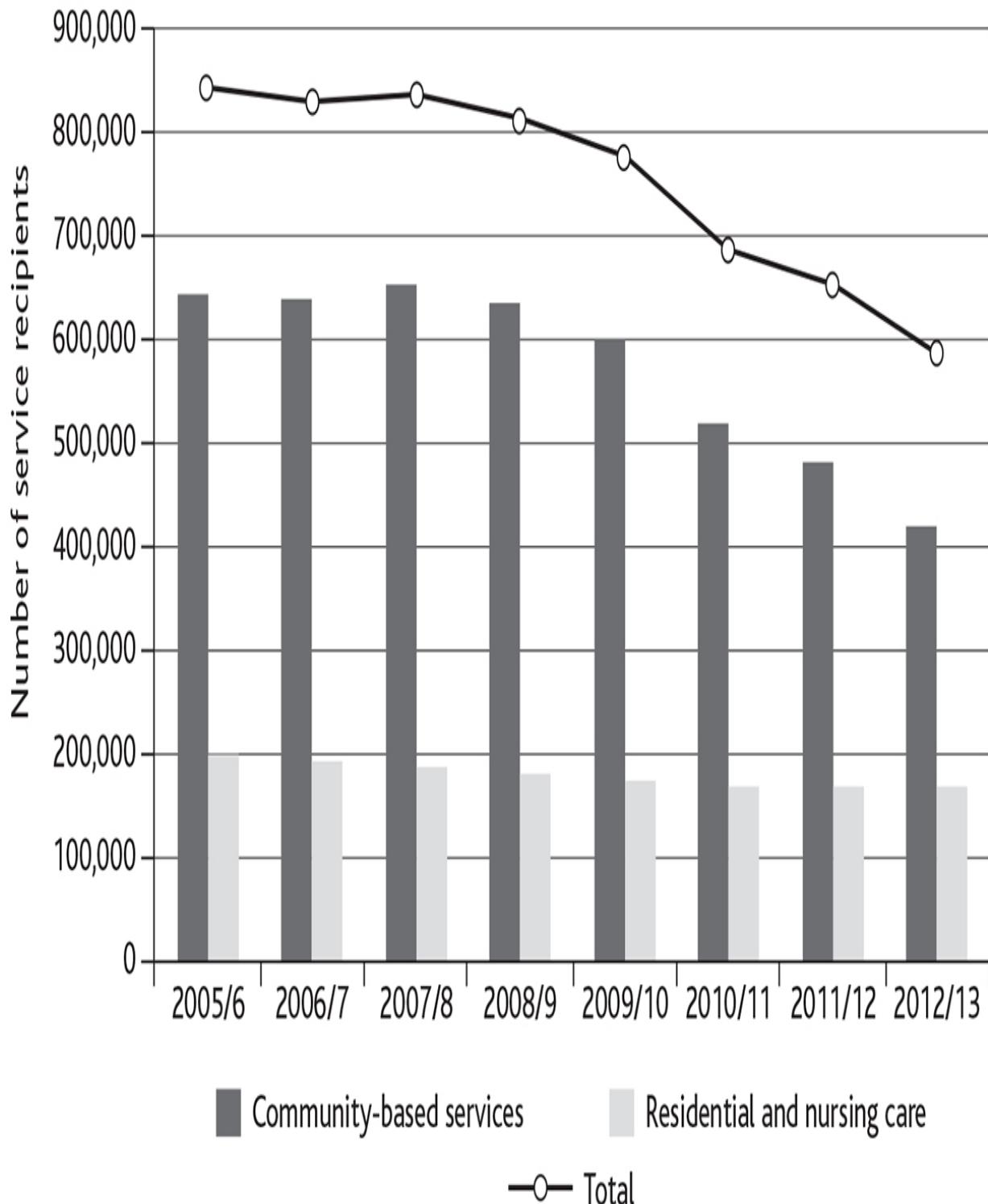
Covering against catastrophic costs

A long-standing social care policy objective in England has been the need to target resources as efficiently as possible (Davies et al, 2000). Already heavily rationed on the basis of a severe income and assets-based means test, over a period of time exceeding two decades, services have become increasingly concentrated on those with the highest needs. Predicated on the need to reduce the risk of institutionalisation, since the 1990s this process has led to continued reductions in the total number of older recipients of local authority-funded social care. As indicated in Figure 3.2, the fall in recipients has accelerated since 2007, fuelled by austerity policies. In contrast with previous trends, however, this fall has been accompanied by real-term reductions in state social care expenditure. Controlling for need and sociodemographic patterns, recent estimates suggest a 39 per cent reduction in the likelihood of receipt of state-supported LTC services among older people over the period 2005/06 to 2012/13 (Fernández et al, 2013).

Not surprisingly, the unprecedented retrenchment of state social care support in England has led to concerns about its impact on the welfare of individuals left with the responsibility to self-fund their care. Given the long-term nature of social care needs, particular concerns have been expressed about the risk of asset depletion linked to the potentially very significant lifetime care costs. These risks are illustrated in Figure 3.3, which depicts the distribution of lifetime care costs for a hypothetical cohort of 65-year-olds in England (as reported in Fernández and Forder, 2011). It shows how even though a sizeable proportion of individuals (approximately a quarter) will not face any significant lifetime care costs, approximately one in ten is expected to be subject to what have been termed ‘catastrophic’ care costs (exceeding £100,000 or approximately €140,000).

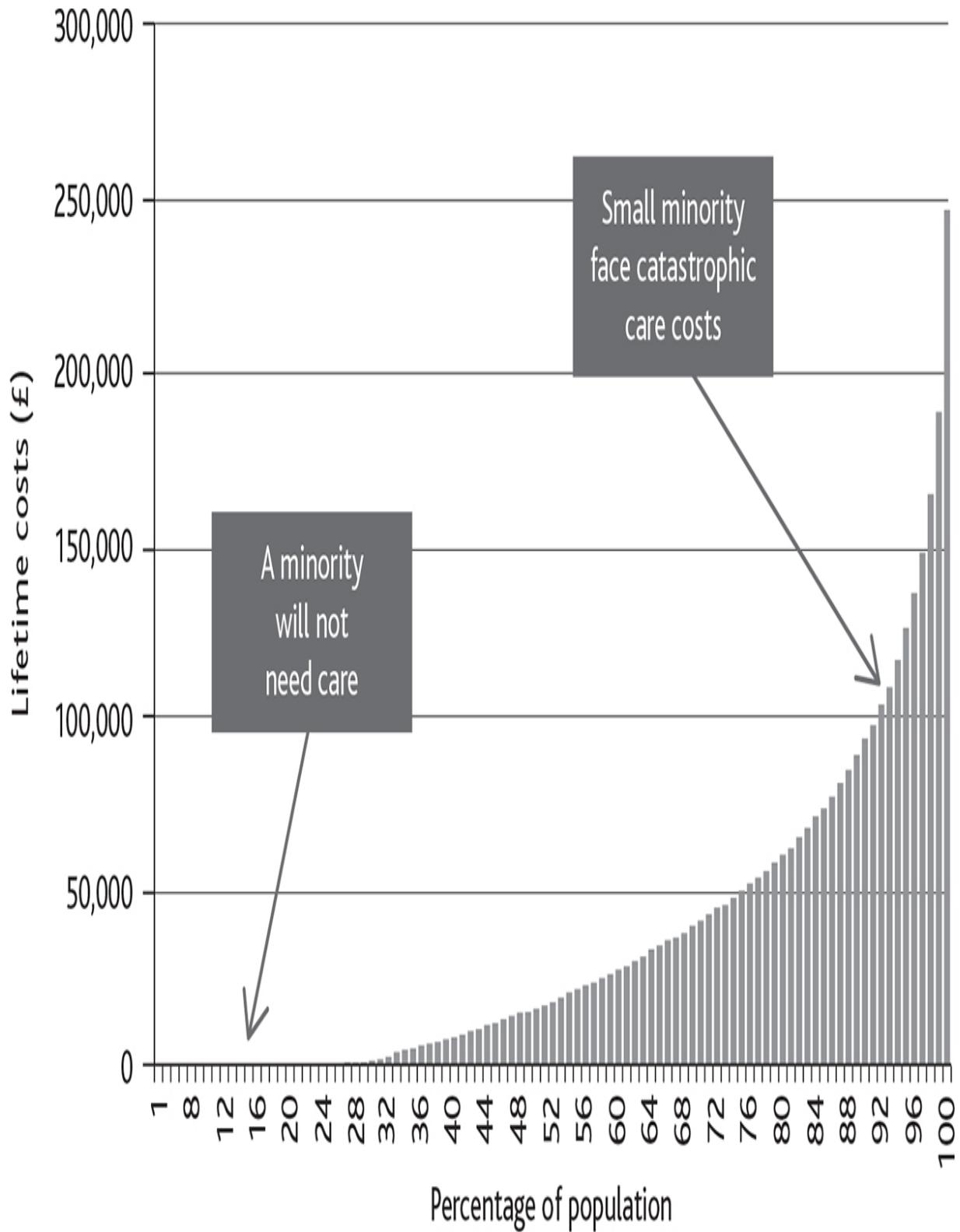
Figure 3.2: Total number of older people receiving state-organised social care services in England by broad service type

Total service recipients by service type (adults aged 65+)



Source: Health and Social Care Information Centre

Figure 3.3: Lifetime care costs for 65-year-olds in England



Source: Reworking of data from Fernandez and Forder (2011)

In 2010, the English Department of Health set-up a Commission on Funding of Care and Support, led by Sir Andrew Dilnot, tasked with the objective to find a new funding system that would meet the costs of care and support as a ‘*partnership* between individuals and the state’, and in such a way as to ‘*protect their assets*, especially their homes’, against the cost of care. In its report, the Commission recommended the introduction (as an addition to the existing means-tested system) of a lifetime cap on private contributions to care costs set at £35,000 (approximately €48,000), together with some changes in the means test asset threshold setting financial eligibility to care. Importantly, the cap would only apply to care costs, with accommodation costs in residential care still being the responsibility of private individuals. The proposed cap on lifetime private care expenditure could be described as a longitudinal extension of the means test, allowing the state to target resources and offer financial protection to those incurring the greatest cumulative care-related financial losses.

The UK government adopted proposals for a lifetime cap in the Care Act 2014. However, the cap was set at a much higher £72,000 (approximately €100,000), thus reducing significantly the number of potential beneficiaries of the policy (as well as its cost to the state). Although the re-election of the Conservative government in the 2015 UK General Election appears to guarantee the implementation of the cap system in April 2016, the planned reforms have come under heavy criticism. In particular, critics have argued that although the explicit aim of the cap is to reduce the risk of asset depletion, in practice it offers little protection against catastrophic costs due to the very high cap threshold, the fact that accommodation costs (equivalent to £230 or €320 per week) are excluded, and that many individuals will be subject to considerable top-ups in order to access residential care homes of reasonable quality. As a result, many individuals could still be expected to contribute significantly in excess of €140,000 before the cap applies to them, and even then would be expected to contribute approximately €14,000 per year in accommodation costs.

Although driven to a lesser extent than the English case by the need to cut public expenditure, the Australian LTC reforms Living Longer Living Better share the principle of targeting care resources on people with the greatest needs and the lowest income and wealth. Enacted into legislation on 26 June 2013, they introduced new means-testing arrangements and the requirement for users to pay fees and charges for LTC services and accommodation costs in residential care. Under the new system, means-testing arrangements take

into account income for home care and a combination of income and assets for residential care.

In line with the Dilnot Commission, the new Australian system has put in place a combination of yearly and lifetime caps on private care costs. For home care services, the annual caps for care are set at AU\$5,069.84 (approximately €3,600) for older people with income below AU\$48,583.60 (approximately €35,000), and \$10,139.68 (approximately €7,200) for older people with income above AU\$48,583.60. For residential care services, the annual cap for care is AU\$25,349.21 (approximately €18,000). The lifetime cap for all types of care is set at AU\$60,838.12 (approximately €43,000), a level much lower than the English cap.

The reforms also saw the creation of the Aged Care Financing Authority, with responsibility to monitor and advise on fees and charges, including accommodation payments. Although no data appears to be available yet on the number of users reaching the cap, the Australian cap system appears to offer a much greater degree of protection against the risk of catastrophic expenditures, and is therefore more likely to gain public acceptance.

Emergence of private long-term care insurance

In most countries, public financing is insufficient to cover the full cost of LTC for those who need it, whether they receive it at home, in residential settings, or in institutions. Safety-net programmes (often locally administered) typically serve to protect the most vulnerable. However, where there are gaps in coverage, some nations are encouraging – or if not encouraging, enabling – the purchase of private LTCI to fill that gap. Such an approach expands protection against the potentially devastating costs of LTC while limiting government liability for programme expansions. Two countries have seen notable growth in the market for private LTCI – France and Germany – while the country with the largest market for private LTCI, the US, is experiencing something of a crisis.

In the US, private LTCI covers roughly 7.6 million lives – about 12.4 per cent of people 65 and older – and accounts for 7 per cent of national spending on long-term services and supports (LTSS) (excluding spending on assisted living) (Johnson and Park, 2011). However, the private LTCI market is in deep trouble there. Despite relatively strong market penetration, sales have been essentially flat for the past decade, and many insurers have exited the market – about a dozen companies are currently still selling a meaningful

numbers of policies, down from the 102 companies the industry reported selling policies in 2002. Trends on the purchasing side are even less promising: over the past 20 years, the average income of LTCI buyers compared to non-buyers has increased, and the average cost of premiums has increased markedly as well (America's Health Insurance Plans, 2012; Cohen et al, 2013). In short, insurers have chased the high end of the market, offering ever more comprehensive (and expensive) coverage, deterring many potential purchasers with the perceived high cost (and complexity) of products. Moreover, US insurers were hit hard by the recession, so that poor investment returns had a significant impact on their reserves. In addition, they have had difficulty predicting costs and setting premiums appropriately. Thus, higher-than-expected pay-outs (due to people living longer and failing to lapse as expected) as well as greater exposure to risk (due to the potentially large size of pay-outs because of the policies' generous coverage) have resulted in insurers increasing premiums significantly, screening applicants more closely, or dropping their LTCI business entirely – and deterring purchase even further. The future of the private LTCI market in the US is therefore highly uncertain.

Moreover, although the private LTCI market has been encouraged in various ways by government policy, it has failed to achieve important public policy goals: significantly reducing the likelihood of people relying on public safety-net programmes covering LTC (the US Medicaid programme), and protecting financially vulnerable individuals from the financial risks posed by LTC needs. Indeed, LTCI is primarily purchased by upper-income individuals who are arguably able to self-insure, and who are at risk neither of 'spending down' to Medicaid (that is, spending all of their resources until they are poor enough to qualify), nor of losing their financial security due to high LTC costs. Attempts to broaden the market – through tax incentives, for example – have evidently failed. However, the current crisis in the market may incentivise insurers to change their tactics to appeal to a broader market; indeed, there are indications that some insurers are investigating innovative strategies for reviving the market (Doty et al, 2015). Given that the political environment in the US makes it highly unlikely that any public solution to the LTC financing crisis will be reached in the short to mid term, innovation by insurers is the best hope for expanded financing for LTC.

In contrast to the stasis in the US market, the French market has expanded remarkably over the past decade, with 5.7 million policy-holders in 2012 (out of a total population of 66 million), up from 1.6 million in 2004 (FFSA,

2009, 2013). Moreover, the French market is growing at a steady rate of roughly 5 per cent per year. Much of that growth has been seen in the group market, which comprises 75 per cent of all policies (FFSA, 2013).

Several reasons have been proposed for the relative success of the French private LTCI market. Probably the most important factor is the structure of the country's public benefit, which was established in 2002. One of the notable features of the APA is its income-adjusted design, which creates strong incentives for supplementation: upper-income individuals (earning more than €2,927.66 in 2013) pay a 90 per cent co-payment toward their APA benefits. Because nearly all French (96 per cent in 2010) have supplemental private health insurance (OECD, 2012), they are accustomed to purchasing private insurance to top up public benefits. Moreover, the cost of the insurance is currently quite low: €345 per year in 2010 for individual policies, a figure that has remained relatively stable over the past few years. Coverage can be even less costly (an average €322 per year) if the contract covers only 'severe' dependency, which about two-thirds do. Group policies are even cheaper: the typical premium averages €74 annually, with 40-50 per cent of the cost borne by the employer (FFSA, 2013). Another factor is that the policies are relatively simple to understand: benefits are paid in cash rather than on an indemnity basis. Consequently, private LTCI in France is held by those most likely to be vulnerable to financial risk: middle-income professionals such as teachers.

However, the low price of the policies comes with a downside. First, and most importantly, the benefit amounts do not come close to meeting the full cost of care. It is estimated that the APA and supplemental insurance together cover, on average, only about 32 per cent of the average monthly cost of care (Le Bihan and Martin, 2010). Second, the level of disability required to claim benefits is quite high, particularly if a policy only covers severe dependency. At a minimum, this requires claimants to be bed- or chair-bound and require daily assistance several times a day, or require constant monitoring due to cognitive impairment. Thus, while private LTCI reduces financial risk to some extent, it benefits only the most severely impaired, and covers only a portion of their liabilities. Moreover, it fails to cover those with existing health conditions.

Clearly, private LTCI represents only a part of the LTC financing solution in France, albeit one that appears to be embraced by many French: a surprising 41 per cent support a mixed public-private approach to dealing with the LTC financing problem (Mutualité Française, 2011). This approach

has been adopted even by the Socialists: President Hollande recently made several legislative proposals that combine enhancements to the APA benefit with a strengthening of the private LTCI market, although the future of these proposals is unclear. Thus it seems likely that French policy-makers will continue supporting the private LTCI market, if not actively encouraging it to the extent of the previous government.

Until recently, Germany had a fairly limited private LTCI market, covering the roughly 9 per cent of the population that opted out of the public health insurance programme to buy private health insurance; private LTCI was offered as a supplement to private health insurance. From January 2013, access to private LTCI was made available to the wider population, with a goal of enabling them to supplement the public LTCI, which provides a benefit that is widely acknowledged to only partially cover care needs. Indeed, the public LTCI was never meant to cover the full cost of care, nor, in the view of Germans, to replace the primary role of families, neighbourhoods or other forms of voluntary care and support. Promoting a broader private LTCI market is seen as a way to encourage people in Germany to take responsibility for their future LTC needs, and to increase awareness of the need for private provision. As such, the government contributes €5 monthly to premium contributions for qualified plans.

The enabling legislation set a number of minimum requirements around these products, but otherwise left the design of the policies up to the private sector, consistent with Germany's overall corporatist approach to social welfare. These minimum requirements include, most importantly, a ban on underwriting (that is, taking the applicant's health status into account when selling a policy), assessing an applicant's health status, using assessed risk to set premiums, and benefit exclusions are not permitted. Only those already claiming benefits from existing LTCI policies can be prevented from purchasing the new private plans. The amount of insurance premiums depends exclusively on the age of the insured at the time of purchase and on the contracted scope of services, although premiums may not be less than €10 per month, net of the subsidy.

When beneficiaries meet the criteria to qualify for benefits, they receive cash payments based on a three-level classification of need: insurers do not pay providers directly and the payments may be used in any way. In this, it replicates one of the notable features of the public LTCI programme – its relative lack of controls over the use of cash benefits. Benefit amounts are tied to the public system's assessment categories with a minimum benefit at

each level of care (for example, €600 per month at care level III) and a maximum not to exceed the public benefit at each level. Further, there is a maximum waiting period of five years before benefits may be claimed. Assessment of care needs is conducted by a quasi-independent body, the same one that determines need for the public programme. Finally, the government set a cap on the insurance companies' administrative costs.

The initiative has proved highly successful: just six months after its launch, 24 insurance companies offered policies under the new legislation. The insurance industry reports that they sold an estimated 400,000 in total contracts by the end of 2014. Moreover, it is not just older people who are purchasing the products, which bodes well for the future of the market: more than 40 per cent of all policies were purchased by people between 25 and 35 years of age. Overall, about 65 per cent of the newly insured are younger than 50 and only 13 per cent are over 60. Thus, the new private LTCI market represents an important and potentially growing component of the LTC financing picture in Germany.

Retrenchment in the Netherlands

Historically, the Netherlands has had one of the most generous LTC programmes in the OECD. In terms of per capita spending, it ranks highest (paying an average €1,209 per participant in 2010); in terms of proportion of GDP spent on LTC, it ranks second. Moreover, these costs have been steadily rising, up to €20.5 billion in 2008, from €12.8 billion in 1998. The proportion of GDP spent on LTC rose from 2.2 per cent in 1985 to 3.8 per cent in 2009 (OECD) – more than twice the OECD average. About a fifth of the programme's funding comes from general revenues, with the remainder from payroll deductions of 12.15 per cent of income (up to €32,000), split between employers and employees, and deductibles (Bootsma, 2011). This payroll deduction is far higher than, for example, the deduction that funds Germany's programme, which is set at 1.95 per cent for most citizens (also split between employers and employees). These high programme costs have resulted in a significant political crisis (in parallel with a similar crisis in the healthcare system) and a consequent overhaul of the LTC system.

The Exceptional Medical Expenses Act (AWBZ) established the programme in 1968. It is the oldest in the OECD and paid out generous benefits, mainly to older people (three-quarters of participants are 65 or older) and physically or mentally disabled people (about 14 per cent are

classed as psychiatric patients, which includes people with autism) – generally speaking, eligibility is much broader than in comparable nations. Benefits included nursing home care as well as in-home services. The programme also offered a cash benefit, which paid participants an individual budget that could be used to purchase supportive services. Despite this support for in-home services, the Netherlands has had a far higher rate of institutionalisation than comparable nations, with roughly 6.6 per cent of older people living in nursing homes (in 2009), often with acuity levels that, in other countries, would be managed in community-based settings. Roughly 43 per cent of programme participants lived in nursing homes and 57 per cent at home in 2010 (Bootsma, 2011). The programme also covered the cost of semi-permanent hospitalisations. These two elements – the high rates of institutionalisation and the growth of personal budgets – along with broad eligibility requirements, raising quality standards and spillover from other social programmes, seem to have been critical in the programme's cost expansions (Mot, 2010; Schut 2013).

Given the high costs of the programme, policy-makers have taken radical steps. The first cost-control strategy involved reining in the cash benefit, which was seen as a cost driver. The Persoonsgebonden Budget (PGB) was originally phased in during the 1990s, due to pressure from disability groups. Under the programme, cash is paid at 25 per cent of the cost of in-kind services. Following its launch, enrolment grew rapidly and significantly – from 13,000 in 2001 to 130,000 in 2011 (Bootsma, 2011), comprising roughly 18 per cent of AWBZ participants. Costs increased at an average rate of 23 per cent per year (van Ginneken, 2015). Not only was the benefit seen as too popular, it was thought that it encouraged caregivers to substitute paid for unpaid care. Others attributed the growth in costs to changes in disability programmes: as services for people with autism were shifted to the local level and became less available, increasing numbers applied for personal budgets (White, 2011). Others alleged that fraud was an important factor, particularly given the relatively lax controls built into budgets (van Ginneken, 2015).

Consequently, programme changes have been introduced, some specific to the PGB and some for the programme as a whole. The biggest changes were to the PGB, which has frozen enrolment since 2010; subsequent rule changes will restrict access to the programme in future. These new regulations, in 2012, also introduced fraud prevention and accountability measures. And while personal budgets could formerly be used for people living in nursing homes, they have been restricted to those receiving in-home care (White,

2011; van Ginneken et al, 2012) who are at risk for residential care (Bootsma, 2011). For the AWBZ programme as a whole, tighter eligibility criteria have been introduced, and, to prevent families from substituting paid for family care, the availability of family care is now a factor in determining benefit levels (Schut and van den Berg, 2010).

The programme has also been re-structured. Most importantly, nursing home care is being moved from the LTC programme altogether and into the health programme (Schut, 2013). Other reforms focused on decentralisation, with certain responsibilities and some costs being devolved to municipalities in 2007, creating a split between ‘care’ (including personal and nursing care), which continues to be funded through the AWBZ programme, and ‘social care’ (including domestic help, home adaptations, psychosocial supports, mobility devices and transport), which are now the responsibility of municipalities (Gadsby, 2013). For the care component, purchasing responsibilities for all but a few services are being shifted from the municipalities that previously administered the programme (which are viewed as having no incentive to keep costs down) to the same insurers who administer the Netherland’s health programme. Thus, these insurers will be responsible for both the health and LTC needs of their members.

A cautious approach to social insurance in East Asia

Japan, South Korea and Taiwan have evolved a distinctive approach to financing LTC. Generally speaking, they share important features of their social welfare development, such that some scholars have hypothesised a unique East Asian approach. The countries are united by their history of authoritarian rule and Japanese domination as well as their emergence as pluralist democracies with a strongly capitalist bent, sometimes characterised as ‘productivist welfare capitalism’ (Holliday, 2000; Ramesh, 2003; Kwon, 2007; Cheung, 2009). For these countries, a comprehensive welfare programme is seen as a marker of a developed nation. Impetus for introducing the ageing-related components of their welfare systems is spurred by their shared demographics: low fertility rates (1.4 for Japan, 1.25 for Korea and 1.1 for Taiwan; see CIA, 2014) and a rapidly ageing population; Japan stands out in this latter regard, with nearly a quarter of its population already 65 or older. Although the proportion for Taiwan and Korea is currently about 12 per cent, it is expected to increase precipitously, reaching 20 per cent of the population by 2025 in both countries.

All three have progressively introduced key components of a social welfare system, although Japan was by far the earliest to do so, and Taiwan has yet to complete its system by implementing a public LTCI programme. However, Taiwan has been explicitly planning such a programme since at least 2000, and the basic outlines of the programme are agreed (Nadash and Shih, 2013). Implementation in the short to mid term seems certain, with 2016 as the current target date.

Their approach to LTC financing also shares important components, not least because they have openly learned from each other and have taken Germany as a model (Campbell and Ikegami, 2000; Chen, 2005, 2009; Kwon, 2008; Campbell et al, 2010; Huang et al, 2010). All three collect programme revenue through a social insurance mechanism, supplemented by general revenue and co-payments. In Japan, only those 40 years of age and older contribute, while in Korea and Taiwan, all of those with income do, and employers are expected to contribute as well; none of the programmes incorporates means testing, although, in all cases, co-payments are waived or discounted for low-income or poor individuals. Both Japan and Korea restrict benefits to older people and those with ageing-related illness, while Taiwan plans to cover people of all ages who need care. However, while Japan covers a significant proportion of those 65 and older (an estimated 18 per cent of the elderly population; see Campbell, 2014), Korea is proceeding slowly with its programme, covering only about 5 per cent of its older people (Kim et al, 2013); although early Taiwan's plans for the new programme show broader eligibility (about 10 per cent of the elderly; see Lee, 2010), it remains to be seen whether these are implemented.

Pressure to develop LTCI programmes was exacerbated by the introduction of universal health insurance in all three countries. Because they all relied on hospitals as a setting for LTC, control of hospital costs meant finding a way to support vulnerable older people in settings other than hospitals (Kwon, 2008; Tatara and Okamoto, 2009; Tsai, 2009). The solution was, of course, to enable people to be supported at home or in appropriate residential settings, via a separate financing mechanism. However, all three countries faced the same conundrum: without a source of sustainable funding for such services, the appropriate service infrastructure did not exist. Thus, efforts to develop public LTCI also meant grappling with questions around how to set up and regulate service providers. Indeed, in Taiwan, the focus was initially on a bill to finance LTC, but passage was delayed while the legislature tackled the regulatory structure and workforce issues that had to

be resolved prior to implementation (Nadash and Shih, 2013), as well as setting exact contribution levels for employees and employers (Tan and Kuo, 2014).

Despite adopting significant design components from Germany, the three countries all chose to eschew cash benefits (in Taiwan and Korea, however, there is flexibility in certain cases – for example, in rural areas where service providers are not otherwise available; see Kim and Choi, 2013). Although the ban on cash payments has much to do with the status of women in East Asia – women's groups oppose them on the grounds that they potentially lock women into tradition caring roles – it also relates to the need to build a strong provider infrastructure, and to concerns about the quality of care provided by non-professional caregivers. Indeed, this was one of the primary arguments used by women's groups in their campaign against cash benefits (Campbell and Ikegami, 2000, Kwon, 2008, Nadash and Shih, 2013). Certainly, such a strategy appears to have been successful in Japan, which has seen a considerable expansion of community-based service providers (Campbell, 2014). All three countries allow both for-profit and non-profit providers to participate, with a goal of encouraging competition (on quality, not price – prices are set by government) and promoting choice for participants – although this goal is elusive in many rural areas in Korea and Taiwan, where the provider infrastructure is still lacking.

One option to keep costs down and improve the provider base is to integrate foreign workers into the programmes; this seems all but inevitable in Taiwan, where the vast majority of unskilled LTC workers are already temporary workers from the Philippines, Indonesia and Vietnam (Nadash and Shih, 2013). Korea is cautiously opening its markets to foreigners (while favouring ethnic Koreans living in China and elsewhere; see Um, 2012), and, in a reversal of its previous policies, Japan is currently considering proposals to open care worker jobs to immigrant workers (Campbell, 2014), having already allowed in some foreign nurses (Um, 2012).

These three nations all demonstrate a commitment to the social insurance approach to financing LTC, as well as an awareness of the need to prepare for their ageing populations. Japan, as the most mature example of this model, has demonstrated success in progressively monitoring and tweaking its programme over time, keeping costs flat (Campbell, 2014). Korea is proceeding cautiously through limiting eligibility, and it remains to be seen how the programme in Taiwan will evolve. In any case, their approach to LTC financing bears watching.

Funding long-term care services in the future

It might be reasonable to expect that once long-term economic growth returns, governments will seek to increase support for people with LTC needs in society. However, it is unlikely that significant steps towards greater universalisation of state funding will be taken until the fiscal situation improves significantly.

In the interim, new funding reforms are likely to focus on improving efficiency in the use of public funds by helping to ensure that resources are targeted optimally. Improvements in targeting might be achieved, for instance, by concentrating resources on those with the highest needs and those most exposed to the financial risks associated with care needs. As we have seen, cap systems offer one mechanism for targeting resources on longitudinal as well as cross-sectional definitions of need.

In addition, new funding reforms are likely to concentrate on finding arrangements that incentivise private contributions and that (re)define funding partnerships between the state and its citizens. The particular mechanisms chosen will depend on the cultural and administrative preferences of each nation. A particularly culturally sensitive element of the debate concerns the treatment of housing wealth. From many perspectives, housing wealth represents an ideal potential source of resources from which to fund the additional resources required for future LTC systems. Indeed, across the OECD a very significant proportion of the housing wealth is in the hands of older people, who in turn represent the largest group of recipients of LTC services. Paradoxically, however, attempts to draw on housing stock to fund LTC systems have faced considerable public enmity, to the extent that some new funding arrangements have been developed with the explicit goal of protecting housing assets. New ways might be developed to allow homeowners to release housing capital, with products such as equity release and reversed mortgages growing significantly in recent years.

Relatedly, an increasing consensus appears to be forming internationally about the need to decouple hotel or accommodation costs from care costs, and the fact that the funding of hotel costs should be considered as a responsibility of the individual rather than the state.

Overall, and from an economics perspective, LTC funding reforms should generate appropriate incentives, and should consider the nudging effects they might generate. Small user charges at the point of use, for instance, might contribute to improving efficiency by deterring excess demand. Excessive co-

payments, in contrast, can easily lead to unmet need and disproportionate reliance on informal care.

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Part Two

Models of care

FOUR

How different countries allocate long-term care resources to older users: a comparative snapshot

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Introduction

Public responsibility for long-term care (LTC) – in particular, care for frail older people – has expanded rapidly in most advanced nations in the past two or three decades. A key issue is resource allocation: how much money to spend and on what. But although the LTC field has drawn more and more attention from researchers – we know far more about how various approaches work than ever before – patterns of resource allocation have not been adequately studied. As a recent report indicates, ‘the current available statistics about public LTC programs are somewhat patchy’ (Carrera et al, 2013, p 31). Actually, information is available about LTC expenditure in most individual countries, and recently several admirable surveys of LTC policy across several countries have appeared (see, for example, Colombo et al, 2011; Riedel and Kraus, 2011; Mot et al, 2012; Rodrigues et al, 2012; Genet et al, 2013; OECD, 2013; Ranci and Pavaloni, 2013; Mor et al, 2014). However, systematic comparative analysis of expenditure and coverage of national LTC systems has been lacking.

The objective is simple; the task is quite difficult. Two of us discovered this in trying to compare expenditures in just three countries, Germany, Japan and the US (Campbell et al, 2010). It took far longer than we expected and required many delicate decisions to match up the categories. The present study takes on seven countries, a number small enough to manage the

necessary mutual adjusting with our limited time and resources, but large enough to represent significant models of LTC policy.

To draw on quite conventional images in the welfare state literature, we have Sweden in social-democratic Northern Europe, Italy in familial Southern Europe, Germany in corporatist mid-continent, Australia, the US and England as quite different versions of the Anglo-Saxon ‘residual’ model, and Japan as the relatively new entry that shares aspects of all the other models. This chapter presents details of each country’s approach to LTC and how their policies have changed over time.¹ This chapter is essentially a ‘snapshot’ cross-sectional analysis of spending and coverage data.

Since our contribution is largely methodological, we begin by explaining how we have tried to deal with the inherent problems of comparing LTC policy. There are four key approaches.

First, although most countries provide more or less the same policies for frail older people, there are big differences in how these policies are organised and budgeted, and in how boundaries are drawn among LTC programmes, and for that matter between LTC and other policy areas (medical care, housing and social welfare). Making the numbers comparable requires delving into government reports and then discussing the difficult distinctions. We therefore relied on LTC experts in each country to dig out the data and to work together on the necessary adjustments (see country-specific details in the Appendix at the end of this chapter).

Second, to make the project manageable, we narrowed the target. We included only spending on people aged 65 and above. It is the increasing number of frail older people and the decline in family supports for them that make up the policy challenge we are examining.² In many countries, LTC spending on young and old is aggregated in published data, so that disentangling them requires estimating, but if younger people were included, they would account for much of the variance in spending and coverage across nations, which would defeat the purpose of the exercise. Moreover, we only examine public expenditure, from government budgets and public long-term care insurance (LTCI). We do not consider private LTC spending because it is difficult to measure for comparative purposes. Except as noted in the text or Appendix, all our data are for the budget year of 2012.

Third, we define LTC functionally, by activity, rather than by organisational or accounting categories. Japan provides good examples: we include care for three months or more in hospitals covered by health insurance, which is received by a relatively large number of older people,

because the services are functionally equivalent to nursing home care; on the other hand, we exclude visiting nurses and ‘medical management’ by physicians, which are significant programmes in the Japanese LTCI system, because medical functions like those are not included in other nations. Similarly, for the US we do not include ‘post-acute’ care provided by nursing homes and home health agencies, paid by Medicare, because these services are predominantly short-term, rehabilitation-oriented care such as physical therapy.

Fourth, for comparability, our main measure of LTC expenditure is calculated by converting annual public spending in national currencies into US dollars by purchasing power parity (PPP), and then dividing by the 65+ population to control for demographic structure. In that sense, we are comparing each nation’s public effort in providing care to its frail elderly residents.

Our overall comparative findings on spending and coverage are presented in the second section of this chapter. In the third section we compare the three main categories of benefits in more detail, including ‘intensity’ or spending per recipient. The fourth section focuses on the implications for sustainability of various strategies pursued by our seven nations, and the fifth section suggests some comparisons by groups of countries. The Appendix includes a table showing our expenditure data in terms of percentage of GDP, the more conventional measure of LTC spending, to allow comparisons with other datasets. The comparable numbers from the OECD’s dataset are added where available, as is the 65+ share of the population in each country. We then present information on sources and methods country by country. Note that the simplifications necessary for comparison inevitably leave out a lot of information that is important for understanding national systems, but Chapter Five includes further explanation for each country, emphasising changes in resource allocation over time.

Broad comparison

Table 4.1 is our basic dataset. It shows total public LTC spending and programme recipients in the four broadest categories, as well as divisions into subcategories described later. Briefly, home and community-based services (HCBS) is an American term that encompasses not only ‘home care’ but also community services such as day care. Cash refers to allowances to encourage informal caregiving, often by family members, or to allow hiring a caregiver.

Institutions refer to residential care, where caregiving services are provided as part of a package. Administration includes costs of certification and care management, covering more than one of the other categories; it is included when reported separately.

Table 4.1: Public long-term care expenditures and coverage, older people, 2012

	Australia	England	Germany	Italy	Japan	Sweden	US					
	\$/65+	#	\$/65+	#	\$/65+	#	\$/65+	#	\$/65+	#	\$/65+	#
HCBS	380		315		390		357		1041	10.3	2598	
Home help	326	13.0	242	4.4	253	3.1	169	5.7	242	4.7	91	
Day care			50	0.8	19	0.2	81		517	6.7		
Respite	42	3.0			28	0.1			159	1.4	0.0	
Material	12	3.0	24	3.3	30		108		79	7.6	0.4	
Unallocated					75				44			
Cash	391	7.4	1294	23.5	355	6.4	1070	12.3				
Institutions	1895	5.0	508	2.8	967	4.0	386	2.1	1587	4.8	3801	4.7
Social		1.0	362	1.9							0.6	
Nursing	-	4.0	146	0.9	967	4.0	386	2.1	1039	3.8	27	1081
Nursing +	-								428	1.0	1.5	
Unallocated	-								120			
Admin	23		163		75		35		204			
	2689		2280		1803	12.3	1849		2832	15.0	6399	
											1525	5.1

Note: \$/65+ is public LTC spending divided by the population age 65 and over. # is the percentage of the 65+ population receiving the service. US and German recipients are as of 2011. Unallocated funds are those that cannot be distributed to subcategories. Explanations of categories and subcategories are given on page 51. See the Appendix for sources.

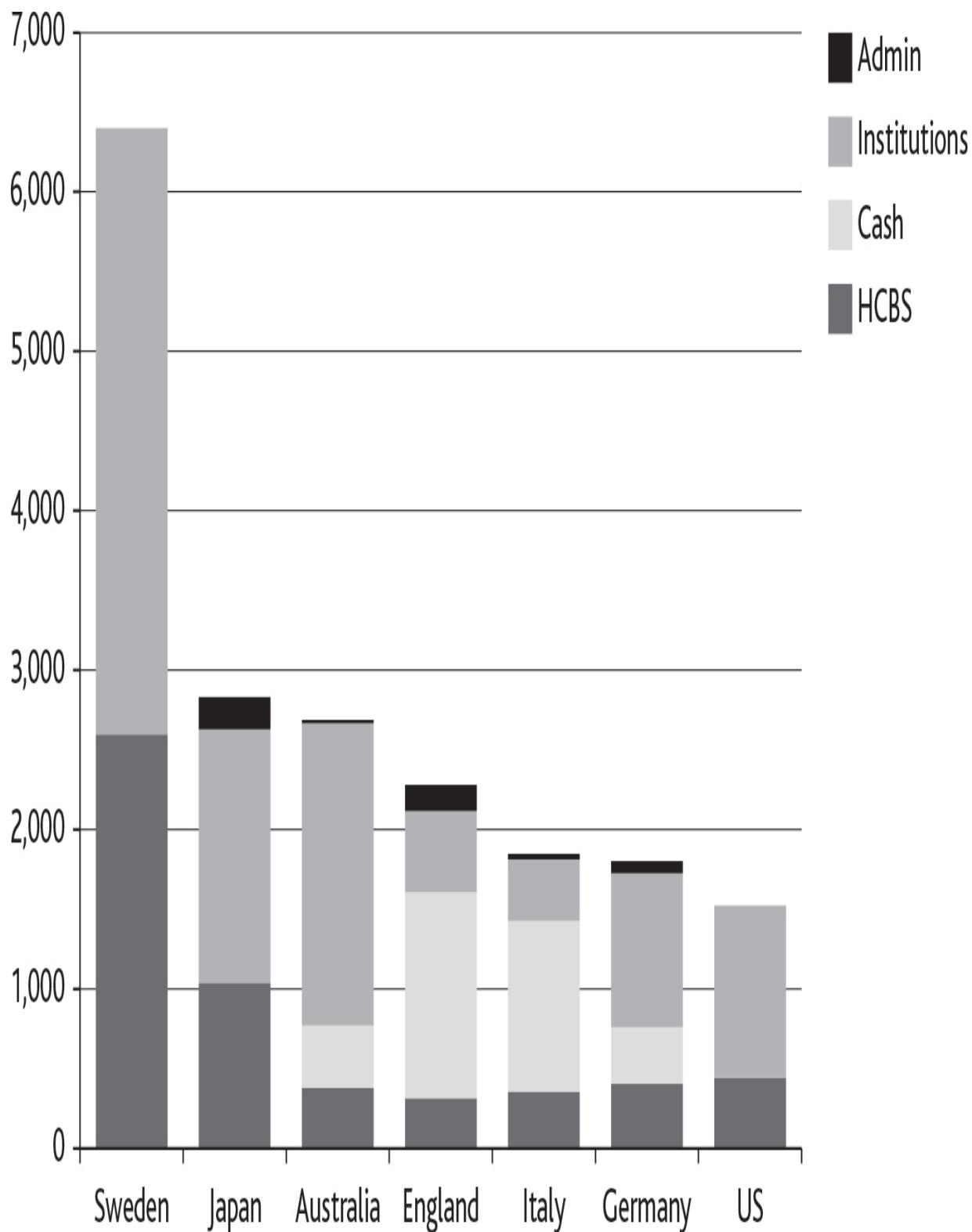
The \$/65+ column for each country shows spending in PPP US dollars per year, per capita for the older (65+) population (not per recipient). The # column is the number of recipients, shown as a percentage of the 65+ population, where those data are available – total coverage for the main categories and overall is often impossible to estimate because of overlaps. Both sets of figures are drawn from official materials, but many of the numbers had to be estimated to include only older people and to fit into our definitions (see the Appendix for details).

Expenditures just by the broad categories are also shown in Figure 4.1, which is arranged from highest to lowest spending. Here, too, the figures are PPP US dollars, divided by the total 65+ population.

The first point that meets the eye is that Sweden is in a league of its own. Its spending on both HCBS and institutions is more than double the others. Outside of Sweden (and presumably other Scandinavian countries and the Netherlands), Japan and then Australia and England are the highest spenders. These results would surprise many observers, for different reasons. Japan is often seen as a family-oriented, even Confucian system with an underdeveloped welfare state; clearly that is not true for LTC policy. The size of the Australian effort may be overlooked because its elderly population is relatively small, but it has developed a large and growing institutional care sector that covers the majority of formal LTC services. The English LTC system has frequently been criticised for its inadequacies, but its substantial cash allowances are often overlooked (perhaps because they are not conventionally perceived as part of old-age LTC).

The low spenders are also interesting. The Italian system is very strongly oriented to cash allowances, with the lowest spending on both HCBS and institutions of these seven countries. The US is the lowest overall, although actually its public LTC spending is remarkably high given that this represents only 55 per cent of total spending on HCBS and nursing home care – the rest is paid privately (see Chapter Five). Finally, Germany's comprehensive but tightly managed system turns out to be the least expensive in terms of public spending of all these nations other than the US.³

Figure 4.1: Public long-term care expenditure for older people, 2012



Note: In PPP US dollars, divided by the 65+ population. See explanations of categories on page 51

Programme comparisons

We turn now to more specific programmes. Some caveats are needed for these comparisons:

- Many data are missing; in particular, because of the way records are kept, we have spending estimates only in the broadest categories for Sweden and the US. Quite a few entries have been estimated (for example, so as to include only recipients aged 65+), but only when we are confident that available information allows a sufficiently accurate estimate.
- Estimates of the number of recipients are inherently problematical. First, it is hard to deal with double counting of people using more than one service. Second, how one counts matters – for example, all recipients on a single day during the year at one extreme, all people who received the service at least once during the entire year at the other. These two methods can lead to differences of 50 per cent or more in estimating the number of recipients.⁴ We compensate as best we can and try to estimate ‘average’ numbers of users (in a month, when possible), but these figures should be used with some caution.
- Estimates of intensity, for which the number of recipients is the denominator, are quite sensitive. Often the differences among countries for particular services are relatively small, certainly within the margin of error.

Having mentioned these problems, we note that they are shared by all the quantitative cross-national comparisons of LTC data that we have seen. Moreover, we believe that our expenditure estimates are the best available, and that our measure that controls spending for the size of the older population is the most appropriate for comparison.

Our definitions for the broad categories and the subcategories are now described before we present the most significant comparative data available. As well as comparing expenditures and coverage, we present some figures for intensity, or spending (in PPP US dollars) divided by the number of recipients (rather than by all older people as in our other calculations).

Institutional care

Our seven countries all provide institutions for older people who lack enough family support or are simply so frail that they need 24-hour support over a long period. Unfortunately there does not appear to be enough literature to allow even descriptive cross-national comparisons of LTC institutions. We define the main function of institutional LTC as providing support in activities of daily living (ADLs; definitions vary but generally include eating, bathing, dressing, toileting, mobility and continence). An LTC institution provides such care services as a package, paid with an inclusive fee, perhaps varying by extent of need, for each resident (whether or not all or part of room-and-board or ‘hotel’ charges are paid out of pocket). An institution is thus more than ‘housing’ (even housing designed for frail older people), where anything beyond small amounts of ADL care is paid for separately.⁵ However, an institution in our terms is less than a hospital, where patients receive medical care aimed at curing or recovering from an illness or injury, or short-term treatments to cope with chronic conditions.

In this range of in-between housing and hospitals, we define and label three levels of public institutional care. (See Table 4.1 for data on expenditure and users in these levels, where available.)

- ‘Social care’ provides substantial ADL care, but the institution itself does not provide much medical care.
- ‘Nursing care’ concentrates on ADL care by aides, with nurses available to provide medical-related services.
- ‘Nursing + care’ is delivered in a setting with physicians and hospital equipment, but the residents are there for a long time and are not expected to improve very much.

The first category listed above is the main form of publicly financed institutional LTC in England (where it is called ‘residential care’), and is also found in Sweden. In Australia, the classification is between low-level and high-level (or nursing) care.⁶ In the US social care is widespread in the form of small board-and-care homes and larger assisted-living facilities, but it is mostly privately paid.⁷ Germany, Japan and Italy also have private-pay housing projects that provide low levels of services; in Germany and Japan residents who qualify for LTCI may get substantial services provided by outside agencies and treated as HCBS.

At the other extreme, ‘Nursing +’ (a term newly coined here) is an important category in Sweden, as a type of institution run by a municipality

that provides relatively intense care, and particularly in Japan, where the institutions are called ‘chronic hospitals’ whether paid by health insurance or LTCI. The other countries do not appear to provide institutional care of this sort over a long period; they do have shorter stays in geriatric wards, regular hospital beds or ‘skilled nursing facilities’ (paid by Medicare in the US) that are not defined as LTC in this study.

Table 4.2: Publicly supported institutional care, 2012 (% and US\$)

	Australia	England	Germany	Italy	Japan	Sweden	US
Coverage, all institutions	5.0	2.8	4.0	2.1	4.8	4.7	2.5
Coverage, nursing homes	4.0	0.9	4.0	2.1	3.8	2.7	2.5
Monthly public spending, nursing homes per resident	\$3,156	\$1,351	\$2,029	\$1,522	\$2,276	\$5,520	\$3,077
Annual public spending for all institutions/65+ population	\$1,895	\$508	\$967	\$386	\$1,587	\$3,801	\$1,081

Note: Coverage is percentage of the 65+ population, Sweden is for all institutions, and the US coverage and monthly spending per nursing home resident is Medicaid only. US coverage is for 2011. The last row is the same as Table 4.1. The second and third rows pertain only to residents who receive at least some public support.

Looking at monthly public spending per nursing home resident, in four countries (England through Japan), the variation is less in the actual cost of

running a nursing home than in how much of the cost is covered by the government. Japanese LTCI has a 10 per cent co-payment, and residents also pay room-and-board charges on a sliding scale (covered by public assistance for low-income people). German LTCI covers about half of the cost (including hotel charges), with the rest paid privately, although this is covered by public assistance for low-income people (the public assistance is included in our data).

In the two countries with low public resource input, many residents pay a substantial share of institutional care fees, based on their means, as determined by local governments. In Italy, a large majority of residents has around 50-65 per cent of the costs covered by the national health system and/or local governments and very few (around 8 per cent) are fully covered (Pesaresi and Brizioli, 2009). In England, as well as having those who are part-publicly financed, part-private pay, nearly half of nursing home residents and 40 per cent of social care ‘residential’ homes are completely self-funded and so are not included in our data (Institute of Public Care, 2011). Both Italy and England have a very low coverage of publicly supported institutional care among older populations, respectively addressing 2.1 and 2.8 per cent.

Three countries have substantially higher public resource input. American nursing homes covered by Medicaid, the means-tested programme, receive enough (the amount varying by states) to cover the total charges including hotel costs, although the resident’s income such as a pension is turned over minus a bit of pocket money.⁸ Australia shares some similarities with the US, in that public subsidies and a public pension cover all charges for those who have limited resources, but the means test is less strict, and public benefits are therefore broader than is the case in the US. Swedish institutions as a whole (expenditures for nursing homes alone cannot be separated out) cost the government far more than in the other countries, partly explained by the inclusion of expensive ‘Nursing + care’ facilities in our data, by generally higher quality (for example, large private rooms), and by the very small portion of private payment.

Obviously, variations in spending on institutions as shown in the second row are explained by how many people are covered and how much is spent on each of them by the government, although not arithmetically in our data set, since the intensity measure is based on partial data.

Home and community-based care

As with institutional care, our seven countries and advanced nations in general provide ADL caregiving services to frail older people who live in the community. Some are on their own and some live with a relative; some are in an ordinary house or apartment and some in special old-age housing. In the great majority of cases, including many older people who live alone, substantial amounts of care come from family members. The balance between public and private caregiving varies widely among countries due to different social customs as well as variations in public policy.

Table 4.3 provides data on public expenditures and coverage for the two largest categories of HCBS. Of these, by far the most prevalent in every country except Japan is home help: an agency sends a careworker with more or less training to the client's home for typically one to three hours several days a week (or sometimes, a month). Although usually the main function of the helper is assistance with ADLs (sometimes called 'body' or 'personal' care), they may also do housework (cooking, cleaning) on the one hand, and light health care including sorting out medication on the other (although visiting nurse services are not included in our data).

Table 4.3: Publicly supported home and community-based services, 2012 (% and US\$)

	Australia	England	Germany	Italy	Japan	Sweden	US
Coverage, all public HCBS					10.3		2.6
Coverage, home help	13.0	5.0	3.0	5.2	4.4	9.1	
Coverage, day care		1.2	0.2	0.9	6.7		
Monthly spending/HCBS client					\$887		\$1,299
Monthly spending/home help client	\$215	\$526	\$684	\$130	\$454	\$2,289	
Monthly spending/day care client		\$449	\$634		\$640		
Annual spending all HCBS/65+	\$380	\$315	\$390	\$357	\$1,041	\$2,598	\$444

Note: Coverage is percentage of 65+ population. Coverage and intensity are 2011 for Germany and the US. US is Medicaid only. For Sweden, monthly spending for home help is based on all HCBS recipients. The last row is the same as Table 4.1.

Another important type of HCBS is day care: the client is brought to a centre for most of the day, often two to four times a week, for socialisation, recreation, a nutritious meal, sometimes exercise or rehabilitation and (in Japan) a bath. Day care is a relatively small programme in most countries except Japan, where it has more clients than home help.

There are two other important types of HCBS for which our data are too spotty to warrant inclusion in Table 4.3, although what we know is shown in Table 4.1 at the beginning of the chapter. Respite care (or ‘short-stay’ or ‘night care’) refers to stays in an institution for one or a few nights, occasionally or regularly, primarily to offer a break to family caregivers.⁹ Material aid is provision of wheelchairs, hospital beds, continence aids, toilets and the like, and also one-time home renovations such as installing ramps and grab bars, all to support ADL. Note that other services such as meal delivery, transportation, training and counselling for family caregivers, garden and home maintenance (distinct from home adaptations), alarm systems and so forth might also be considered HCBS, but they are generally smaller and less central than the main four, and in principle are not included in our data.

It is clear that coverage of HCBS programmes varies more across countries than is true of institutional care. Because it is difficult to account for clients who use multiple services, we do not have data for the total number of recipients for five countries, although we have solid data for Japan, and an estimate for the US.¹⁰ However, since home help is the largest HCBS programme everywhere but Japan, it is something of a proxy for total coverage. As Table 4.3 reveals, Sweden and Australia have very extensive publicly supported home help; England, Italy and Japan have moderate levels; while Germany and especially the US have low levels of home support.¹¹

In looking at monthly spending per recipient (intensity), Italy and then Australia stand out as the opposite of Sweden. Many of the quite numerous Italian recipients are visited by home helpers infrequently (an average of 20 hours per year), which brings down average spending. Australia provides home visits to a great many older people living independently under its Home and Community Care programme,¹² but the average number of hours is only 30-40 per year.¹³ On the other hand, we lack a number for home help spending in Sweden, and so use total HCBS spending, but since home help is overwhelmingly the largest service, this figure cannot be far off – clearly there are many recipients of home help and they receive a very high level of

services. The US is also very high in spending per recipient, although coverage is quite low.

As for the other three countries, there is a striking similarity in monthly spending per recipient for both home help and day care. The relatively low intensity for home help in Japan is probably due to the number of clients who use day care or respite care as their main service, and so take only one or two visits a week.

Cash allowances

Many countries offer cash allowances to cover the costs of LTC along with institutional care and HCBS. The advantages of cash allowances are that consumer choice is maximised, in particular allowing informal caregivers, often family members, to be compensated. Also, they can be relatively simple to administer, and are often seen as saving money (although see below). In many cases the allowance is provided to people with disabilities of all ages, but only spending relating to care for people aged 65+ is included here. These allowances are all specifically designated as covering LTC, whether paid to the caregiver or care recipient, although in many cases it is uncertain how people actually use the money.

As seen in Figure 4.1 above, four of our countries rely on cash allowances and three do not.¹⁴ An important distinction is that in Australia, Italy and England, eligibility for most cash allowances are decided in a completely separate process from decisions about HCBS, and the criteria to determine physical and mental capacity can also differ. The allowances are mostly decided at national level and are not means tested, while both institutional care and HCBS are decided at local level and are means tested.¹⁵ In Australia, cash and care benefits are subject to separate processes but both are standardised and coordinated nationally. Germany has a comprehensive system: after determination of eligibility and level of need, the recipient may choose freely between cash and services, or elect to take some of each according to a formula. In most cases controls over how the cash should be spent in all three countries are minimal, although in Germany, recipients who elect cash only are visited by a nurse at least every six months to talk about caregiving.

In Table 4.4 we show the principal cash programmes in the four countries. We do not have usage figures for the total number who receive any sort of cash allowance because of overlaps (some people may receive more than

one). In any case, clearly many older people receive one of the two big allowances (Attendance and Disability Living) in England, and the Italian *Indennità di accompagnamento* (IA).

Table 4.4: Cash allowances, 2012 (% and US\$)

	Australia	England	Germany	Italy		
	Carer Payment	Carer Allowance	Disability Attendance	Cash Living only	Also gets services	IA
Coverage/65+	2.4	7.4	15.2	8.2	5.1	1.3
Monthly spending/ recipient	\$856	\$158	\$426	\$522	\$468	\$424
Annual spending other cash/65+				\$151		\$12
Annual spending all cash/65+	\$391		\$1,294		\$355	\$1,070

Note: 'Cash only' payments for Germany include social security benefits and respite care for people who remain home. Spending for cash allowances not included in the first row is shown in the third row (as PPP US dollars/65+). The English figure is for five other cash allowances, and the Italian for *Assegni di cura* and vouchers. The final row shows the same data as in Table 4.1.

Administration

Some administrative expenses are inherent to LTC, particularly the costs of assessing eligibility and extent of need, and of care or case management. These costs are calculated separately everywhere but in Sweden and the US, although what is included varies somewhat. Because they cannot be attributed to particular programmes, they are included as administration in our dataset (see Table 4.1).

Cost control in long-term care policy

What lessons can we draw about LTC policy? Since our data are confined to spending and coverage, we have no basis for drawing conclusions about ‘good’ policy (other chapters in this volume have many such suggestions), but we can talk about cost containment. ‘Financial sustainability is the most important policy priority for LTC systems in the OECD’, as a recent survey of governments revealed (Colombo et al, 2011, p 39). Here are important strategies that nations adopt to hold down public LTC spending, with some observations drawn from our data as well as analyses by the country specialists.

Limit access by controlling eligibility

All nations have criteria to assess the physical and mental (as well as sometimes social) need for care; they can be generous or tough, and consistent or varied, and they can be changed. Both Germany and Japan rely on a long list of questions mainly about ADLs, administered in the home by a trained local government officer (in Japan) or usually a nurse who works for the medical service of the insurers (in Germany). The answers are analysed to see if the applicant meets the legal standard of disability, and at what level. The bar is set higher in Germany than Japan, resulting in 11-12 per cent of the 65+ population being eligible there compared with 16-17 per cent in Japan. Australia has a nationally standardised assessment service that acts as a gatekeeping function as well as guiding individuals to appropriate care services.

In England, Italy and Sweden, eligibility for HCBS and nursing homes and/or the amount of care provided are both decided by care managers at municipal and/or local health authority level, who take the availability of family care and other factors (including income) into account. In these

countries variation across municipalities and regions can be considerable, leading to worries of a ‘postcode lottery’ to use a British term (Robbins, 2008).¹⁶ Again, the same eligibility system can set the bar high or low: coverage is very high in Sweden, but fairly low in England due to tight criteria (as well as the means test). The main cash allowances in England, on the other hand, require individuals to undertake a totally separate process that involves applying to national rather than local government. As of 2010 the criteria were expansive enough to make about one-quarter of the 65+ population eligible for a cash benefit.¹⁷

With growing financial pressures there has been a trend in advanced countries to target LTC benefits to people most in need. This was done explicitly in Japan with a reform in 2006 that limited services for lower-need beneficiaries (with a further step in 2015), and more subtly in Germany by improving benefits disproportionately for higher-need people, particularly those with dementia, while other recipients lost ground to price inflation (Tsutsui and Muramatsu, 2007; Theobald and Hampel, 2013). Similarly, changes to supply restrictions and co-payment charging arrangements in Australia have favoured more complex care in an institutional setting at the expense of less intensive care. In England and Sweden local criteria were tightened up mainly as a response to shrinking revenues, including lower transfers from central government. Targeting often leads to less savings than hoped, because average intensity will rise.

Limit access by means testing

All nations restrict some social benefits to low-income people with few assets to avoid ‘wasting’ resources on people who don’t really need help (for example, always for public assistance); an additional rationale in LTC policy is that allowing people to retain substantial assets such as a house amounts to a subsidy to their heirs. Means testing is employed by the US and Australia for nearly all public LTC programmes, and by England and Italy for institutional care and HCBS, but not for most cash allowances. Our dataset indicates that means testing is effective in holding down coverage, but we cannot analyse the possible downsides: administration is complicated and expensive, decisions about particular cases are often seen as unfair, the question of where to draw the line on eligibility for public support draws broad political controversy, people who need care may feel a stigma and not apply, and pressures for higher quality services and fewer cutbacks may be

weaker without middle-class constituents. In asset testing, whether and how to include housing has been a contentious issue in Australia, England and the US.

Limit public spending and usage with higher out-of-pocket charges

Japan imposes a 10 per cent co-payment for all services under LTCI, and charges some or all hotel costs for institutional care according to income levels.¹⁸ German LTCI has no co-payments and in principle covers about 50 per cent of assessed need for both institutional care and HCBS, the remainder to come from the beneficiary or family, or public assistance. In Italy and England, and even Sweden, municipalities levy income-adjusted charges for services. In Australia the means test operates to limit access to public subsidies as well as reduce them by clawing back costs (up to a cap) via private contributions that depend on an individual's income and assets.

The primary effect of co-payments or limits on public support is simply to transfer costs from public to private sources. The secondary effect is to inhibit usage, which is positive from the point of view of cost-saving. The co-payment is at least one reason why Japanese who live in the community use only about half of the services to which they are entitled. In Germany, where the private pay portion is much higher, people who have experience with LTC are relatively satisfied with access and quality, but compared with other Europeans, they are quite unhappy about the financial burden for both HCBS and institutional care (Carera et al, 2013).

Modify the supply side

Governments can and regularly do limit the supply of services by direct rationing, constricting the number of providers, cutting back construction of facilities (note that capital expenditure is not included in our data), setting ceilings on the amounts paid from public funds, and cutting subsidies. In particular, when local governments administer HCBS paid from their regular budgets, they are likely to respond to fiscal problems by rationing usage or tightening eligibility criteria (degree of frailty or income), often without public notice.

Another strategy is that governments can directly or indirectly encourage provision through the private market; for example, employment and immigration regulations can be structured to make it relatively easy to hire individual careworkers, as in Italy. Demand for expensive institutional care

can be reduced by encouraging suitable housing for frail older people (such as ‘assisted living’ in the US and ‘old-age housing with services’ in Japan).

Adjust the policy mix: cash over services

A recent trend in LTC policy is to move to one or another form of ‘cash for care’. From a neoliberal point of view, paying cash not only avoids bureaucracy and maximises consumer choice, it should also hold down public spending because a recipient would be satisfied with a lower amount if free to decide how to spend it. Our broad spending comparison very weakly supports this proposition: in terms of total LTC public spending, the third through sixth highest countries use cash allowances while the first, second and seventh do not. For a finer-grained comparison we can look at Germany and Japan.

For people living in the community, Germany offers a choice between cash and services (or both); the services are worth roughly twice as much as the cash, but most people take the cash. It would seem to be obvious that this approach saves money, and indeed, German total spending is 44 per cent lower than Japan. When we look more closely, however, we see that most of the difference between the two countries is in institutional spending. If we compare all home-based spending (just HCBS for Japan, HCBS as well as cash for Germany), the difference is only 20 per cent – and that 20 per cent is explained by Japan’s broader coverage and higher benefits.

The lesson is that cash is not necessarily less expensive than services. This is simply because everyone always wants cash but many people do not want services, such as ‘body care’ by a home helper or day care, except when they need them. Also, as noted above, having a co-payment will inhibit asking for more services than is needed, and it also appears that newly receiving cash often does not change actual caregiving patterns very much.

Adjust the policy mix: care at home over institutions

It is an explicit government policy everywhere to encourage frail older people to live in the community rather than an institution, on quality-of-life as well as financial grounds. Since the cost per client is much lower (compare Tables 4.2 and 4.3), savings should be considerable. However, from Figure 4.1, we can see that high HCBS spending does not necessarily go with low institutional spending – if anything, the opposite is true. One reason that better HCBS does not necessarily limit institutional spending is that many

people who could somehow get by on their own without going into a nursing home would be eager to get HCBS if it were available – as Americans say, they would ‘come out of the woodwork’ (Weissert and Frederick, 2013). Note, also, that for very frail people with complex needs, institutional care may be more cost-effective than HCBS unless very low-wage labour is available (or great burdens are placed on the family). Despite these caveats, favouring HCBS over institutional care appears to be a reasonable policy for sustainability. Indeed, it was the second most selected policy priority in the survey of policy-makers mentioned earlier (Colombo et al, 2011).

‘Systematise’ long-term care systems

The most fundamental strategy is to rationalise the system. Public LTC programmes have commonly evolved piece by piece, mostly as extensions of programmes designed for other purposes back when frail older people were not an explicit significant concern of governments. LTC in Sweden was a natural outgrowth of its already extensive social welfare programmes managed by local authorities. When Medicaid was started in the US it was aimed at providing medical care to poor people, and its increasing commitment to care for frail older people in nursing homes (and later, HCBS) happened without much notice or debate. Current LTC policy in England developed from both these trends – extension of National Health Service (NHS) responsibilities beyond medical care per se, and of local government responsibilities beyond helping the poor – as well as the ageing of the population that is protected by cash allowances for disability care. The story in Italy was much the same, on a smaller scale. Australia’s LTC system evolved from subsidies to non-profit care homes and then local home care programmes that saw increased national government involvement.

Germany and Japan followed similar paths until heightened public attention as well as growing problems with existing programmes led to high-level debates, and ultimately to major policy change in the 1990s (Campbell, 2002). Both countries took the radical step of establishing comprehensive and well organised LTCI systems. In principal, all important aspects of public LTC are under one roof. This can increasingly also be said for Australia: even though the programmes have been historically disparate and suffered from differing levels of responsibility across levels of government, reforms have brought a greater level of structural clarity. For these countries, both financing and spending are clearly specified, so that political leaders and the

public can see the link between revenues and benefits and what adjustments are desirable. Applicants have only one path of entry, with clear-cut rules and an objective process to determine eligibility and extent of need. There are various types of providers (including for-profit companies), but they operate under common rules with clearly set fees.

In carrying out this study, we found that data for Australia, Germany and Japan were much easier to obtain and to analyse than for the other four countries precisely because their systems are so systematic. This is not just a boon for researchers; policy-makers, too, can grasp all the components of the system and their interrelationships at once. This makes it much easier to plan and carry out reform. Everything is harder to accomplish in a system where the financing, provision, eligibility rules and so on are fragmented, as is true of Italy, England and the US. Sweden's LTC system is quite systematic at the level of its 290 municipalities, but nationwide data are hard to come by, and national reforms including cost-containment (for example, by targeting care on heavy-need people) can be carried out only by indirect economic or administrative pressure (Trydegard and Thorslund, 2010).

Conclusion

We conclude by going back to our dataset, as shown in Table 4.1, to consider groups of our countries that are interesting to contrast, albeit for different reasons. Far more information would be required for anything like adequate comparisons of these LTC systems, but our approach offers at least a new perspective.

Sweden and the US are extremely different. American overall public LTC spending (using our measure that controls for the size of the old-age population) is less than one-third that of Sweden; with its severe means testing, the US leaves a substantial burden on individuals and families. A characteristic the two nations share, however, is high intensity for both institutional care and HCBS – both countries spend a lot relative to the number of recipients. The reason is some combination of quality, prices, and level of support when it is offered. Another shared characteristic is that these are the two countries where comparable data were hardest to gather, albeit for different reasons – Sweden is too local, the US too complicated. It is difficult for scholars, citizens and policy-makers in both countries to get a clear view of reality, and to imagine alternatives.

Italy and England are surprisingly similar, as noted earlier. Both rely heavily on cash allowances, a substantial payment to be used for any purpose including compensating for care by family members or, particularly in Italy, by privately employed caregivers. The allowances are somewhat less generous in England but they go to many more people – at least a quarter of the elderly population versus 13.4 per cent for Italy. Although institutional care and HCBS are means tested in England and universal in Italy, in practice the difference is probably not so great because in both countries private pay is quite prevalent. A difference is that England had been a pioneer in the development of services for older people, and still has among the world's best networks of policy experts; Italy has a much older population, but has less in the way of an LTC tradition or policy community.

Finally, we juxtapose Australia, Germany and Japan as countries that have created dedicated, highly systematised LTC programmes, based on tax financing in Australia and social insurance in Germany and Japan. Their biggest differences are programmatic: Australian LTC is dominated by high-cost institutional care, but also has wide-ranging and low-cost HCBS; Germany relies mainly on cash allowances, and Japan only on services for beneficiaries living at home – Japan's coverage of HCBS is close to that of Sweden (although its spending is much lower). The point that most stands out, however, is total LTC spending. Compared to Germany, it is 50-60 per cent higher in Australia and Japan (controlling for the size of the elderly population). The reason is that people at lower levels of need are eligible in Japan and not in Germany, and Australia and Japan offer higher benefits (particularly for institutional care) at a given level of need.

Which country's LTC arrangements perform better is not an issue here: how much of its resources a nation devotes to LTC for frail older people is ultimately a subjective choice. However, at any level of spending it is a government's obligation to make its LTC policy as efficient and effective as possible.

Notes

¹ Note that there are small discrepancies in expenditure and coverage data reported in the two chapters because different adjustments in definitions are sometimes needed to make consistent cross-sectional and over-time comparisons. Note also that this chapter includes Australia, although Chapter Five does not.

² Younger people with disabilities are obviously worthy of attention, but in many cases their needs (centred on more independent living, job training, and so forth) are quite different from the needs of frail older people.

³ Note that this figure includes spending under Germany's nominally private LTCI system, because although managed by private firms, it is compulsory for a well-off tenth of the population not covered by the regular system; it is highly regulated to conform to the public system (Theobald, 2011).

⁴ A good example is from Germany: 14 per cent of surveyed LTCI recipients living at home said they had used day care and 13 per cent respite care during the last 12 months, although on a given day only 2 per cent use each service (TNS Infratest Sozialforschung, 2011).

⁵ Public support for old-age housing is usually to compensate for low income, rather than severe frailty, and so should be seen as social welfare policy rather than LTC. Residents in old-age housing, public or private, may well receive public ADL services, but these are paid on a fee-for-service basis (from outside providers or the residential facility itself), so they are counted as recipients of HCBS.

⁶ The distinction is at the level of the subsidised bed place offered by a given institution rather than a formal distinction between institutions themselves. Past distinctions between even these two levels are being blurred with recent reforms.

⁷ Regulation of such facilities are at the state level in the US and vary considerably; in some states a portion of costs of residents are supported by public funds (but counted here as HCBS because data are lacking).

⁸ Payments from pensions are considered private and so not are included in our data. The US also has a substantial number of self-funded residents, but many temporarily so because they are in the process of 'spending down' their assets before they meet the Medicaid means test. Available data do not allow estimates of these numbers.

⁹ This term in Germany also refers to cash payments to a relative or friend for care when the family is away; this type comes under cash allowances in our data.

¹⁰ The US estimate is based on Medicaid records, and includes mainly recipients in 'waiver' programmes run by states. Some who should be in the institutional 'social care' and the cash allowance categories are included here under HCBS. On the other hand, some people who receive HCBS under state and local programmes with federal subsidies, mainly under the Older Americans Act, are not included in our data because comparable information is not available.

¹¹ In England, an estimated 2 per cent of the 65+ population pays for ADL HCBS fully out of pocket, and they are not included in our data (Institute of Public Care, 2011). We have no equivalent data for other countries, but the number is probably negligible in Australia, Germany, Japan and Sweden.

¹² Since the data were collected, the name and some features of the programme have been reformed into the Home Support Programme.

¹³ Australian Extended Age Care at Home packages, as they have until recently been known, are far more intensive, with monthly costs of over AU\$1,500, and even the Community Aged Care packages for less frail older people average a public cost of about AU\$500 a month per recipient, although these are provided to a much smaller number of people.

¹⁴ Sweden and the US have offered cash under titles like ‘personal budgets’, ‘cash and counselling’ or ‘participant-directed care’. Because the number of recipients is small and reliable data hard to come by, those programmes are included in the HCBS category.

¹⁵ One of England’s six types of allowances, called ‘direct payments’, is administered locally as part of HCBS.

¹⁶ Although this variation by area will change in England due to the Care Act 2014. See Chapter Five for more details.

¹⁷ Research indicates that these recipients are more likely to be experiencing income deprivation than the rest of the older population (Hancock et al, 2012).

¹⁸ Japan charged a 20 per cent co-payment for higher-income people and more hotel costs from 2015 as a way to curtail public expenditures.

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Appendix

Overall

For purposes of comparison with other studies which use percentage of GDP as their main indicator, Table A4.1 shows the spending totals from our data set in national currencies, along with GDP, the resulting percentage and the percentage of the population aged 65 and over. The comparison across countries is quite different than in our analysis. Most dramatically, note that in this table England appears to spend much less than Japan, while they are at about the same level in Table 4.1. The difference, of course, is that Table 4.1 controls for the 65+ population, and as can be seen in the top row below, Japan is far older than England.

Table A4.1: Background data

	Australia	England	Germany	Italy	Japan	Sweden	US
% population 65+	14.0	16.4	21.0	20.8	24.1	18.7	13.7
GDP	1,503,944	1292481	2,666,400	1,566,911.6	473,777,100	3,549,709	16,244,600
Spending	12,585	8,737	23,639	17,248	9,119,158	101,756	73,906
%	0.8	0.6	0.9	1.1	1.9	2.9	0.5
OECD %	0.1*	-	1.0	-	1.9*	3.6	0.5

Notes: GDP and Spending in millions of national currencies. GDP for England calculated from gross value added data.

* is data for 2011; - = data not available.

Source: OECD health data 2014

Country-specific

Australia

Data are primarily for the fiscal year 2011/12 (year up to June 2012). Unless otherwise stated, the source of data is the Productivity Commission (PC, 2013). In some cases, data include services for the (relatively small) indigenous population aged 50 and over.

HCBS home help includes: domestic help and personal care services delivered as part of the Home and Community Care (HACC) programme; Veteran's Home Care (VHC); and care packages (which consist of Commonwealth Aged Care packages – CACP, Extended Aged Care at Home – EACH, and Extended Aged Care at Home-Dementia – EACH-D). There are some international comparability issues resulting from the way the above programmes are included. For example, VHC services consist largely of domestic help and personal care, but also include some home maintenance (excluded for other countries) and respite services (included separately for other countries and for Australia with respect to civilian population). Packaged care includes a range of coordinated services mainly related to home help, but the EACH and EACH-D packages, which are tailored for more complex home care needs, include some nursing services (explicitly excluded for other countries). These packages are intensive, with high costs per user, but are relatively small, with 17,000 people making use of them in the year to June 2012.

Expenditure on HACC domestic help and personal care is estimated by using unit cost per hour of service, hours of service received per 1,000 people aged 65 and over, and Australian population estimates (ABS, 2013a, 2013b). The number of users is based on Australian Institute of Health and Welfare (AIHW, 2013) and PC (2013). The total number of HCBS users assumes that there is no overlap between users of HACC, VHC and packages (that is, these are summed), but that there is full overlap between users of the two HACC sub-programmes (that is, the larger of the two figures is used).

The LTC system in Australia does not have an obvious equivalent of day care centres as defined in some other countries. Day therapy centres, which offer allied health and rehabilitation services, are likely to qualify as a health system function in other countries, so are excluded here. Activity programmes under HACC offer community-based socialisation and recreation services, with some 70,000 users in 2011/12. Since these are impossible to allocate to home help or day centres (some may take place at provider facilities), these services are excluded here. It is likely that users of these services are already included in the total for home help since they may be the same people who require domestic and personal help.

Respite figures represent the National Respite for Carers Programme. Materials figures relate to funding and utilisation of continence aids.

Other HACC services excluded from the analysis of HCBS consist of transport, meals, home and garden maintenance, social support and other

non-specialist services. Total HACC cost in 2011/12 was AU\$1.6 billion, and the overall programme had approximate 750,000 users.

Two other (smaller but not insignificant) mixed-setting programmes are excluded from the analysis: the Transition Care Programme, which mainly offers home-based rehabilitation services after hospital stay, but may include some home help; and the Multi-Purpose Service Programme, which offers LTC services in rural areas in conjunction with health centres.

Cash expenditure and receipt relates to Carer Allowance (which covers carers' costs) and Carer Payment (which covers carer's absence from work). While the benefits go directly to carers, the figures used here relate to the population of people aged 65 and over benefiting from the care. Data are from Chomik and MacLennan (2014). In estimating the number of beneficiaries, it is assumed that there is a full overlap of those receiving care subsidised by the two payments.

Expenditure data for institution-based care is from PC (2013). Use relates to permanent residents as at June 2011, split by low and high care places (assumed to be equivalent to 'social' and 'nursing' as defined in this chapter), and is based on data from AIHW (2014).

Administration expenditure relates to care assessment only.

References

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England

Data are for the fiscal year 2012/13. All information pertains to England because LTC policy differs in other parts of the UK; however, some data are reported only at the UK level and the numbers for England had to be

estimated. Similarly, some programmes report the older population group as those who receive a pension, and so an estimate was needed to remove those under the age of 65.

HCBS includes: home care, day care and equipment and adaptations. The main source for usage data for HCBS and institutional care (and the ‘direct payments’ cash allowance), all administered by local authorities, is the Health and Social Care Information Centre (HSCIC, 2013). Note that for home help and day care, these figures are estimates. In 2009/10, Fairer Charging community services was introduced and replaced home care and day care/day services for net current expenditure as councils can no longer separate the income from sales, fees and charges for these services. These figures are therefore estimates based on the new Fairer Charging community services category, using 2008/09 where 83 per cent of the budget was spent on home care and 17 per cent on day care. This ratio was the same for the last three years of available data.

Expenditure data for all these programmes are from HSCIC (2012).

Most references to cash allowances in England are based on Attendance Allowance and Disability Living Allowance alone, as it is not possible to get an accurate figure for the total number receiving cash allowances without duplication. For Attendance Allowance and Disability Living Allowance expenditure see <http://research.dwp.gov.uk/asd/asd4/index.php?page=expenditure>

The number of users of cash allowances is estimated for English only users aged 65 and over using data from NOMIS (<http://data.gov.uk/>) and population data from the Office for National Statistics (ONS). The ‘other cash’ row in Table 4.4 includes: Carer’s Allowance, Independent Living Fund and the Disabled Facility Grant. For the various cash allowances, the sources for user statistics vary. The number of individuals receiving Carer’s Allowance and caring for individuals aged 65 or over has been estimated using the total number of recipients from the NOMIS database and adjusting it using a 24 per cent rate that emerged from a Department for Work and Pensions survey as an estimate of the proportion of carers of individuals aged 70 and over (<http://research.dwp.gov.uk/asd/asd5/reports2011-2012/rrep739.pdf>, and combined with expenditure data from NOMIS: http://data.gov.uk/dataset/carers_allowance_ca).

The total expenditure of the Independent Living Fund has been obtained from the annual report and accounts (www.dwp.gov.uk/docs/annual-report-201011.pdf). Estimates for expenditure on English users aged 65 and over

has been calculated using the number of recipients from the year 2010-11, as detailed in the users' profile statistics for the year 2010-11 (ILF, 2011).

For expenditure on the Disabled Facility Grant, see www.communities.gov.uk/housing/housingresearch/housingstatistics/housingstatisticsby/housingfinance/livetables/. Expenditure is estimated based on the number of service users, itself estimated using housing renewal statistics published by the Department for Communities and Local Government (DCLG). The proportion of English only recipients aged 65 and over was obtained from statistics available in DCLG (2011).

Administration expenditure in England is grouped in with programme expenses. Therefore the administrative costs reported in Table 4.1 report solely on what is classified in the original data as 'assessment and case management': the cost of determining eligibility, need and packages of care.

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Germany

Spending data are for calendar year 2012 and coverage data for 2011; they are drawn from official sources. As noted in the text, we include both 'social' LTCI and the 'private' but mandatory system for people not covered by the social system. Social and private LTCI in Germany covers personal care, household-related services within home care, cash payments, day care, respite (short-term) care, material support, case and care management

services and institutional care services. Within home care nursing care services are covered by health insurance. In 2012, the expenditure of private LTCI was approximately €677 million for beneficiaries 65 years and older (Private Health Care Insurances, 2013).

For a calculation of the proportion among beneficiaries 65+ using different types of benefits, see Federal Statistical Office (2013).

For a calculation of expenditure separated in different areas for public LTCI, see Federal Ministry of Health (2014).

For a calculation of expenditure separated in different areas for mandatory, private LTCI, see Private Health Care Insurances (2013).

For a calculation of the number/proportion among beneficiaries 65+ receiving social assistance for domestic/home care or institutional care support, based on the whole year 2011, see Federal Statistical Office (2014).

For a calculation of the costs for home-based/domestic and institutional care services within the framework of social assistance, see Federal Statistical Office (2012).

For a calculation of the population aged 65+ in 2012, see Federal Statistical Office (nd).

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Italy

Italian data are for the fiscal year 2012 (1 January-31 December). At the date of finalising this publication, not all data for both coverage and expenditure were available for 2012, due to the high fragmentation of sources; some estimations from 2011 data were indeed necessary.

Expenditure data were mostly retrieved from official sources. When sources presented spending only in terms of percentage of GDP, the absolute value was calculated with official 2012 data on Italian GDP by the National Institute of Statistics (ISTAT) (www.istat.it). When estimations were made on the basis of data from previous years, net inflation rate was calculated based on prices for January 2012 using deflators from ISTAT (<http://rivaluta.istat.it/Rivaluta/>).

Home help is an estimation based on the sum of two domiciliary programmes, ADI and SAD. ADI spending for people 65+ is calculated from official 2011 data by the Ministry of Economic Development (www.dps.tesoro.it/obiettivi_servizio/servizi_infanzia.asp) and the Ministry of Health (www.salute.gov.it/imgs/C_17_pubblicazioni_1780_allegato.zip). A marginal amount of resources allocated by municipalities for integrating home help with health services has been added to the ADI spending: it concerns the category of *assistenza domiciliare integrata con servizi sanitari*, and its spending for people 65+ is retrieved from official 2011 data by ISTAT (www.istat.it/it/archivio/122975). SAD spending for people 65+ is retrieved from official 2011 data by the same ISTAT source. The mentioned cost items were summed to obtain the cost per user for 2011, and this value was used with the 2012 coverage of both ADI and SAD for estimating the total expenditure for 2012.

Day care includes those services provided by facilities fitting into the category of *assistenza semiresidenziale* by the Department of General Accounts (Ragioneria Generale dello Stato, RGS). Day care spending for people 65+ is calculated from official 2012 data by RGS as percentage of GDP (www.rgs.mef.gov.it/_Documenti/VERSIONE-I/Attivit--i/Spesa-soci/Attivita_di_previsione_RGS/2013/06-capitolo4.pdf).

Material aid includes those supports fitting the category of *assistenza protesica* by RGS. Spending concerning *assistenza protesica* for people 65+ is an estimation based on official 2012 data on spending for *assistenza protesica* by RGS (www.rgs.mef.gov.it/_Documenti/VERSIONE-I/Attivit--i/Spesa-soci/Attivita_di_previsione_RGS/2013/05-capitolo3.pdf; http://www.dt.tesoro.it/it/analisi_programmazione_economico_finanziaria/documenti_programmatici/sezione1/rge.html and on the latest available proportion of dependent people aged 65+ retrieved from ISTAT (www3.istat.it/dati/catalogo/20100513_00/arg_09_37_la_disabilita_in_Italia.pdf).

Cash allowances include the major benefit provided at national level, that is, *Indennità di accompagnamento* (IA). Its spending for people 65+ is calculated from official 2012 data by RGS as a percentage of GDP. Other cash programmes mentioned in the work refer to minor allowances provided at local level, which include the benefits fitting in the following categories of ISTAT: ‘Voucher, assegno di cura, buono socio-sanitario’ and ‘contributi economici per cure o prestazioni sanitarie’. Spending for people 65+ is retrieved from official 2011 data by ISTAT (www.istat.it/it/archivio/122975), assuming there were no significant differences in 2011-12.

Nursing homes include those services provided by facilities fitting into the category of *assistenza residenziale* by RGS. Spending is calculated from official 2012 data by RGS as a percentage of GDP (www.rgs.mef.gov.it/_Documenti/VERSIONE-I/Attivit--i/Spesa-soci/Attivita_di_previsione_RGS/2013/06-capitolo4.pdf).

Administration is the sum of those administrative services for healthcare (fitting into the category of *amministrazione e servizi generali* by RGS) and those administrative services for social care (fitting into the category of *servizio sociale professionale* by ISTAT). However, spending data of *amministrazione e servizi generali* have not been available separately since 2005 (due to a changed data treatment system). Spending for people aged 65+ in this category was estimated through proportional calculations, based on official 2006 and 2012 data on administration, health care and LTC

spending categories by RGS (www.rgs.mef.gov.it/VERSIONE-I/Attività-Spesa-soci/Attività_di_previsione_RGS/2008/; www.rgs.mef.gov.it/VERSIONE-I/Attività-i/Spesa-soci/Attività_di_previsione_RGS/2013/). These materials allowed a rough estimation by reallocating administrative costs and recalculating the total amount for LTC for people 65+. Concerning the *servizio sociale professionale* category, spending for people 65+ is retrieved from official 2011 data by ISTAT (www.istat.it/it/archivio/59169), assuming there were no significant differences in 2011-12.

Coverage data were retrieved from official sources, in particular:

Home help is an estimation based on the sum of two domiciliary programmes, that is, ADI and SAD. ADI coverage for people 65+ is retrieved from official 2012 data by the Ministry of Economic Development (www.dps.tesoro.it/obiettivi_servizio/dati.asp). SAD coverage for people 65+ is retrieved from official 2011 data by ISTAT (www.istat.it/it/archivio/122975), assuming there were no significant differences in 2011-12.

Cash allowance (IA) coverage for people 65+ is retrieved from official 2012 data by ISTAT (<http://dati.istat.it/>). The coverage of other minor cash allowances provided at local level for people 65+ is retrieved from official 2011 data by ISTAT (same categories used for expenditure) (www.istat.it/it/archivio/122975), assuming there were no significant differences in 2011-12.

Nursing homes coverage for people 65+ is retrieved from official 2011 data by the Ministry of Health (www.salute.gov.it/imgs/C_17_pubblicazioni_1677_allegato.pdf), assuming there were no significant differences in 2011-12.

Where the sources presented only the absolute number of users of a LTC service, coverage has been calculated with official demographic projections by ISTAT (<http://demo.istat.it/>).

In the categorisation of LTC services, we did not include the activity of long-term wards in hospitals (*reparti di lungodegenza*) since the mean period of stay is below three months, a threshold chosen in our work for including residents in hospitals under the ‘institutions’ category.

Japan

Japanese data are for the fiscal year 2012, ending 31 March 2012. The spending figures are for outlays, not including the 10 per cent co-payment. The usage figures are reported on a monthly basis, using October as half way through the financial year, that is, someone with one usage per month is included, but not with one usage per year unless it happened in October.

All of the spending data for the LTCI system proper are as reported in two annual publications of the Ministry of Health, Labor and Welfare (MHLW) for 2012 (MHLW, 2012a) and MHLW (2012b) for some small supplementary payments that are not included in the regular breakdowns.

Usage for LTCI proper is from the annual of MHLW (2012a) for the total HCBS (which do not double count for people who use more than one programme), and of MHLW (2012b) for institutional care. Detailed usage (at least one use per month in that category) throughout is from the monthly report of MHLW (2012a) for October. However, for home repair and purchase (rather than rental) of assistive devices, once per year is counted.

Usage by long-term hospital patients covered by health insurance rather than LTCI is estimated from MHLW (2012b), compiled on the basis of a survey of a sample of hospitals and clinics in one day. These data are from 2008, the last available, but the numbers did not change much and the estimates are rough anyway. Still, including them with the best estimate available is far more accurate than simply leaving them out. To estimate spending, the usage is multiplied by what the cost would have been had the patient been in a nursing home under LTCI, from MHLW (2012a).

The LTC expenses of people on public assistance are covered under that budget rather than LTCI, and are reported in *Fujobetsu Hogohi no Nenjisui* (www.ipss.go.jp/s-info/j/seiho/seiho.asp), compiled annually by the National Institute of Population and Social Security Research.

Under administration, we have included the following:

- care management costs in HCBS;
- costs of professional supervision of care plans by physicians, dentists, pharmacists and dieticians;
- direct costs of classifying eligibility levels such as visits by assessors and honorarium of committee members.

Indirect costs of administrating the programme borne by local governments are not included. The costs of care planning in officially recognised

institutional care settings, such as nursing homes, are included in the per diem amount.

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Sweden

Data on use of LTC (HCBS and institutional care) are derived from the National Board of Health and Welfare (nd). All data relate to people aged 65 years and older. Use of services is related to a specific date (nowadays collected two times a year, 1 October and 1 April).

The typology of different forms of institutional care is based on data that are collected for *The elderly guide* [Äldreguiden] by the National Board of Health and Welfare (annually since 2007). In *The elderly guide*, data on 11 indicators (mostly structural and process indicators) of quality in both HCBS and institutional LTC are collected from all LTC services in the whole of Sweden.

Basic information on the type of services is also collected.

Data on expenditure for home-based and municipal institutional care services as well as expenditure data on health care for older people (65+) are collected by Statistics Sweden [*Statistiska Centralbyrån*] and presented in *Annual accounts* [*Räkenskapssammandrag för kommuner och landsting*]. To estimate spending on health care for older people, calculations are based on regional data of spending on elderly people (37 per cent of the total healthcare costs in all Sweden), a method that is in official use in Sweden.

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United States

Public LTC expenditure for people aged 65 and older was estimated using published and unpublished data from the Centers for Medicare and Medicaid Services, Office of the Actuary (2014a).

The portion of LTC expenditure in 2012 attributable to services for people aged 65 and older was estimated because the national health expenditure accounts report total national amounts. The most recent year for which official national health expenditure data are available by age groups is 2010 (Centers for Medicare and Medicaid Services, Office of the Actuary, 2014b). This source was used for the proportions of spending for people aged 65 and older for selected categories of spending. The proportion for Medicaid HCBS waiver services was estimated using data from Ng et al (2014).

In addition, because expenditure for HCBS under the Older Americans Act is not included in the HCBS categories in the official national health expenditure accounts, these were obtained from O'Shaughnessy (2011).

The percentages of the 65 and older population receiving services (shown in Tables 4.1–4.3) are the estimated number of recipients of services financed by the means-tested Medicaid programme in 2011. The amounts shown therefore underestimate by a small amount the percentages receiving any publicly funded LTC from all sources. The Medicaid programme accounts for about 90 per cent of public LTC expenditures for the 65 and older population. Two sources were used for the estimated recipients. First, total recipients of all ages in 2011 were drawn from MACPAC (2014). Second, the number of recipients aged 65 and older was estimated by applying the proportion of recipients in this age group in 2007 from O'Malley Watts et al (2011). The intensity amounts (that is, average monthly expenditures per recipient) shown in Tables 4.2 and 4.3 are similarly based only on Medicaid expenditures and estimated recipients in 2012.

References

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FIVE

How different countries allocate long-term care resources to older users: changes over time

Cristiano Gori, Francesco Barbabella, John Campbell, Naoki Ikegami, Francesco d'Amico, Holly Holder, Tomoaki Ishibashi, Lennarth Johansson, Harriet Komisar and Hildegard Theobald

Introduction

A key policy debate in long-term care (LTC) policies across OECD countries today can be summarised by the following question: what measures and strategies can be adopted to optimise resources? New policies are required for balancing finances and access to care, with different options on the table and waiting for governments' decisions.

This chapter looks at changes over time in public resource allocation among LTC users in the same OECD countries considered in the previous chapter (except for Australia). As in Chapter Four, this chapter focuses exclusively on public care inputs, defined as those inputs that are (at least partially) publicly funded, and looks at users aged 65 and over. Chapter Four led the way to reconsidering how public resources are allocated in different LTC systems through an in-depth analysis of current spending. To complement that analysis, this chapter adopts a long-term perspective, investigating the changes that have occurred over the last 20–25 years in three crucial dimensions of resource allocation: the mix of LTC services for older people, their intensity, and their coverage.

The countries considered are representative of the OECD environment with respect to both the overall welfare models and the models of LTC policies. Concerning the former, as Campbell et al have noted in Chapter Four, ‘we have Sweden in social-democratic Northern Europe, Italy in familial Southern Europe, Germany in corporatist mid-continent, Australia,

the US and England as quite different versions of the Anglo-Saxon “residual” model, and Japan as the relatively new entry that shares aspects of all the other models.³ From the point of view of LTC policies, the sample of countries selected represents the different models in the OECD context:

- *Universal coverage within a single programme*: this model guarantees people access to formal services without taking into account users’ income or assets as eligibility criteria. It is also organised as a single system, separated or integrated with the overall health system (Germany, Japan and Sweden).
- *Mixed systems*: in this case, LTC is provided through a mix of different universal programmes and benefits operating alongside, or a mix of universal and means-tested LTC entitlements (England and Italy).
- *Means-tested systems*: under this type of scheme, LTC coverage is provided through safety-net programmes. In countries using this system, income and/or asset tests are used to define thresholds for eligibility to publicly funded care. Only those falling below a set threshold are entitled to publicly funded services or benefits (the US) (Colombo et al, 2011).

This chapter is organised as follows. First, it addresses the issue of resource allocation, providing a definition of the topic and the methodology used. The main policies implemented in each of the six countries are then examined. Finally, a comparative discussion on the trends emerging across our sample is presented, followed by a final paragraph looking ahead.

Topic and methodology

By ‘resource allocation’ we mean how LTC publicly funded services and benefits are distributed among older people under different circumstances. Resource allocation refers to the underlying question ‘who gets what?’, that is, who are the LTC users and how does the utilisation of LTC resources vary across them, with related implications? In this sense, resource allocation of LTC inputs depends on three main dimensions: the *policy mix*, meaning the mix of public services and benefits provided to older people; *coverage*, meaning the percentage of older people receiving public care inputs; and *intensity*, meaning the average amount of care inputs per user offered by public providers.⁴ Table 5.1 presents an overview of the three dimensions and of the related indicators used here.

With respect to the methodological aspects of data collection, treatment and analysis, various problems related to comparing LTC policy have been taken into account and addressed. Generally speaking, the main elements are in common with Chapter Four, including:

- the inclusion of only people aged 65 or over as users;
- consideration of only publicly funded services in the policy mix and related data on coverage and intensity;
- a focus on average intensity and not on how intensity varies among users under different circumstances;²
- a focus exclusively on public unit costs in the measurement of intensity;
- distinguishing between three main categories of services, that is HCBS (when users live in the community and receive services in-kind: home care, day care, respite care, etc), institutions (when users are residents in a nursing home or similar facility), and cash allowances (when a monetary benefit is granted to users).

Table 5.1: Resource allocation in publicly funded policies

Dimensions	Sub-dimensions	Indicators
Policy mix	<i>HCBS vs institutions</i>	The ratio between the coverage (% users 65+) of HCBS and of institutions
Mix of services and/or benefits provided to older people	Proportion of coverage by HCBS ³ and by institutions ⁴	
	<i>Cash benefits vs services in-kind</i>	The ratio between the coverage (% users 65+) of cash benefits and of services in kind
	Proportion of coverage by cash benefits and by services in-kind	
Coverage	<i>HCBS</i>	% of users among the population 65+
% of older people (aged 65+) receiving care inputs	% of older people receiving HCBS	
	<i>Institutions</i>	% of users among the population 65+
	% of older people living in institutional care settings	
	<i>Cash</i>	% of users among the population 65+
	% of older people receiving cash benefits.	
Intensity	<i>HCBS</i>	One of the following indicators is chosen for each country, depending on data availability:
Average amount of care per user provided	Average amount of care inputs of HCBS per user provided	<ul style="list-style-type: none"> • mean number of periodical accesses (visits) • mean periodical public unit cost⁵ (net inflation rate, national currency)
	<i>Institutions</i>	Mean periodical public unit cost (net inflation rate, national currency) ⁶
	Average amount of care inputs of institutional care per user provided	
	<i>Cash</i>	Mean monthly amount per recipient (net inflation rate, national currency)
	Average amount of cash per user provided	

Note: HCBS = home and community-based services.

However, an important difference between the two chapters consists in how data have been reported and treated. In this chapter, the aim is not to build a cross-sectional data set that is comparable among countries, as is the case in Chapter Four. In fact, given the data available, such an exercise – referring to changes over time in the indicators listed above (see Table 5.1) – would not be possible. The aim here, thus, is exclusively to compare policy trends in a longitudinal way, over a time frame of around two decades, considering situations at the beginning of the 1990s, 2000s and 2010s. Different years have been considered for each country, according to data availability, in order to show differences in the provision of policy mix, coverage and intensity over the time frame. Furthermore, in some cases, data are not strictly comparable among countries because they do not refer exactly to the same input and/or they are calculated with different methodologies. This means that data collected are strictly comparable only within the same country in the time period considered. Our database has several limitations, but it is sufficient for describing how each LTC system evolved and to compare the trends among the different countries.

Trends and changes in the six countries

The first function of this section is to illustrate the main trends in LTC service provision in each national system, including a table showing how the three dimensions outlined in Table 5.1 changed over the last few decades. The second is to explain LTC system trends and characteristics in relation to policies implemented during the same period.

England

Long-term care in England can broadly be separated into three categories: health care provided by the National Health Service (NHS); assisted living support provided by local authorities and the independent sector, known as social care; and cash benefits administered by central government. Whereas access to health care is universal and largely free at the point of contact, and eligibility for LTC-related cash benefits is based solely on need, access to publicly funded social care is tightly restricted within a needs and means-tested system. As discussed below, the result is that coverage of home and institutional care among the older population in England is lower than in many other countries (see Chapter Four), and is becoming further restricted as a result of budgetary pressures.

The figures in Table 5.2 illustrate that during the 1990s, there was growth in the proportion of the population aged 65 and over supported in publicly funded residential care and nursing homes. However, since then, the overall provision of publicly funded social care – home care and institutions – has fallen. This is partly because of a growth in the older population (in the decade between 1990/91 and 2000/01 the number of older people rose by 3 per cent, while in the following decade the figure increased again by 10 per cent), but we also know that the number of older people receiving services has declined. For example, in the period 2006/07 to 2011/12, the number of older people receiving community-based services reduced by 22 per cent (Humphries, 2013), a trend that became even sharper from 2010 onwards when the government introduced budgetary cuts to public services. Real term expenditure on social care for older adults fell by 15 per cent from 2009/10 to 2012/13, and there was a 26 per cent reduction in the number of older adults receiving community-based care, equating to almost a quarter of a million fewer people (Ismail et al, 2014).

Table 5.2 also indicates that while local governments have reduced the overall proportion and number of older people receiving care, they have increased the intensity of home care provided. The average monthly number of hours of home care provided per household has, in fact, significantly increased. These figures imply that local governments have responded to increasing demand and decreasing budgets by focusing their resources on those most in need.

Table 5.2: Evolution of the English long-term care system during the last few decades

Dimensions	Sub-dimensions	Data		
		Early 1990s	Early 2000s	Early 2010s
Policy mix	Home care vs institutions (ratio) ^a	3.5:1	1.5:1	1.6:1
	Cash benefits vs services in-kind (ratio) ^a	1.3:1	3.1:1	4.8:1
Coverage	Home care ^b	5.3%	3.9%	3.0%
	Institutions ^c	1.5%	2.6%	1.9%
	Cash ^d	8.9%	20.3%	23.5%
Intensity	<i>Home care</i>			
	Average weekly number of hours of home-care provided per household ^e	3.2	6.7	12.4
	<i>Institutions</i>			
	Mean weekly public unit cost (net inflation rate, £) ^f	n.a.	£450	£522
	<i>Cash</i>			
	Mean monthly amount per recipient (net inflation rate, £) ^d	£211	£272	£317

Sources and notes:

n.a = information not available.

^a Coverage ratios: data sources listed below.

^b Figures for 1992, 2000 and 2008 are based on a survey week in September. Estimates for the proportion of people 65 years and older were taken from RAP (Referrals, Assessments and Packages of Care return) data from 2000. Sources: DH (2000); HSCIC (2009).

^c Figures for 1994, 2000 and 2013 refer to the number of people in either nursing or institutional care on the 31 March of that year (a one-day census). Sources: estimate from DH (1998, 2007); HSCIC (2012).

^d Figures for 1990/91, 2000/01 and 2012/13. Net inflation rate based on prices for 2013 using GDP deflators from Office for National Statistics (ONS). Cash benefits include Disability Living Allowance (DLA) and Attendance Allowance (AA). Sources: Department for Work and Pensions (DWP) (various years); ONS (various years); and official databases http://data.gov.uk/dataset/disability_living_allowance_dla, and http://data.gov.uk/dataset/attendance_allowance_aa. Both for DLA and AA, expenditure and caseload for older people in England have been estimated for the years 1990–91, 2000–2001 and 2010–11 (only expenditure) by using DWP figures for GB pensioners and adjusting those to the English older people counterpart on the basis of ONS population data. With regard to 2010–11, the number of DLA and AA recipients aged 65 and over has been obtained using data from NOMIS. Concerning DLA, data for 1990–91 refer to Mobility Allowance (MA) since in that year DLA was not yet active. Concerning AA, since 1992–93, AA is a benefit restricted to people 65 or older.

^e Figures for 1992, 2000 and 2008, based on the HH1 (Home Help) data, collected on a survey week in September and discontinued in 2008. Home care intensity is based on users aged 65 and over. Sources: DH (2000); HSCIC (2009).

^f Figures for 2000/1 and 2012/13. Net inflation rate based on prices for 2013 using GDP deflators from the ONS. Source: HSCIC (2011).

Access to social care is a decision often influenced by the availability of budgets, and as a result of recent budget cuts from central government, local authorities have been tightening their needs-based eligibility criteria, as well as increasing fees (ADASS, 2014). The result of imposing a stricter needs-based eligibility criteria and combining it with a means-test is that there are a large number of people who are paying for their care, known as ‘self-payers’ (who are not included within the scope of this chapter).

In contrast to the tightly restricted access to social care, a large number of older people in England receive cash benefits intended to allow them to live independently at home. The two main cash benefits available from central government – AA and DLA – accounted for over £7.8 billion of public expenditure in 2013, supporting over 2 million older people in England (authors’ calculation based on data from the DWP). These benefits are awarded on needs alone and are not means tested, as indicated by the high rates of coverage indicated in Table 5.2. Table 5.2 also shows the increase in monthly spend (with prices inflated to 2013).

As with other countries, demographic pressures, alongside a constrained financial situation, mean that funding LTC based on current population projections is of critical concern. When implemented, the Care Act 2014 will establish a national minimum eligibility level – in order to reduce local area variation – and enhanced support for carers (DH, 2013). Other plans to introduce a limit to the amount an individual would spend on social care over their lifetime and to provide a more generous means-test, have been postponed until 2020 (DH, 2015). This means that, once again, the country is without a strategy for how to fund long-term care in the future and in the meantime, it seems likely that the number of people in receipt of state support will continue to decline.

Germany

With the introduction in 1995/96 of LTCI (Long-Term Care Insurance), public support in Germany changed from means-tested, but needs-oriented, funding to universal support based on capped lump sum benefits. Before the social assistance-based Long-term Care scheme had provided means-tested public support for either home-based or institutional care provision by covering all LTC needs, home help services and institutional accommodation costs. By 1994 the uptake was very low, with only 2.4 per cent of older adults claiming such benefits, mainly related to institutional care provision (see

Table 5.3; German Federal Statistical Office, 1997). The establishment of LTCI finalised a gradual increase of universal-oriented public support, which had started in 1989 and 1991 within the framework of statutory health care insurance. New regulations granted without means testing either a cash benefit or a capped lump sum benefit related to home-based care services for beneficiaries living at home. By 1992, 79 per cent of beneficiaries opted for cash benefits (Alber and Schölkopf, 1999).

The establishment of universal LTCI in 1995/96 fundamentally restructured existing social rights, and little has changed since, with the exception of the introduction of different measures to support people suffering dementia illness (to be discussed later; for more information, see Theobald and Hampel, 2013). LTCI provides cash payments, home-based or institutional care services at three levels of care dependency, related to freedom of choice for beneficiaries between types of support and registered mainly private non- or for-profit care providers. The LTC-related regulations governing statutory health care insurance were abolished and the means-tested social assistance for Long-term Care scheme was restructured to complement benefits granted by LTCI.

Table 5.3: Evolution of the German long-term care system during the last few decades

Dimensions	Sub-dimensions	Data		
		Early 1990s	Early 2000s	Early 2010s
Policy mix	Home care vs institutions (ratio)	0.1:1	0.7:1	0.8:1
	Cash benefits vs services in-kind (ratio)	0.3:1	0.9:1	0.7:1
Coverage	Home care	0.1%	2.8%	3.0%
	Institutions	1.8%	3.8%	3.8%
	Cash	0.5%	5.3%	4.6%
Intensity ^a	<i>Home care</i>	na	I: 384	I: 440
	Mean monthly public unit costs in different users' categories (net inflation rate, €)		II: 921	II: 1,040
			III: 1,432	III: 1,510
		(1,918)	(1,918)	DE: 100–200
	<i>Institutional care</i>	na	I: 1,023	I: 1,023
	Mean monthly public unit costs in different users' categories (net inflation rate, €)		II: 1,279	II: 1,279
			III: 1,432	III: 1,510
		(1,688)	(1,825)	
	<i>Cash</i>	na	I: 205	I: 225
	Monthly amount in different users' categories (adapted per loss of purchasing power, €) ^b		II: 410	II: 430
			III: 665	III: 685

Sources and notes:

na = information not available

^a Data on intensity refer to lump sums per month that depend on different levels of care dependency (I, II, III). For home care, this indicator was kept since data on average number of visits or hours per user are not available. Amounts between brackets refer to lump sums per month given in extraordinary severe cases of care dependency. Amounts indicated with 'DE' refers to lump sums per month given as additional support for people with dementia. Net inflation rate based on prices for 2010/11 using GDP deflators from the ONS. Source: HSCIC (2011).

^b In Germany, there is no regular or automatic adaptation of the benefit level to the inflation rate. After the introduction of long-term care insurance (LTCI) in 1995/96 the first increase of the benefits was in July 2008. For the purposes of this chapter, calculations on the loss of purchasing power related to the prices of home-based and institutional care provision have been carried out (German Federal Statistical Office, 2011b), instead of calculations of net inflation rate. Sources: elaboration from German Federal Statistical Office (1997, 2001, 2011a).

The newly defined social rights changed public support according to the following pillars. First, the principle of universalism within the framework of LTCI resulted in a considerable increase of the number of care recipients, with a stable proportion of 11–12 per cent of older adults receiving benefits since 1999 (German Federal Statistical Office, 2001, 2003, 2005, 2007, 2009, 2011a, 2013; Rothgang et al, 2009). Second, the emphasis of public support shifted from institutional care services towards support in beneficiaries' own homes. Due to demographic ageing, the proportion of beneficiaries opting for institutional care services increased from 28.4 to 31.8 per cent between 1999 and 2005 (German Federal Statistical Office, 2001, 2007; Rothgang et al, 2009). Despite an ongoing process of demographic ageing, since 2005 the proportion among beneficiaries opting for residential care services declined to 28.0 per cent in 2011 (German Federal Statistical Office, 2013). The decline may be partly explained by an increasing use of 24-hour care provided by migrant care workers within the family framework, from 2 per cent of beneficiaries living at home in 2002 to approximately 6 per cent in 2009 (Runde et al, 2003; Neuhaus et al, 2009; Theobald, 2011).

Finally, despite a dominance of the use of cash payments compared to home-based care services, there has been a slight decrease of payments utilisations since the introduction of LTCI (see Table 5.3; German Federal Statistical Office, 2001, 2003, 2005, 2007, 2009, 2011a, 2013).

Within the framework of LTCI, the capped lump sum benefits only partially cover the costs for home-based and institutional care provision. The intensity of public support is likely owing to the interrelationship of public and private costs of care provision. Private costs emerged due to the principle of capped lump sum benefits, which presuppose beneficiaries complementing these with private means. A further reason for the rise of private costs was the non-indexing of benefits despite rising service costs, which led to a loss of purchasing power in home-based care provision of 18.8 per cent relative to the Consumer Price Index (CPI) between 1995 and 2008 (Schneider and Reyes, 2007). The benefit levels were modestly increased step by step between 2008 and 2015. In home-based care the amount of increase differs between the care dependency levels (I, II, III) and ranges between 9.7% of former benefit level and 16.7%. In residential care, benefit levels were raised by only 4% equally on all care dependency levels.

The decline of public support is reflected in the rising level of private costs and the high care burden on informal family carers. According to a representative survey of LTCI beneficiaries, average monthly private care

costs for those living at home almost doubled from €130 to €247 between 1998 and 2010, with the highest costs of €337 for the most care-dependent beneficiaries on level III (TNS Infratest Sozialforschung, 2011). Rising private costs also ensued for institutional care services. In 2011, on average and depending on the care dependency level, private monthly costs amounted to between €341 and €760 for care provision, followed by accommodation costs of €627 and, possibly, further investment costs (German Federal Statistical Office, 2001). Depending on the care dependency level, private user costs grew by 33 to 48 per cent between 1999 and 2011, while public unit costs for residential care services as a whole only increased between 15-18 per cent (authors' own calculations based on German Federal Statistical Office, 2001, 2013). Recent statistics show that LTCI covers only about 50 per cent costs for institutional care provision (including accommodation and investment costs) (Rothgang et al, 2011). Germany's population is circumspect with regard to private costs. According to a 2007 survey from Eurobarometer statistics, 54.9 and 77.1 per cent of respondents complained of high private costs related to home-based and residential care provision, respectively (Carrera et al, 2013).

An additional service benefit was introduced for people suffering from dementia in 2002 (reformed in 2008, and modestly increased in 2015) with the Complementary Nursing Act, which meant the first significant change of social rights since the introduction of LTCI. Nonetheless, a representative sample of social LTCI members, polled in 2011, considered that public funding in situations of dementia was insufficient (Zok, 2011). With the reforms in 2013 and 2015, benefits related to cash payments and home-based service provision were reformed and substantially increased, apart for people suffering by dementia illness. At the moment there are reform efforts to improve assessment procedures in order to be more sensitive to the needs of applicants with dementia.

With the introduction of universal LTCI, the number of beneficiaries rose considerably and promoted a shift of public funding from institutions to beneficiaries living in their own homes. Since 2002, in several reform steps, the situation of (older) adults suffering dementia illness was improved. Weaknesses of LTC policy concern the intensity of support based on capped lump sum benefits, which, despite several reforms, have resulted in considerable private costs for services, care burdens for family carers and, in combination with the family orientation, promoted the emergence of often irregular 24-hour migrant care work within the family framework.

Italy

Far from providing widespread in-kind care services, the Italian LTC system relies a great deal on a cash-for-care scheme that constitutes the main policy measure to support dependent older people (Gori and Da Roit, 2007). In fact, the policy mix for older people is unbalanced towards cash allowances, whose number of beneficiaries currently constitutes almost twice the sum of those accessing HCBS and institutional care (see Table 5.4; Barbabella et al, 2013).

In this context, the most important measure offered by the state is the indennità di accompagnamento (IA), a cash benefit provided, after a needs assessment, to dependent people of all ages: the IA is not means tested and can be spent without any constraints. It was introduced in 1980 only for people of working age, and in 1988 it was extended to older people. This allowance has seen a significant growth in the number of users during the last decade, rising from coverage of 5.5 per cent of older people in 2001 to 12.3 per cent in 2012.

Taking into account the fact that no specific policies aimed at widening the coverage of this cash benefit were implemented, the clear trend in its growth is mainly due to specific factors, including: demographic factors (the rise in the percentage of people aged 80 and over, the main IA users, among the elderly population); not adequate availability of in-kind public services; and implicit support to use private markets (that is IA is widely used to pay for part of the salaries of privately hired care assistants) (Gori, 2012).

Table 5.4: Evolution of the Italian long-term care system during the last few decades

Dimensions	Sub-dimensions	Data		
		Early 1990s	Early 2000s	Early 2010s
Policy mix	Home care vs institutions (ratio)	2.2:1	2.7:1	3.2:1
	Cash benefits vs services in-kind (ratio)	1.7:1	1.1:1	1.7:1
Coverage	Home care ^a	2.0%	3.8%	5.5%
	Institutions ^b	0.9%	1.4%	1.7%
	Cash ^c	5.0%	5.5%	12.3%
Intensity^h	<i>Home care</i>			
	Mean number of yearly hours, ADI programme ^d	na	24	21
	Mean yearly public unit cost (net inflation rate, €), SAD programme ^e	na	1,906	2,037
	<i>Institutions</i>			
	Mean monthly unit cost (net inflation rate, €) ^f	na	3,081	3,169
	<i>Cash</i>			
	Monthly amount per recipient (net inflation rate, €) ^g	577	531	493

Sources and notes:

na = information not available.

^a Figures respectively for 1990, 2000 and 2011. They are calculated as the sum of *assistenza domiciliare integrata* (ADI) and *servizio di assistenza domiciliare* (SAD) programmes. Sources: Gori and Casanova (2009); Ministero della Salute (2014); ISTAT (2014a).

^b Figures respectively for 1991, 2000 and 2011. They refer only to dependent older people in nursing homes. Sources: Gori and Lamura (2009); Pesaresi and Brizioli (2009); ISTAT (2005, 2013).

^c Figures respectively for 1991, 2001 and 2012. They refer to *indennità di accompagnamento* (IA). Sources: Gori and Lamura (2009); ISTAT (2014b).

^d Figures respectively for 2000 and 2011. They refer to the ADI programme. Source: Ministero della Salute (2001, 2014).

^e Figures respectively for 2004 and 2011. They concern the SAD programme. Source: ISTAT (2007, 2014b).

^f Figures respectively for 1999 and 2006. They refer to *residenze sanitarie assistenziali* (RSA) (nursing homes), and include both public and private spending, since data concerning only the public sector are not available. Source: Pesaresi (1999, 2011).

^g Figures respectively for 1990, 2001 and 2012. Sources: Law no 508 21 November 1988, Circolare INPS no 211, 18 December 2000 (see www.inps.it).

^h Net inflation rate based on prices for January 2012 using deflators from ISTAT (<http://rivaluta.istat.it/> Rivaluta/).

In fact, the cash-for-care scheme deeply contributed to fostering a private market for home care in Italy: the phenomenon of privately hired care assistants has reached impressive numbers, totalling (in official statistics) 872,000 domiciliary workers in 2010, of which 711,000 are migrants (Ministero del Lavoro e delle Politiche Sociali, 2012). However, their actual number is certainly much higher, considering also the parallel market and migrant care workers employed by households on irregular contracts: the phenomenon has probably reached over 1 million people (CENSIS, 2010).

The employment of care assistants helps households to overcome long-established weaknesses in health and social care delivery by public services. HCBS in Italy are mainly provided through home care, whereas day care and respite care constitute very marginal areas. In particular, home care is provided through two different programmes: the ADI by local health authorities (known as ASLs), which mainly provides nursing and medical care; and the SAD by municipalities, which provides social care at home. The overall coverage of these two programmes together has increased significantly during the last 20 years (from 2 to 5.5 per cent), mostly thanks to the increasing trend in ADI provision, whereas SAD provision has decreased slightly.

In terms of intensity, it is clear that the mean number of hours spent by care professionals in the ADI programme is very low, according to international standards, that is currently just 21 hours per year per older user. However, the situation is quite fragmented in Italy, since it is possible to find some regions providing over 60 hours and others below 10 hours, depending on the mix of care services implemented. With regard to SAD, the overall amount of public resources dedicated to this programme remained the same in the 2000s (around €300 million), but the municipalities have progressively limited the service to people with high needs: this explains why intensity kept on increasing (slowly) until 2011. However, the situation has changed more recently as a consequence of the economic crisis and spending reviews by public bodies in the health and social care sector: consequently, public resources in the last few years have decreased significantly and the process of targeting the frailest users has been even further emphasised (Gori and Pelliccia, 2013).

Institutional care is the least developed sector in LTC, since the percentage of dependent older people in nursing homes – who get public support – is still quite low (below 2 per cent), almost three times lower than home care coverage. In the early 1990s, the majority of users in residential

facilities were still independent (Gori and Lamura, 2009): however, policy pressure at national and regional levels had an impact, encouraging many facilities to convert themselves from care homes or housing services to proper nursing homes. Monthly co-payments by users for nursing homes increased from an average of €1,071 in 2004 (40 per cent of overall costs) (Pesaresi and Brizioli, 2009) to over €1,582 (up to €1,840) in 2012 (AUSER, 2012).

Apart from the introduction of IA in the 1980s, Italy had seen very few policy attempts to reform the LTC system. In the early 1990s, some legislation (Legislative Decrees 502/1992 and 517/1993) reformed the organisation of local health authorities and introduced efficiency and standard quality indicators. With specific regard to LTC, major policy discussions included the development of guidelines for geriatric evaluation units and individual care plans.

It was only in 2000 that a general reform of the social care sector was accomplished, introducing – among other things – regional social plans, quality standards for social services and requisites for institutional care (Law 328/2000). Furthermore, new updated quality standards for health services (known as LEA) were proposed by an ad hoc commission in 2006/07 and a national fund for dependent people (*Fondo nazionale per le non autosufficienti*) was created in 2007 with the aim of providing more resources to regions and local authorities (although it greatly depends on yearly availability of funds from the Ministry of Welfare, ranging from between €100 and €400 million per year).

However, the impact of these measures has been very limited, and they cannot be considered to be part of a thoroughgoing LTC reform. In this context, the general lack of formal services and the dominant cash-for-care scheme has contributed to create a fragile system, where cash allowances are complementary to informal care provided – without any remuneration – by family networks (the so-called ‘familistic’ approach), still vital for the sustainability of the overall LTC sector.

Japan

There are three factors that have shaped the Japanese LTC system. The first is rapid ageing. The population 65 and over has increased from 12 per cent in 1990, to 17 per cent in 2000, to 25 per cent in 2013; it is projected to be 34 per cent in 2035. Caring for elders has long been perceived as the number one

social policy issue in Japan, which has led to the generous funding of new programmes. The Gold Plan (Ten-year Strategy to Promote Health and Welfare for the Elderly), launched in 1990, led to huge expansions of home help visits, day care and social service nursing homes. The public LTCI (Long-Term Care Insurance) implemented in 2000 integrated LTC services in the health and social service sectors. LTCI expenditure has doubled since then. As Table 5.5 shows, coverage has expanded rapidly, especially in HCBS, which has more than trebled.

The second factor is that cash allowances have never been pursued as an option. All benefits are in the form of services. When LTCI was being debated, women's rights groups strongly opposed their inclusion on the grounds that daughters-in-law would be under even more social pressure to care for their in-law parents and, moreover, would be compensated at a low level. The strict immigration policy preventing the entry of non-skilled labour has also dampened any potential demand for cash allowances.

The third factor is the government's attempt to reduce the number of long-stay inpatients in hospitals, which had increased greatly following the decision to make medical care free (no co-payment) to older people aged 70 and over in 1973. Many hospitals had become de facto nursing homes. Transferring long-stay convalescent beds from health insurance to LTCI was one of the rationales for initiating LTCI. There has been a steady decrease of LTCI-financed hospital care, as well as efforts to decrease the number of long-stay inpatients covered by health insurance. This policy goal has met with some success: the combined LTCI and health insurance-financed hospital-based care expenditure decreased by 11 per cent from 2002 to 2012 – the main reason for the decline in intensity of institutional care during this period.

Table 5.5: Evolution of the Japanese long-term care system during last few decades

Dimensions	Sub-dimensions	Data		
		Early 1990s	Early 2000s	Early 2010s
Policy mix	HCBS vs institutions (ratio)	0.9:1	1.4:1	2.2:1
	Cash benefits vs services in-kind (ratio)	na	na	na
Coverage	HCBS	2.8%	5.7%	10.3%
	Institutions	3.3%	4.2%	4.8%
	Cash	na	na	na
Intensity	HCBS			
	Mean monthly unit cost (net inflation rate, ¥)	54,388	101,028	92,228
	Institutions			
	Mean monthly unit cost (net inflation rate, ¥)	358,166	371,318	269,547
	Cash	na	na	na

Notes:

The early 1990s data are estimates for 1990 based on various assumptions since only aggregated data, such as the total number of home help visits and the amount allocated by budget were available. The early 2000s data are for 2002 when the breakdowns for LTCI expenditure became available. The early 2010s data are for 2012, the latest year available.

HCBS and institutions have been dichotomised based on our functional definition of whether service charges are billed together with bed and board charges or not (in institutions they are), and not that of the official definition.

Expenditure of patients covered by health insurance who have been hospitalised for more than 90 days in non-psychiatric beds are included in the above. Their expenditure has been calculated at the average inclusive rate for convalescent beds in hospitals.

Administrative costs of care management and medical supervision are included in HCBS, but those of LTC insurers and government agencies are excluded

Purchasing power parity (PPP) rate to US\$ is ¥111 as of October 2012, and the amounts have been GDP deflated by using 2005 as the base year (see http://data.worldbank.org/indicator/PA.NUS.PPP?page=1;www.esri.cao.go.jp/jp/sna/data/data_list/kakuhou/files/h23/h23_kaku_top.html).

Sources: National Institute of Population and Social Security Research (2012); Japan Ministry of Health, Labour and Welfare (1990a, 1990b, 2002a, 2002b, 2011, 2012a, 2012b).

The above three factors were key in the design of LTCI. Because of the influx of generous funding under the Gold Plan, services had been made available to those with relatively light care, albeit means-tested and unevenly distributed. When these services were transferred to LTCI, those who had been receiving services could not be dropped. Thus, when these services were made available universally, the number of beneficiaries eligible just for light care increased rapidly. Those increases are mainly responsible for the doubling of HCBS coverage and the decline in intensity from the early 2000s to 2010s, although reducing benefits for light care levels in 2006 also contributed to this.

Eligibility in LTCI is determined by assessing functional status by a 74-item questionnaire. Applicants are sorted into seven levels by a computer algorithm, and the decisions reviewed by a panel of experts in each municipality. The applicant's income and availability of family support is not taken into consideration. These levels determine the maximum cash equivalent amount of benefits. Within this amount, beneficiaries may purchase any service from any accredited provider, covering a 10 per cent co-payment plus some hotel costs in institutional care. Services include home help, visiting nurse services, day care, night (respite) care, rental or purchasing of equipment (wheelchairs etc) and home renovation (installing a slope and rails). Day care has been particularly popular, with more recipients than for home help.

To expand access to services, LTCI allowed the entry of new types of providers, including for-profit companies. Consumers' right to choose providers and the government's tariff regulations, particularly on the qualifications and number of staff, are the main mechanisms for quality control (Ikegami et al, 2014). The LTCI tariff is revised every three years and resets incentives and penalties to meet policy goals. For example, in the 2009 revision, home help agencies were paid more if they had more experienced staff. In institutional care, new types of providers, such as group homes for those with dementia, have expanded greatly.

The government policy is now focused on expanding special housing for older people. In 2012, they announced that 600,000 units of 'elder housing with services' would be built in the next 10 years (150,000 had already been built in 2014). The residents pay the hotel costs entirely out-of-pocket and, aside from a small subsidy, the capital costs are recovered from the rent. Remaining problems include the extent to which these units can provide adequate HCBS for heavy care users; whether public assistance can cover the

out-of-pocket payments for low-income people; and how cost-containment goals can be met as demand increases with ageing.

Sweden

Swedish elder care is based, driven and financed by local government (290 local governments, or municipalities). All Swedish citizens are eligible for LTC services, and access to services is needs-based, not means-tested. There are no national regulations on the eligibility – local governments decide the service level, eligibility criteria and the range of services provided, in HCBS as well as in institutional care.

The Swedish elder care system is home-based, has a high level of in-kind service provision and thus results in a rather high cost to local government. Although some cash allowance programmes do exist, they constitute a marginal area of benefits, and data on users have not been collected in the national statistics since 2006. This means that the overall LTC system relies on a strong offer of home and institutional care.

This profile is mirrored in the results shown in Table 5.6. Regarding the policy mix the development is quite obvious. Nowadays, Swedish elder care has a distinct ageing in place profile – for example, substantially impaired older people are cared for at home, instead of in institutions. Over the last two decades, the home-oriented approach has been further sustained: even if the overall home care coverage has remained at around 8–10 per cent, institutions have reduced their number of places, currently reaching 5.2 per cent of older people.

In terms of intensity, both home care visits and the costs of providing institutional care have increased substantially. In the first case – home-based care – the mean service input per recipient (in number of hours of home help per month) has increased by over 20 per cent in relative terms, between 1993 and 2012, even if the situation remained quite stable in the 2000s (around 30 monthly hours per user).

In the second case, the increased intensity of expenditure for institutional care can be explained by the fact that fewer older people are admitted but they need more care and attention: there are fewer beds/places in institutional care, but required assistance is higher among those older people residing, compared with 20 years ago. This, in turn, raises the cost, due to the need to increase staffing. Moreover, the level of dependency and degree of cognitive impairment are crucial elements in needs assessment for accessing

institutional care: in fact, the proportion of older people with cognitive impairments in LTC institutions in Sweden has increased over the years, to reach two-thirds today.

Table 5.6: Evolution of the Swedish LTC system during last few decades

Dimensions	Sub-dimensions	Data		
		Early 1990s	Early 2000s	Early 2010s
Policy mix	Home care vs institutions (ratio)	1.3:1	1.0:1	1.6:1
	Cash benefits vs services in-kind (ratio)	na	na	na
Coverage ^a	Home care	9.8%	7.9%	8.3%
	Institutions	7.7%	8.3%	5.2%
	Cash	na	na	na
Intensity	<i>Home care</i>			
	Mean number of monthly hours	24.4	30.8	29.3
	<i>Institutions</i> ^b			
	Mean monthly public unit cost (net inflation rate, SEK)	na	46,144	52,112
	Cash	na	na	na

Sources and notes:

na = information not available.

^a Data on use of service and care (both home-based and institutional care) from Swedish National Board of Health and Welfare (annually).

^b All costs are in SEK, calculated in (fixed) 2012 prices. Data on costs/expenditures for LTC services are derived from Statistics Sweden (annually).

In general terms, the development of modern Swedish elder care is the result of a long (over 30 years) historical process. Even if the given overview starts from the early 1990s, it should be noted that the Swedish LTC sector had already passed the period (in the early 1980s) when the system peaked in terms of service levels. Since then, service levels have gradually declined. Still, an affluent system is still providing generous levels of services and care to older people in Sweden. However, given the demographic phenomenon of population ageing, the main issue regarding care for older people (especially considering those with dementia) is how to continue the adequate financing of health and social care services. As regards costs, there are still gains in efficiency that could be attained by more effective targeting of care resources. Therefore, the current ‘buzz-words’ are transparency, benchmarking and open comparisons of service quality and effectiveness.

Although efficiencies in service provision may still be achieved, there is a growing need for a system of additional financing. Thus, a gradual transfer of costs to the users (or care responsibilities over to the families) is to be expected in the future, in that a greater part of services, that is help with household chores, will be paid for directly as out-of-pocket costs. This development also goes hand in hand with a more market-oriented system of elder care. More providers also means increased competition that will hopefully reduce costs and increase quality.

The trend is that Sweden is converging towards a system of welfare for older people where public responsibility is becoming more narrowly defined, and more responsibility is being placed on those people in need of care, family members and the private market. As such, we are heading towards a mixed system of social welfare and care for older people.

United States

In the US, most people who need LTC rely solely on assistance from family and friends at home, and do not receive paid long-term care services at home or in institutional settings. The main sources of financing for paid LTC services for people aged 65 and older are a public, means-tested, programme called Medicaid (48 per cent of the overall public and private expenditure in 2012) and out-of-pocket payments by individuals (34 per cent).⁷ A small proportion (7 per cent) of LTC is financed through other public programmes, some of which are not means-tested (including a programme for military veterans). Although nearly everyone aged 65 and older has medical care

insurance through a social insurance programme (called Medicare), this programme's benefits do not cover LTC. Private LTCI exists in the US, but only about one in ten people aged 65 and older have this type of insurance (Johnson and Park, 2011), and it accounted for only about 5 per cent of LTC spending for people aged 65 and older in 2012.

The public Medicaid programme (which accounts for about nine-tenths of public LTC spending for people aged 65 and older) is administered separately by each state in the US, subject to federal rules, and financed jointly by state and federal governments. To be eligible for Medicaid coverage of LTC, individuals must have a low income and limited savings, or must exhaust their financial resources paying for medical and LTC (Stone, 2011). States have considerable flexibility in designing their programmes, resulting in wide variation among states in specific eligibility requirements and covered services (Feder and Komisar, 2012). All state Medicaid programmes must cover nursing facility care for eligible beneficiaries, but coverage of HCBS for Medicaid-eligible individuals is not guaranteed. Most states have limits on enrolment and establish waiting lists for HCBS (Howard et al, 2011).

Over the past two decades, publicly funded HCBS has expanded relative to institutional services, but institutional services continue to account for about 70 per cent of public LTC spending for people aged 65 and older. Estimates suggest that a slightly larger number of people aged 65 and older receive Medicaid-financed HCBS than Medicaid-financed nursing home services. The mix has shifted significantly over the past decade – between 2002 and 2011 the proportion of the 65 and older population using Medicaid-financed institutional services decreased from 3.4 to 2.5 per cent, while the proportion using Medicaid-financed HCBS grew from 1.9 to 2.6 per cent (as shown in Table 5.7). States vary considerably in their provision of HCBS, however – one study found the share of Medicaid LTC spending for people aged 65 and older that went to HCBS ranged among states from 8 to 58 per cent (Reaves and Young, 2013).

Table 5.7: Evolution of the US long-term care system from the early 2000s onwards

Dimensions	Sub-dimensions	Data	
		Early 2000s	Early 2010s
Policy mix	HCBS vs institutions (ratio)	0.6:1	1.0:1
	Cash benefits vs services in-kind (ratio)	na	na
Coverage	HCBS	1.9%	2.6%
	Institutions	3.4%	2.5%
	Cash	n.a.	n.a.
Intensity	HCBS		
	Mean monthly unit cost (net inflation rate, US\$)	na	1,299
	Institutions	na	3,077
	Cash	na	na

Notes:

na = information not available.

Based on Medicaid services, which constitute about 90 per cent of public spending for LTC for the age 65+ population.

Source: Estimates for 2002 based on data from Sommers et al (2006); estimates for 2012 based on data from several sources as documented in Chapter Four; policy mix and coverage are for 2011. Comparable data on intensity are not available for the two time periods, but data that are more directly comparable indicate that intensity increased for both HCBS and institutions. Specifically, estimates indicate that between 2002 and 2007, intensity increased by 17 per cent for HCBS and 7 per cent for institutions. Estimates for 2002 based on Sommers et al (2006); estimates for 2007 based on Watts et al (2011). There are not comparable data available for the period between 2007 and the early 2010s, but various sources indicate that intensity continued to increase between 2007 and the early 2010s in both HCBS and institutions, although at a slower rate (Centers for Medicare and Medicaid Services, 2013; MedPAC and MACPAC, 2015). Sources available also show that, between the early 2000s and early 2010s, in HCBS, coverage (+37 per cent) rose to a larger extent than intensity.

Although comparable data on intensity are not available for the two time periods shown in Table 5.7, data that are more directly comparable indicate that intensity for Medicaid-financed services has increased for both HCBS and institutions since the early 2000s. In HCBS, intensity rose to a smaller extent than coverage.

As HCBS expands, more states are offering an option of ‘participant-directed’ services, an approach that offers individuals more control and flexibility in their services than traditional agency-provided services (Wiener, 2009). Under this model, participants manage a personal care budget; hire, supervise, and fire their own personal assistants; and, in some programmes, may use funds to hire family members to provide assistance.

One current focus of attention in health care and LTC policy development is on efforts to improve the coordination of service delivery. Older adults who need LTC typically receive it from an uncoordinated patchwork of programmes and providers, and there is also little coordination between medical care and LTC. Several government-sponsored demonstration projects are currently exploring ways to improve the coordination of medical and LTC services for people who need both. Under one major initiative, states are testing programmes that combine public funding sources for medical care and LTC for low-income people who are eligible for both types of public coverage, including elders who qualify for Medicaid.

In 2010, the US enacted landmark legislation (the Affordable Care Act, also known as ‘Obamacare’) requiring most Americans to have medical insurance coverage beginning in 2014. The legislation included provisions to establish a self-financing, public insurance programme for LTC, with voluntary participation (the Community Living Assistance Services and Support, or CLASS, Act), but the LTC programme’s implementation was suspended in October 2011 (O’Shaughnessy, 2013) and the programme was repealed in 2013.⁸ The LTC programme was intended to provide a limited cash benefit to participants (that is, people paying premiums) with an eligible level of functional impairments who had already paid premiums for at least five years. The government agency charged with implementing the programme concluded that it was unable to identify a specific programme design consistent with the law, including the requirements that the programme be fully funded by premiums and be actuarially sound for the next 75 years.⁹

Trends across countries

Coverage

Overall trends

The previous sections looked at LTC trends in the six case study countries over the last 20 years or so. This section takes the analysis a step further as it provides a comparative examination of the sample, beginning with issues related to coverage. With respect to overall coverage of the LTC public systems, during the period examined, the countries followed different paths (summarised in Table 5.8)¹⁰:

- *Increase of coverage due to an entitlement-led reform:* both Japan (in 2000) and Germany (in 1995/96) implemented major reforms that shared the same key goal, that is to expand LTC coverage to a larger number of users by introducing an entitlement to public services for all dependent people with a certain level of care needs, irrespective of income level and amount of family support. Following the introduction of these policies, the overall coverage of the public system rose enormously in both countries: in Germany, from 2.4 per cent of older people to 11.4 per cent, and in Japan from 6.1 to 15.1 per cent. The same trend occurred in other countries, such as Austria, France and Spain (not featured here), which carried out similar reforms (Ranci and Pavolini, 2013).
- *Increase of coverage due to demand pressures without reforms:* in England and Italy, the need for major national reforms to strengthen LTC policies has been widely discussed from the second half of the 1990s onwards, with no positive outcomes.¹¹ The development of in-kind services was a main aim in all the proposals put forward in both countries. In fact, England and Italy have in common under-funded systems of services in-kind, managed at local level. Since their supply is inadequate, the growing demand for public support has increased the provision of national cash benefits, as they are universal benefits, that is delivered not according to means but exclusively according to needs. In addition, the eligibility criteria for these benefits are quite broad and are not conditional on public budget availability (whereas this is the case for services in-kind). The percentage of older people receiving cash benefits rose from 5 to 12.3 per cent in Italy and from 8.9 to 23.5 per cent in England, substantially enlarging the overall coverage of the public systems.

- *Maintaining coverage at the bottom*: the US emerged as the country with the lowest coverage level for its public LTC system, both in the early 2000s and today.¹² There are many differences in the services provided by the various states, and changes occurred between community and residential care over time (see below), but the overall coverage of the system has remained substantially stable, that is, around 5 per cent of the older population. In order to increase coverage, a strong federal reform to develop LTC policies has long been advocated, but as events related to the recent health care reform ('Obamacare') – enacted in 2010 and beginning in 2014 – proved, success was illusive. In fact, this reform originally encompassed a national programme to develop LTC (the Class Act), but (as mentioned on page 94), the latter was repealed in 2013.
- *Decrease of coverage, but still leading*: the Swedish LTC system developed far earlier than the other systems examined in this chapter, and reached its peak, in terms of service coverage, in the 1980s. Since then, the overall coverage of the LTC public system has declined significantly, from 17.5 per cent of the older population to 13.5 per cent. Nevertheless, nowadays Sweden is – as shown in Chapter Four – the biggest public spender in LTC (in terms of expenditure per older person), providing generous levels of services and care to users. Similar trends of slow, long-term decreasing coverage can also be found in other Northern European countries, such as Norway and Denmark (OECD, 2005, 2013, 2014), whose systems followed an historical pathway similar to Sweden.

Community care versus institutional care

We discuss here the differences between the main types of care provided by public systems. The ratio between the coverage of services (in-kind and, where available, in cash) delivered in the community and in institutions grew in all the countries considered. This occurred irrespective of the trends in overall coverage: the ratio, in fact, rose where the latter increased (such as in Japan, from 0.9 to 2.2), where it remained steady (US, from 0.6 to 1.0) and where it decreased (Sweden, from 1.3 to 1.6).¹³

The enlargement of the ratio between community services and institutional care over the last two decades is a trend that affects not only these countries, but most of those within the OECD, as noted by several studies (see Rodrigues et al, 2012; Carrera et al, 2013).¹⁴ In fact, in the early

1990s most LTC systems were chiefly focused on institutional care whereas, during the period examined, prioritising care provided in the community has gradually become a main policy aim everywhere (see below). The evidence available, including that in Chapter Four, agrees that not only the ratio has increased, but in OECD countries ‘most LTC users receive care at home than in institutions’ while ‘spending in institutions is higher than spending at home’ (Colombo et al, 2011, pp 40, 48).

Table 5.8: Overall coverage of public long-term care systems, early 1990s onwards

Trend	Main reason	Countries
Increase	Introduction of a major reform aimed at enlarging coverage and guaranteeing entitlements to care	Germany, Japan
Increase	Major reform widely discussed but not introduced. The rise in demand for care turned mostly to needs-tested cash benefits	England, Italy
Steady	Major reform widely discussed but not introduced. LTC system continues to rely mostly on the means-tested Medicaid programme	US
Decrease	LTC system reached its peak in the 1980s and has decreased since. Still the biggest public spender	Sweden

Cash benefits versus services in-kind

The presence of cash benefits sharply divides the countries considered into two groups: some have a national cash benefit programme¹⁵ (England, Germany and Italy) while others do not (Japan, Sweden and the US). In each country where they are available, these cash benefits are both the care inputs with the highest percentage of users and those whose coverage has increased most during the period considered. The trend provides a policy lesson: cash benefits may or may not exist, but once they are established, they become a main pillar of the LTC system, with a number of implications for the care provided and for the different stakeholders involved.

The diffusion of cash benefits is primarily due to two factors, concerning both the demand side and the supply side. With respect to the latter, as previously stated, in several countries the eligibility criteria for cash benefits are quite broad, and allow wide access by users. Concerning the demand side, in many countries older people and their families prefer cash benefits to services in-kind, although differences exist according to national cultures and values (see Chapter Four). We do not move further into the discussion of cash benefits here because Chapter Seven (by Barbara Da Roit and colleagues) provides an in-depth analysis of the reasons behind their wide provision and of the implications for users, families, workers and the overall welfare system.

Coverage versus intensity

We now include intensity in the discussion, in order to look at the key question concerning trends in resource allocation: which of the two has been the main policy driver – coverage or intensity of LTC services? By ‘main policy driver’ we mean which of the two dimensions was privileged by LTC policies, according to the available data. When both intensity and coverage have increased, it can be argued that the driver is the one with the major increase; if one dimension has decreased and the other has risen, the driver is the latter.¹⁶ We do not use the term ‘policy priority’ because it is usually associated with an explicit political choice, whereas the main driver could be the output of an explicit political decision and/or the effect of other factors – such as growing needs, changing demands, inertial adjustments of the LTC systems, and so on – in the absence of choices by policy-makers. As public resources are always limited, it is not possible to escape the tension between ‘how much care’ to provide (intensity) and ‘how many people’ to reach

(coverage): policy-makers can address these aspects explicitly or not, but the issue still stands.

We look here at the trends since the early 2000s as our data set is more complete for this period and because these trends strongly influence the current features of the national LTC systems. They therefore set the scene where (difficult) policy decisions need to be taken in the near future.

Institutional care

Figure 5.1 summarises the trends in coverage and intensity in institutional care since the early 2000s in the countries studied (with the exception of Japan, whose data on this typology of services are not fully comparable).¹⁷ In three of the countries – England, Sweden and the US – the percentage of older people in institutional care has diminished, while mean public unit costs have risen in parallel.¹⁸ Thus, a decrease in coverage, along with a rise in intensity, has taken place. Intensity has also grown in Germany,¹⁹ where coverage has remained stable at 3.8 per cent of older people. Italy stands out as the only country where both coverage and intensity have increased; not by chance, this is the country with the lowest coverage both in the early 2000s and today. If we then look at the first decade examined, the early 1990s up to the early 2000s, the data available are less complete, especially with regard to intensity. Nevertheless, it is possible to notice that during this decade coverage increased everywhere.

Overall, in our country sample some consistent trends concerning institutional care come to light: up to the early 2000s, coverage increased everywhere, whereas from the 2000s onwards, it stopped growing in all countries where it had reached a certain threshold, and in most of them it started to decrease. Intensity, on the other hand, has risen in all the countries considered since the beginning of the century (see Figure 5.1). It is now possible to answer the question on the policy driver, raised above, with respect to the period since the early 2000s: in that period, intensity was the main policy driver in institutional care in most countries, in all those with coverage above a certain threshold (see Figure 5.2).

Figure 5.1: Trends in coverage and intensity, institutional care, early 2000s onwards

Intensity (trend +)

England, Sweden, US

Germany

Italy

Coverage (trend -)

Coverage (trend +)

Intensity (trend -)

Figure 5.2: Main policy driver of institutional care, sample of the countries considered, early 2000s onwards

Intensity main driver

INSTITUTIONAL CARE

Coverage not main driver

Coverage main driver

Intensity not main driver

A common picture emerges internationally: maintaining dependent elderly people in the community has become a priority, and those in institutions are older (most are currently aged 80 and over) and need more care (with respect to physical dependency and cognitive impairments) than in the past (van den Brink et al, 2013). This, in turn, raises the mean costs per user (intensity) borne by the public budget.²⁰ In several nations, the increased need of care has also led to a relevant rise in the costs covered by users' private finances. In fact, while users' co-payments have remained low in Sweden, in other countries, such as Italy, Germany and England, they have increased considerably in the period considered, and have become quite high, with a number of implications in terms of equity.

Community care

We now examine the care provided in the community, in our country sample, since the beginning of the 2000s.²¹ In order to present a comprehensive view of all the publicly funded inputs delivered to older people not in institutions, both services in-kind and cash benefits (where available) provided to those living in the community are taken into account.²² Figure 5.3 summarises the trends concerning coverage and intensity, differentiating between cash benefits and services in-kind if applicable. It shows that everywhere, with the exception of home care in England, coverage has risen, whereas the picture is mixed with respect to intensity.

Figure 5.3: Trends in coverage and intensity, community care, early 2000s onwards^a

	<i>Intensity (trend +)</i>
England – in-kind	England – cash Germany – in-kind Germany – cash US
<i>Coverage (trend –)</i>	<i>Coverage (trend +)</i>
	Italy – in-kind ² Italy – cash Japan Sweden
	<i>Intensity (trend –)</i>

Notes:

^a By 'community care' we mean the overall package of public care inputs provided to older people not living in institutions (both cash benefits and in kind services).

^b Italy has two programmes of services in kind, named SAD and ADI. We refer here to the latter, which is (by far) the leading programme in terms of public expenditure devoted to it (see pages 85-88 and Chapter Four).

Which has been the main policy driver? Countries followed various paths, but the result is the same: coverage has been privileged over intensity (see Figure 5.4). In Japan and Germany, the differences in the change in intensity hide the occurrence of the same trend. In fact, both countries introduced major reforms with the overall goal to increase coverage, along with the aim to prioritise community care over institutional care. Data show that these goals were actually met, as the percentage of older people receiving publicly funded care in the community rose. Nevertheless, the more time passed, the more a tension between increased coverage and adequate intensity became apparent. In Germany, the value of services was not upgraded between the introduction of the new social insurance scheme (1995/96) and 2008, leading to a loss of 18.8 per cent. In Japan, data show a decrease in intensity by 21 per cent, which occurred because the number of users eligible just for light care increased rapidly and because in 2006 the level of the benefits devoted to them was reduced.²³ in 2015 the intensity of the benefits for light care users was reduced further. To sum up, more coverage in the community was the explicit political priority and was actually achieved, but to maintain it over time has turned out to be increasingly difficult in terms of intensity.

In Italy coverage has been privileged over intensity in both home care services and cash benefits, whereas the English situation is mixed. Nevertheless, the two countries can be considered together – as we did with respect to overall coverage (see above) – because in both most of the care provided in the community is based on cash benefits. In England, the huge rise in the number of recipients of cash benefits has exceeded the drop in those receiving services in-kind, leading to an overall increase of coverage in community care. Therefore, in both countries, an increase of coverage in the community, led by the rise in uptake of cash benefits, has taken place. At the beginning of the period examined, in both countries, the value of the benefits was particularly low in comparative terms, and this is still the case today.²⁴ In fact, in England the monthly amount, even if it increased, has remained extremely low in comparative terms, and in Italy it has decreased in real terms. To summarise: significant growth in coverage occurred, mostly due to cash benefits, whose amount per user has remained particularly low.

The transformations that occurred in Sweden and the US follow a different scenario as these are the only countries in our sample where overall coverage of the LTC system has not increased; instead, it decreased in the former and remained stable in the latter. Nevertheless, community care in both countries has followed a path that is similar to the other nations

examined: coverage in this sector has risen and has been prioritised over intensity. In the US, both the dimensions increased but to different degrees, with coverage rising to a larger extent.

In Sweden, the preference assigned to coverage has been narrow, but the changes that occurred in this country are particularly meaningful from a comparative perspective. In the 1990s, the targeting of in-kind services delivered in the community (that is, focusing on the most dependent people providing them with quite intensive care) was a strategy that was widely discussed internationally, and carried out in England and Sweden. However, from the beginning of the 2000s Sweden changed direction – even if to a small degree – and focused on increasing coverage. This change of direction is symbolic of a period, starting in the early 2000s, that have seen the push to increase coverage predominating everywhere.²⁵

Figure 5.4: Main policy driver of community care, sample of the countries considered, early 2000s onwards

Intensity main driver

Coverage not main driver

Coverage main driver

COMMUNITY CARE

Intensity not main driver

An overall view

Drawing from the evidence collected and discussed above, it is possible to define a set of specific trends that have affected national LTC systems in terms of resource allocation in community and institutional care since the beginning of the 2000s onwards. These trends – as previously stated – strongly influence both the current features of the national LTC systems and their future perspectives. The two types of care have followed opposing pathways, as the main policy driver has turned out to be intensity in institutional care and coverage in community care (see Figure 5.5).²⁶ What is striking is that, even if policy designs, institutional settings, cultures of care and levels of public expenditure vary to a relevant degree within our country sample (see pages 77-78 and Chapter Four), with respect to resource allocation some common trends clearly emerge. The initial aim of this analysis was – as in previous chapters – to identify various patterns in countries representing different welfare models. However, the results we have uncovered, with respect to the main policy drivers in resource allocation, actually show that the LTC systems examined seem to behave in quite a similar way.

Why have such common trends in community and institutional care occurred? Although an in-depth answer to this question goes beyond the scope of this chapter, it is possible to list some factors, which, to various extents,²⁷ contributed to them. These factors concern the policies carried out in the past as well as their more recent developments, older people's and relatives' preferences and needs, and the economic incentives connected with the different care arrangements.

Figure 5.5: Main policy drivers, sample of the countries considered, early 2000s onwards

Intensity main driver

INSTITUTIONAL CARE

Coverage not main driver

Coverage main driver

COMMUNITY CARE

Intensity not main driver

Policy legacy

The first step in understanding what has happened since the early 2000s is to look at the policy arrangements that countries inherited from the past. In the early 1990s, most LTC systems across the OECD were scarcely funded, related policies were underdeveloped and up to then public intervention had chiefly focused on institutional care (Glendinning, 1998). Historically, in fact, the low-level development of LTC systems is linked to a widely shared priority assigned to institutional care. Since the early 1990s, LTC systems started to grow in scope and ambition in most countries; and while in some this was not the case, internationally they shared a substantial policy effort to further strengthen institutional care, whose coverage actually grew, almost everywhere, until the beginning of the new century (OECD, 2005). In the early 2000s, therefore, LTC systems had to face a policy legacy that – due to both long-term and medium-term trends – made institutional care the main service for older people.

Older people and families' preferences

The rise in the overall coverage of LTC systems, in most countries, and the priority assigned to care provided in the community reflect the preferences of older people and their families. The steady growth in the demand for public LTC interventions during the period considered, in fact, was due not only to the rise in the number of potential users, but also to increased expectations – both of older people and of their families – to receive public support. In fact, as previous research has shown, even though there are significant differences due to different national cultures, in most countries older people and their families have increasingly reckoned that LTC needs should not be considered an entirely private obligation, and should also be addressed by public interventions (Ranci and Pavolini, 2013). Such a cultural change is connected with the weakening of the capacity of informal and family ties to provide support, and with the increasing participation of women in the labour market (Saraceno, 2008; Rodrigues et al, 2012). Along with these factors, there emerged a widely shared preference by most older people to receive care in community settings, instead of resorting to institutional care (Ecken et al, 2004; Da Roit, 2007; Eurobarometer, 2007; Dixon et al, 2013).

Users' needs

The growth in intensity in institutions is due to the effects of the re-balancing between the main typologies of care on users' profiles. As previously mentioned, in fact, to maintain dependent older people in the community has become a priority, and this change has led institutions to admit users who need – on average – more care than used to be the case in the past (Schram et al, 2008; van den Brink et al, 2013). This transformation has produced a rise in intensity in institutional care (see page 98).

Stated policy aims

To care for more people in the community, as an alternative to institutionalisation, has been promoted as a main policy aim over a long period of time by most experts internationally (see, for example, OECD, 2005; Genet et al, 2013) and, in the period examined, it has been increasingly adopted by governments across the OECD as their own policy goal. In fact, as the increase in the coverage ratio between community and institutional care shows, this policy has been pursued in most countries. Expanding coverage of care provided in the community has been a political priority shared by all the countries examined and, in some, the rise in overall coverage within the publicly funded LTC systems also constituted a stated priority. This occurred in countries that enacted national reforms leading to the introduction of entitlements to public care for older people in need, such as in Germany and Japan.

In contrast, increasing intensity of care was not a stated goal anywhere, either in community care or in institutional care, the exception being home care services in England. In institutional care, in fact, it was not an explicit policy goal, and intensity increased as an indirect consequence of changing users' profiles (see above).

In the period considered, the expansion of community care has been an explicit aim everywhere and, in several countries, the increase in overall coverage of the LTC system too. In contrast, augmenting intensity in order to deliver an adequate package of care has been a priority in hardly any country. Therefore, in the political discourse on LTC since the early 2000s, the key phrases have been 'more people cared for in the community' (everywhere) and 'more coverage of the overall public system' (in some countries), not 'more adequate packages of care'.

Policy trajectories without explicit strategies

Not surprisingly, decreasing coverage of the overall LTC system has not been an explicit aim anywhere. In Sweden, the only country where overall coverage actually diminished, it occurred in the absence of any open policy debate on the issue, also thanks to the highly decentralised nature of the system. In this Scandinavian country, various factors, such as strong population ageing, the high levels of generosity reached by the system in the 1980s and difficulties in public financing, led local governments – which are in charge of LTC – to gradually reduce coverage since the early 1990s (Meagher and Szebehely, 2013).

Other countries in our sample followed various policy trajectories not based on explicit strategies and that can be summarised by the same ‘rule of thumb’: if proper LTC policies are not set up, care needs are met by the available provision, no matter its appropriateness. In Italy and England, in the absence of widely advocated reforms, increasing demand for public support has been met – to a relevant degree – by national cash benefits, for the very simple reason that they are the easiest care inputs users can access, thanks to their broad eligibility criteria. In both countries, many experts doubt that current care arrangements stemming from this process are the most appropriate for the dependent older population²⁸ (see, for example Humphries et al, 2010; Costa, 2013). Another country where a reform has been requested by many for a long time, but not introduced, is the US. Here, those on middle and low income can receive public support through the Medicaid programme only once they have exhausted their financial resources paying for medical care and LTC. Most US experts agree that Medicaid arrangements do not constitute a proper answer to the care needs of the older population (see, for example, Feder et al, 2007; Kaye et al, 2010).

Conversely, in both Japan and Germany, a key driver leading to major reforms was the acknowledgement that, before their introduction, many care needs were inappropriately met by other branches of the welfare state, respectively hospitals and social assistance.²⁹

Economic incentives

Increasing coverage in the community at the expense of institutions is consistent with the economic incentives underlying public budgets as the costs per user are, in most cases, lower in the former than in the latter. This conclusion is supported by the data presented both in this chapter and in Chapter Four, as well as by a substantial amount of literature published

internationally on the trade-offs between different care settings (see, for example, Tarricone, and Tsouros, 2008). Economic incentives, therefore, are definitely an element to take into account in order to explain the changes that have occurred since the early 2000s.

Conclusion

This chapter follows the common framework of the book, presented in Chapter One, only to a partial degree. Indeed, it contains national profiles for resource allocation in LTC and identifies the main trends that occurred among our sample of countries, but it does not assess the implications for the various stakeholders involved (older people, families and others) and for the respective LTC systems. Furthermore, the analysis has a number of methodological limitations, namely: (a) while it is possible to identify trends within a single country on the basis of the data collected, it is not possible to compare data between countries; (b) some data are not available at national level, especially in earlier years (early 1990s); (c) information is available only for average intensity and not for different levels of intensity among various users' profiles; and (d) various indicators are used to measure intensity and some of them, such as unit costs in institutions, are particularly difficult to interpret.

The chapter is, therefore, an explorative exercise in the comparative analysis of resource allocation. Its explorative nature is linked to the fact that patterns of resource allocation have not so far been adequately studied (see Chapter Four) in the comparative research on LTC. This means, for instance, that we were not able to rely on existing data sets, but had to build a new one of our own.

Rising tensions

In the period examined, coverage has been the main driver in community care and intensity in institutional care, due, among other things, to the list of contributing factors mentioned above. Within these common trends, as time has gone by, tensions between coverage and intensity have come to the surface in both types of care, and constitute key challenges that policy-makers will have to address in the near future.

In the community, difficulties in guaranteeing adequate intensity of care to various groups of users have become apparent in several countries, increasing the burden on informal carers and often requiring stronger involvement of

families and informal networks to organise care for older people. In some cases, this has also required older people and their families to bear substantially high private economic costs (AA.VV, 2012). At the same time, in institutions, the increased pressure on the public purse makes it difficult (also in the several countries where coverage is decreasing or stable) to match the higher intensity of care required by current users, with the risk, in various contexts, of not assuring the delivery of the highly intensive care that is needed (van den Brink et al, 2013) and/or of doing so with huge increases in co-payments. Overall, even if the main policy drivers are different, in both typologies of care the capability of the emerging care packages to match users' needs and to assure the appropriate intensity of services is more and more disputed.

Simultaneously, over recent years, awareness of the circumstances of older people with specific, highly demanding, impairments – such as dementia – has increased in several countries and many LTC systems, with respect to both institutional and community care, have been criticised for being unable to adequately meet the needs of these users (ADI, 2013).

The breadth of these tensions is going to widen in the foreseeable future, due to predicted further increases in the number of older people (see Chapter Two). Therefore, a broader set of dilemmas and tensions concerning the interplay between the 'who' (coverage) and the 'what' (intensity and policy mix) is going to come to the forefront. The challenge is to illuminate and discuss them.

Notes

¹ This is one among the various possible operative definitions of 'intensity'. A more accurate choice would have been to look – in each country – at various levels of intensity, for users with different profiles, but such an exercise goes beyond the scope of this chapter in terms of data collection.

² Data used for describing home care intensity in Germany are exceptions to this approach (they do not refer to average care inputs to users), since data availability and comparison issues do not allow identification of other appropriate indicators.

³ HCBS is an American term that encompasses not only 'home care', but all the services in kind provided to users living in the community, such as day care. We use it in this chapter in order to gain maximum consistency with Chapter Four. In the countries where data on the overall HCBS are not available, only home care is considered.

⁴ In this chapter we consider institutional care as support in activities of daily living (ADLs), in line with the definition adopted in Chapter Four. However, for simplicity, we do not use the three levels of public institutional care defined there (that is social care, nursing care, and nursing + care), but just the overall sum.

⁵ Unit costs in HCBS refer to the mean public spending for each beneficiary of a service over a time period (monthly or yearly). In this respect, data in each country have been adjusted to the net inflation rate through different methods: even if this makes data not strictly comparable between countries, our intent was to guarantee internal data consistency and validity within single countries.

⁶ Unit costs refer here to the public expenditure for institutional care, no matter if they are complemented by co-payments by users, which are not considered here. If a country has no data availability of mere public spending but only the sum of both public and private costs, it is made explicit in the related section.

⁷ Distribution of total public and private spending for LTC for people aged 65 and older in the US by source of payment was estimated using data from several sources, as documented in the Chapter Four.

⁸ Public Law No 112-240, American Taxpayer Relief Act 2012.

⁹ HHS Letter to Speaker of the House of Representatives Regarding the CLASS Act, 14 October 2011 (<http://healthreform.kff.org/en/document-finder/hhs/hhs-letter-to-speaker-of-the-house-of-representatives-regarding-the-class-act.aspx>).

¹⁰ Due to methodological limitations in our data set it is not possible to compare data between the different national systems (see pages 78 and 105). Despite these limitations, trends in coverage within single countries clearly emerge and are confirmed, for each, also by the standard data set produced by the OECD (2005, 2013, 2014).

¹¹ The English Care Act 2014 (see page 82) is not considered here as at the time of writing (2015), implementation had only just begun. Thus, it is not yet possible to assess the legislation's actual effects, and it is also difficult to predict its impacts.

¹² With respect to the US, our analysis starts with the early 2000s. Chapter Four shows that the US is the country with the lowest public expenditure within the sample considered.

¹³ These examples consider countries without a national cash benefit programme, but the trends highlighted are confirmed if we also take into account countries with such programmes. In fact, the ratio between community and institutional care increased in Germany and Italy if we take into account just services in-kind, but as cash benefits are provided mostly (Italy) or entirely (Germany) to older people living in the community, if we also consider the latter, the ratio has grown to a wider degree. In England, the ratio between home care and institutional care actually decreased, but if we also consider cash allowances among community services, the proportion rose there as well.

¹⁴ According to OECD data, across the OECD countries for which data are available, in the year 2000 the average coverage of people aged 65 and over was 6.4 per cent in the community and 4.2 per cent in institutional care, whereas in 2012 the former was 8.7 per cent and the latter 4.1 per cent, meaning that the ratio between coverage in community care and in institutions rose from 1.5 to 2.1 (authors' elaborations from OECD, 2013, 2014). However, this database does not provide data concerning the early 1990s.

¹⁵ We refer to the benefits introduced at national level. Once local schemes are also taken into account, the broad picture does not change, as their coverage is low in all the three countries without a national scheme.

¹⁶ Although it is obviously possible, none of the countries examined experienced a decrease in both coverage and intensity in the period considered.

¹⁷ In Japan, in fact, data on institutional care also include many older people in long-stay inpatient care in hospitals as 'social hospitalisation' is widespread. Social hospitalisation is still quite prevalent in the provision of LTC in institutions, although it is declining. This has been the main reason why intensity has decreased in contrast to other countries (see pages 88-90 and Chapter Four).

¹⁸ Note that, due to the growth in the older population, a decrease of coverage as a percentage of those aged 65 and over does not necessarily mean a reduction in the absolute number of users.

¹⁹ Please note that in Germany both the increase in the benefit levels for institutional care which started in 2008 and the introduction of additional support for residents suffering from dementia have to be taken into account.

²⁰ As previously stated, our analysis focuses on the intensity in terms of public expenditure (see pages 78-79).

²¹ With respect to Germany, we consider the period since the late 1990s, a time when the introduction of the social insurance scheme deeply transformed the community care system, in a way that currently still defines its main traits. In order to capture the 'before and after' effects of the introduction of the social insurance scheme, we compare the data from the early 1990s with those from the early 2010s. Also note that the trends highlighted in England have been present since the early 2000s, but took shape in the previous decade.

²² With respect to the framework presented on pages 78-79, we consider here both HCBS and cash benefits provided to users living in the community (see Table 5.1). As stated in Chapter Four, some English scholars do not include the cash benefits administered by central government as part of the LTC policies, whereas most comparative studies do.

²³ The 21 per cent reduction in intensity occurred between early 2000s and early 2010s.

²⁴ For comparisons see, for example, the data on Austria, France and Germany in Table 7.1, Chapter Seven. For more comparative data, see the references quoted in that chapter.

²⁵ Note that the targeting strategy (as discussed and implemented) concerns services in-kind, which in Sweden represent the whole provision of care in the community, whereas in England services in-kind are only part of community care, as most consists of cash benefits.

²⁶ Bear in mind that, by ‘community care’, we mean all the publicly funded inputs delivered to older people not in institutions, both services in-kind and cash benefits, where available. It is noteworthy that the presence or absence of cash benefits (see page 97) does not alter the trends highlighted.

²⁷ The factors listed apply to the countries examined to various degrees. Some of the factors seem to apply to a lesser extent to Sweden, the only nation considered that already had a well-established LTC system at the beginning of the period examined, and where a decrease in the overall coverage of the LTC system has taken place. As previously noted, both in this chapter and in Chapter Four, the Swedish trajectory has been unique among the nations considered.

²⁸ Various features of the national cash benefits have been identified (by many experts) as important shortcomings in both countries, such as: (a) their delivery is detached from the system of services in-kind provided at local level; (b) there are no clear guidelines on how they can be actually utilised; and (c) the eligibility criteria and the amount per user could be better designed in order to effectively meet the care needs of the older population.

²⁹ Note that the aim to reduce the role, respectively, of hospitals and of social assistance in LTC has been actually achieved only to a partial degree (see pages 82-85 and 88-90).

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SIX

Commissioning long-term care services

Joanna Marczak and Gerald Wistow

Introduction

Previous chapters in this volume have highlighted the critical importance of identifying strategies for optimising the use of limited financial resources. The choice of types of support and of providers is vital for efficiency in the long-term care (LTC) system. The broad aim of this chapter is to review changes in the arrangements for commissioning services across OECD countries, to explore the consequences of these changes for the system and to identify lessons for policy and practice. Some of the themes related to commissioning mechanisms, such as the regulation of care markets, multilevel governance and personalisation of service delivery are covered in Chapters Seven, Eight and Twelve in this book.

Examples from a number of OECD countries are employed to illustrate variations in commissioning processes and outputs. Variations exist, for example, in the timing and degree of marketisation, the market shares of public, for-profit and not-for-profit providers, the degree of service user involvement in commissioning decisions and the nature of relationships between purchasers and providers. However, comparable information currently available on commissioning LTC in OECD countries is uneven and incomplete. Consequently, this chapter draws together data from a variety of sources, including the OECD, the European Commission and recent research in the area.

The chapter is organised as follows. In the next section we give an overview of changes in the arrangements for commissioning services in different countries, briefly describing different approaches to commissioning as well as its conceptualisation in this chapter. The different market and related mechanisms in the LTC sectors of several OECD countries are then described, with further elaboration on the purchaser–

provider split. We go on to explore changes in the balance between different types of providers (public, for-profit and not-for-profit). The outsourcing of services triggered the more widespread emergence of tendering and contract management processes to handle purchaser-provider transactions and associated relationships, and these developments are discussed next. Marketisation also brought greater emphasis on consumer/user choice in the LTC sector, and we look at the advantages and challenges of more recent commissioning models involving users as co-producers and budget holders. We then explore the consequences of these changes for cost-effectiveness in LTC systems. It has been a working assumption of policy-makers, for example, that greater provider pluralism and competition in care markets would enhance flexibility in service provision, thereby enabling the heterogeneous needs of service users to be met more readily, in turn, leading to a better match between resources and needs and, in consequence, to a more cost-effective use of resources (Fernández and Knapp, 2004). We therefore review the evidence about changes in the prices of services, the quality of care and discuss the balance between different services provided following the introduction of commissioning and markets in LTC. Finally, we consider how far commissioning arrangements appear to have delivered increased competitiveness, and we assess the nature and extent of transaction costs associated with marketisation. We conclude with observations and recommendations for future developments in this area.

The formal LTC sector tends to be underdeveloped and commissioning processes deregulated in countries with a strong cash-for-care orientation and where spending is unregulated, such as Austria, Southern European and Central and Eastern European (CEE) countries (Arksey and Kemp, 2008; Colombo et al, 2011; Bauer and Osterle, 2014). Consequently, we offer some insights for policy developments in these nations as they move towards more organised supply systems, based on evidence from countries with a longer history of commissioning arrangements in formal LTC markets. However, while recognising that many governments have endorsed the integration of health and social care commissioning to improve cost-effectiveness and continuity of care, the challenges of joint commissioning between these services are beyond the scope of this chapter.

Recent trends in commissioning arrangements

Commissioning is a multidimensional link between purchasers and providers, and the term can be used in a broad way to capture relationships, processes and structures related to decisions about the allocation of resources. At its broadest, the concept of commissioning has been used to include arrangements related to: defining, identifying and assessing needs; designing and specifying service models to meet such needs within available resources; procuring relevant services; monitoring and reviewing their associated outputs and outcomes in relation to costs incurred and needs met; and renegotiating, terminating or extending contracts following such reviews (Wistow et al, 1996). Some models draw a distinction between strategic and operational aspects of commissioning. The former relates to wider policy processes such as determining strategic outcomes and priorities; designing preferred models of interventions, care and support; decisions about the preferred balance between prevention, early intervention and more intensive supports; and decisions around contingency plans to manage risks and unexpected challenges. Such strategic aspects of commissioning inform the operational and procurement processes that, in turn, inform the ongoing development of strategic commissioning through a continuous process that typically includes four broad categories of activity, as illustrated in Box 6.1.

Box 6.1: Elements of the commissioning cycle

Analysis

Population needs assessment, clarifying priorities, identifying existing resources and services and decisions on what outcomes should be achieved, legislation and guidance.

Planning

Design how the gaps in needs will be addressed using available resources/services, development of a commissioning strategy to decide how services will be developed and assessed as well as workforce-related plans.

Action

Appropriate actions taken to meet the objectives set out in the former stage ensuring service quality.

Review

Monitoring and assessing the impact of the services against expected outcomes, analysing feedback to identify any revisions in the process needed before starting the commissioning cycle again.

Source: Newman et al (2012)

The concept of commissioning has been used more narrowly to describe the nature of relationships between purchasers and providers, and used interchangeably with procurement, contracting, strategic purchasing or competitive tendering (Newman et al, 2012; Willis and Bovaird, 2012). In this chapter we use the concept of commissioning to cover activities that agents of the state undertake to purchase LTC services including the processes that define which services are purchased, from which providers and by what means (Greeve, 2008). We thus focus our analysis on the link between such arrangements and the cost-effectiveness of the LTC system in respect of purchaser-provider structures; the extent of outsourcing; the use of tendering and contracts to manage purchaser-provider relationships; and the degree of user involvement in the commissioning process.

Use of market-type mechanisms in commissioning long-term care services

Many of the attempts to reform LTC systems in industrialised countries have relied on market mechanisms (Pavolini and Ranci, 2008) and New Public Management (NPM) theories. These approaches generally led to increased provider competition, together with greater emphases on formal contracts and performance measurement (Theobald, 2012). Prior to these reforms, a key assumption in many countries was that the public sector offered more equal access to the provision of welfare services whereas the involvement of for-profit organisations would tend to reduce the coverage of more complex needs and harder-to-reach service users. These assumptions have been overtaken by neoliberal beliefs in the power of the free markets, consumerism, competition and a split between financing/purchasing and providing services (Pavolini and Ranci, 2008). Although different forms of marketisation may be context-related, an OECD (2005) publication defines market-type arrangements for commissioning publicly funded services as those where at least one

important feature of free markets is present, including, but not restricted to, the following:

- *Outsourcing* (also called contracting out, privatisation and competitive tendering): unlike in-house or direct provision, the objective is to develop a market and promote provider competition.
- *Consumer choice*: users are assumed to have more incentives than public authorities to choose providers and services that best meet their needs, thereby encouraging greater competition among providers, increasing the quality of services and promoting the more cost-effective use of resources.
- *Consumer vouchers* (or personal budgets): these mechanisms are intended to support the split between providing and financing LTC services, reinforce consumer purchasing power in relation to their particular needs and promote provider competition while the user, as voucher- or budget-holder, is personally empowered to choose services from different providers (OECD, 2005; Le Grand, 2007).

These mechanisms are often advocated and adopted in the belief that they will deliver a combination of both improved quality of care and improvements in cost-efficiency (Brennan et al, 2012; Theobald, 2012).

Purchaser-provider split

The emergence of commissioning as a concept and function in the public sector was a direct consequence of the shift from organisational forms that combined responsibilities for decision-making about funding levels and priorities with those for delivering services. The move from this traditional model of structural and functional integration to one based on the separation of roles between agencies that specialise in purchasing or commissioning services and those that provide the commissioned services is the most fundamental organisational consequence of introducing markets and market-type arrangements into the care sector (Glasby, 2012; Newman et al, 2012). Its primary justification is that purchasing authorities, free from direct managerial responsibility for provider interests, are better placed to act in the interests of users and, by exercising their purchasing power on behalf of users, will have greater freedom to adjust the mix of services available according to population needs and user preferences, to contract for

the most cost-effective services and to ensure that services are delivered in the most appropriate settings (Street, 1994).

Although this functional division can operate internally between the purchasing and provider units within a public authority (Le Grand and Bartlett, 1993; Karsio and Anttonen, 2013), the principle of separating purchasing/funding from the provision of services has led in most countries to the inclusion of private organisations in the supply system, and an emergence of new public–private partnerships (Pavolini and Ranci, 2008). Countries nonetheless vary in the degree of implementation of the purchaser–provider model. For example, the split became mandatory for English local authorities in 1990 (Wistow et al, 1994), and was legally mandated in Denmark in 2003 in the case of home care, but may also be employed in residential care (Bertelsen and Rostgaard, 2013). Although the split is not compulsory in Sweden, it had been introduced in 80 per cent of the municipalities by 2003 (Erlandsson et al, 2013). At the other end of the spectrum, only about 30 and 12 per cent of Finish and Norwegian local authorities were using the purchaser–provider model in 2009 and 2006 respectively (Karsio and Anttonen, 2013; Vabo et al, 2013).

Changes in the balance between public and private providers

Following the implementation of market-type reforms, LTC services have been increasingly outsourced to private for-profit and not-for-profit organisations, although public providers have continued to play a role to varying degrees in different LTC jurisdictions (see Table 6.1 for details). Australia, the US and Canada have a long history of private providers delivering publicly funded services, and state involvement in managing LTC services has usually been limited to the registration and licensing of facilities and the monitoring of standards (Armstrong, 2013; Banerjee, 2013; Harrington, 2013). For example, nearly half of Australia’s nursing homes and over 70 per cent of these in the US were privately owned in the 1980s (van Nostrand et al, 1995; Brennan et al, 2012). Similarly most residential care in Canada was privately owned in the late 1980s (McGregor and Ronald, 2011).

Conversely, in many other OECD countries the involvement of private providers, particularly of for-profit organisations, is a more recent phenomenon. In England, the marketisation of social care services was

formalised under the Community Care Act 1990 that obliged local authorities to spend at least a minimum level of public funds on for-profit and not-for-profit care services (Pavolini and Ranci, 2008; Brennan et al, 2012; Curry et al, 2013). This nationwide mandated shift towards outsourcing services was building on a trend that was well underway (Wistow et al, 1994), and currently the bulk of supply is outsourced (see Table 6.1). The Care Act 2014 in England further encouraged local government commissioners to expand provider and care options while imposing an obligation on them to develop care markets that deliver sustainable high-quality care (HM Government, 2014). In France, the introduction in 2002 of the *allocation personnalisée d'autonomie* (APA, allowance for autonomy, which partially funds human, technical assistance and some housing installations for dependent people over the age of 60) has particularly stimulated an increase in private home care providers, although not-for-profit organisations have a much bigger share of the market relative to for-profit providers (Pavolini and Ranci, 2008). In CEE countries, market mechanisms, including privatisation of care, were introduced from 1989 onwards, following the fall of socialist regimes. Both for-profit and not-for-profit providers have played an increasingly important role in the LTC sector of those countries, especially the Czech Republic, Poland and Hungary. Nonetheless, it has to be noted that this has occurred in a context where the overall supply of formal LTC services remains limited (Lipszyc et al, 2012; Golinowska and Sowa, 2013).

Table 6.1: Estimated market share of different providers in long-term care services by type of services in selected OECD countries in 2010 (as % of market share)^a

Country	Public providers		Private not-for-profit		Private for-profit	
	Homecare	Residential	Homecare	Residential	Homecare	Residential
Austria	8	55	91	24	1	21
Germany	1	6	37	55	60	40
France	15	23	65	55	20	22
Denmark	na	99	na		41	
Netherlands			80		20	
Sweden	84	75		10	16	15
Finland	93	54		7	44	
Norway		89.9		4.2		5.9
Italy		30		50		20
Spain		23		24		53
Czech Republic		30		30		40
Slovak Republic		75		20		2
England	14	7	11	13	75	80
Australia	11	6	86	59	6	35
Canada		24		25		51
US	5.7	7	15.6	25	78.7	68

Notes:

na = data not available.

^aThe situation in several countries is more complex as the provider ownership can vary, not only by the type of care, but also by region or municipality (for example, in the UK, the US, Canada and Denmark).

Sources: Data for Denmark refer to 2012, from Rodrigues et al (2014a); data for Norway, from Vabo et al (2013); data for Canada, from Meagher (2013); data for Australia, from Brennan et al (2012); data for the US refer to 2012, from Harris-Kojetin et al (2013) (data refer to home health agencies and residential care: in community, nursing homes and hospices). Remaining data from Allen et al (2011)

In several countries entry of for-profit providers into the LTC sector was linked to the implementation of long-term care insurance (LTCI) schemes. In Germany, for example, for-profit providers entered the market from 1995 with the implementation of statutory (LTCI which introduced provider competition with the objective of increasing the range of services, expanding choice for users and encouraging cost-containment within a universal social rights scheme (Theobald and Hampel, 2013). To stimulate the German care market for-profit and not-for-profit private providers were given preference over public organisations in contract negotiations (Glendinning and Moran, 2009). The reforms succeeded in securing a sharp increase in for-profit providers, and in 2010 40 per cent of home care and 60 per cent of residential care was provided in the for-profit sector.¹ Similarly, Japan implemented an LTCI scheme in 2000 to create a care market and to improve system efficiency. Following these reforms, services expanded rapidly, and today Japan has an active market for LTC dominated by a mix of for-profit and not-for-profit private providers that compete with decreasing numbers of public and quasi-public organisations (Kubo, 2014).

Nordic countries are distinctive in that despite a visible growth in for-profit providers in the last two decades, the vast majority of LTC services across the region are still provided by public organisations. For example, little more than 20 per cent of LTC services were provided by for-profit organisations in Sweden in 2012 (Erlandsson et al, 2013). In Denmark, where the outsourcing of home care was legally mandated in 2003, the market share of for-profit organisations grew from 3 per cent in 2000 to 37 per cent in 2012. However, residential care is still predominantly provided by the public sector (Bertelsen and Rostgaard, 2013). In Finland and Norway, outsourcing is less extensive, with less than 15 per cent² of LTC services being provided by the for-profit sector in 2012 (Karsio and Anttonen, 2013; Vabo et al, 2013).

Regulation and management of the care market

The emergence of the purchaser-provider model (whether internal or external) and the development of outsourcing to providers independent of the state necessitated the development of contracts and contract management as new mechanisms for regulating the delivery of care. Tender documents and contracts, rather than hierarchy, have become essential tools for managing the specification and control of services to be delivered within a wider

framework of purchaser–provider relationships (Rostgaard et al, 2011; Karsio and Anttonen, 2013; Vabo et al, 2013). As Malley and colleagues show elsewhere in this book (see Chapter Eight), contract design and other aspects of public procurement processes play a significant role in creating financial and other incentives intended to promote better outcomes, such as improved quality. In countries where the purchasers use fixed reimbursement rates (for example, Sweden, Germany, Denmark and Japan), providers are particularly incentivised to compete on the quality of services. Contracts have also become an important tool to limit the costs of publically funded services and stimulating efficiency in service delivery (Miller et al, 2013). Table 6.2 provides an overview of contracts and procurement procedures in selected OECD countries.

Table 6.2: Procurement procedures and types of provider contracts in selected OECD countries

Country	Procurement procedures/types of contracts
Austria	<p>Public procurement procedures are set by the authorities at <i>provincial</i> level.</p> <p>Criteria on the provision of home care services, volume of service and staff requirements can be specified in recognition proceedings or as preconditions prior to the completion of funding agreements and contracts.</p>
Germany	<p>Framework contracts: regulate quality standards, type of care, contents, specifications of the care tasks, financial reporting, personnel requirements and inspection rules. Usually negotiated between funding agencies (insurance funds, governments and communities) and providers.</p> <p>Only services included in a care package can be offered on the market.</p> <p>Fixed reimbursement rates, competition exists mainly on quality with minimum standards, limited price competition.</p>
France	<p>Service providers must be authorised in residential sector.</p> <p>Contracts detail standards required to be fulfilled by providers.</p>
Denmark	<p>Tendering mostly with fixed prices, and competition on quality with minimum standards.</p> <p>Care managers tend to purchase services.</p>
Netherlands	<p>Services are commissioned through annual contracts and tendering procedures. The Care Authority monitors competition and establishes tariffs for providers.</p> <p>Purchasers include: insurance funds, municipalities, users of personal budgets.</p>
Sweden	<p>Public tender specifies service delivery requirements.</p> <p>Fixed rates for homecare, competition on quality.</p> <p>Since 2009 users can choose providers.</p>
Finland	<p>Open competition is preferred.</p> <p>Requirements for providers are specified by the municipality in their initial call for bids. Contracts between municipalities and providers specify terms for service provision.</p> <p>Vouchers may be used to purchase services only from authorised providers.</p>
Norway	<p>Limited use of external providers.</p> <p>Public procurement is open to all providers.</p>
Italy	Public procurement is commonly used. Providers need to meet registration criteria.
Spain	Open competition and tendering process with contracts setting the specifications of the services to be provided.
Czech Republic	Service providers have to register and licensing is based on regional-level procedures.

**Table 6.2: Procurement procedures and types of provider contracts in selected OECD countries
(continued)**

Country	Procurement procedures/types of contracts
Slovak Republic	Limited use of external providers; occasionally tenders are used.
Ireland	Tender processes are used with national quality standards.
England	Agreed contracts (spot, block contracts, framework contracts) specify services' details. Competition takes place on price and quality. Commissioning practices vary between local authorities; they have to comply with best value, that is to purchase most effective and cost-effective services that deliver value for money.
	Local authorities set prices. The purchasers are: care managers, personal budgets, self-funders.
Japan	Competition takes place on the basis of quality and convenience. Prices are fixed by national fee schedule.
US	There is a shift from fee-for-service payments to managed care and capitated contracts. Pay-for-performance payments.

Sources: Data for England from Glasby (2012); data for Denmark, Germany, the Netherlands and England from Rodrigues et al (2014b); data for the US from Nadash (2014) and Miller et al (2013); data for Japan from Campbell et al (2010) and Kubo (2014). Remaining data adapted from Polacek et al (2011)

Providers are accountable to the public agency funding services, and sanctions may be imposed in the event of failure to meet the contracts' specifications, up to and including contract cancellation (Polacek et al, 2011). However, the imposition of such sanctions depends both on the existence of alternative suppliers and the ability to avoid penalising recipients of care rather than providers. Where public agents outsource services to external providers, competitive tendering processes are common (see Table 6.2). The merit of competitive tendering is that it motivates suppliers to improve the efficiency of their productive processes as, in principle, the more efficient providers can submit lower priced bids than their competitors and thus win (more) contracts (Street, 1994). Other mechanisms such as accreditation or certification rules were also introduced following the purchaser-provider split to manage the market and assure quality, and are either compulsory or a condition for reimbursement or pre-qualification to tender in the majority of OECD countries (for example, the US, Canada, Australia, the UK, Germany, Spain, Portugal and Nordic countries) (OECD/European Commission, 2013).

In Box 6.2, we provide further details of different arrangements for procurement in the form of vignettes outlining the approaches adopted in three OECD countries: Denmark, Germany and the US. As we show, these countries are illustrative of the considerable diversity that can be found even within countries in the same economic 'club'. Thus municipalities have significant responsibilities in Denmark, whereas insurance funds, regional and federal authorities have substantial roles in Germany. The US has a complex system of procurement for LTC services linked to Medicaid and Medicare insurance schemes.

Box 6.2: Contracting and procurement processes – examples from Denmark, Germany and the US

Denmark

Municipalities typically use competition with fixed prices for tendering home care, and competition takes place on quality by, for example, ensuring the continuity of the workforce. Municipalities are obliged to contract with any private for-profit provider that meets the requirements on quality standards and price. Public and for-profit providers co-exist, and the latter are not permitted to refuse to provide care for any individual. Recent legislation now allows private home care providers to compete on price in the privately-paid-for sector and, although municipalities are no longer obliged to contract with all bidders who meet minimum tender specifications, they must contract

with at least two such providers. Residential and nursing care may also be included in these tendering and contracting arrangements (Bertelsen and Rostgaard, 2013).

Germany

Framework contracts are usually negotiated annually by the regional associations of LTCI funds, and providers compete on quality with limited price competition (Leichsenring, 2010; Rodrigues et al, 2014b). Since the differences between bidders on their quality of care scores are minimal, in reality, competition is largely limited to accommodation and catering costs for private payers in residential care,³ and, in the case of home care providers, to their preparedness to waive user co-payments (Rodrigues et al, 2014a).

US

There has been a shift in provider payments from fee-for-service to capitated rates in the attempts to contain Medicaid costs and to improve quality of services (Nadash, 2014). In September 2014 as many as 26 states were reported to contract with managed care organisations under capitated rates (Agency for Healthcare Research and Quality, 2014). This shift has raised concerns that managed care contractors will reduce services over time to lower costs, and that existing providers may not participate in care networks, thus limiting competition and consumer choice. An early evaluation of the transition to capitated managed care in 14 states found that the choice of providers in most states was indeed limited, although the majority of surveyed states provided a choice of care contractors (Saucier et al, 2013). Another recent shift in provider payments involves moving from fee-for-service to pay-for-performance schemes where payment received by providers is tied to targeted levels of quality achieved (usually supplementing daily rates) (Konetzka and Werner, 2010; Miller et al, 2013). Few studies assessed the results of the schemes; the existing evidence suggests that pay-for-performance models produce some quality improvements (Miller et al, 2013).

User-led commissioning

An increased emphasis on customer choice and the personalisation of service delivery led a number of governments to engage users in the commissioning process, initially to help shape services, but increasingly as budget holders and purchasers of care in their own right. Thus the primary aims of consumer-led commissioning have included individual empowerment through the exercise of consumer sovereignty together with cost reduction by utilising their expertise and self-interest in the service of increased effectiveness. The underlying rationale for extending user influence over the services they receive is, therefore, that they are best placed to judge what services will maximise their wellbeing, and they have a more direct incentive

than state agents to ensure that the resources available for their care will spread as far as possible (Watt, 2012; Szebehely and Meagher, 2013). This switch towards personal budgets and self-directed commissioning has, of course, significant implications for case managers and other public officials since their role shifts to one of supporting individual users to be effective micro commissioners together with that of stimulating new local services and shaping care markets.

In Germany users have been purchasers of services from the onset of marketisation in 1995. However, they can purchase services only from providers that meet quality standards and are registered with insurance funds (Rodrigues et al, 2014a). Direct payments introduced in England in 1996 and extended to older people in 2000 provide cash to eligible users of home care to purchase their own services or employ a personal assistant. As in Germany, users of direct payments have more freedom to select not only a provider, but also the type, time and mode of care (Glasby and Littlechild, 2009; Brennan et al, 2012). More recently, the introduction of personal budgets for social care, with the option of taking those budgets as a direct payment, greatly extended the potential scope for personal commissioning (NAO, 2011). From 2011, all new publicly funded users of home care in England were provided with a personal budget that could be used as a direct payment or managed by the local authority on behalf of the user, taking the latter's preferences into account. A third option is that a third party, including a provider, can be chosen by the user to manage their personal budget. In practice, the uptake of direct payments remains comparatively modest among older people: in 2012/13, 88 per cent of older personal budget holders were managed by local authorities or a third party, and only 7 per cent of this group took it as a direct payment (Rodrigues et al, 2014a).

Voucher schemes can also involve users directly in commissioning processes and have been implemented in several OECD countries (for example, Finland, Denmark, Sweden, France, the Lombardy region in Italy and the US). Vouchers are given by the public authority to the citizen-user for acquiring care services from competing suppliers. It is believed that vouchers can prevent the potential for abuse inherent in cash payments while being no less effective in stimulating provider competition and cost-effective care delivery (Vaarama, 2012; Szebehely and Meagher, 2013; Rodrigues et al, 2014a). In Nordic countries voucher-holders can buy services either to support themselves at home or in institutional settings, but their choice is limited to purchasing care from accredited providers (Meagher and

Szebehely, 2013). More recently, vouchers have also been introduced in the US (Doty, 2010; Kunkel and Lackmeyer, 2011). Around one-third of the ageing services and Area Agencies on Aging provide users with vouchers, whereas about half of the Area Agencies on Aging use personal budgets to give users choice and control over the services, including the ability to employ, manage and terminate contracts with care workers and to manage their care budgets (Kunkel and Lackmeyer, 2011).

However, as Campbell and colleagues in this volume noted in chapter 4 , the number of voucher recipients in the US is very small. Likewise, despite the hopes of enthusiasts in the Nordic countries that vouchers would stimulate competition and contain costs, their relatively low uptake has restricted such impacts. For instance, although Finland piloted vouchers as early as the 1990s and in 2012 they were used by half of municipalities, voucher-users constituted approximately only 9 per cent of all home care users (Karsio and Anttonen, 2013). Denmark introduced vouchers in 2009, but by 2011 only 3 out of 98 municipalities had implemented the scheme, and in only one municipality had users actually taken up vouchers (Bertelsen and Rostgaard, 2013). In Sweden, there are no data on the actual uptake of vouchers, and by 2012 the scheme was being implemented by less than half (44 per cent) of municipalities (Erlandsson et al, 2013).

Involving users in commissioning brings a distinctive set of challenges for public authorities, including how to ensure financial flexibility while simultaneously safeguarding market stability, how to plan services for the community and how to develop new partnerships between different stakeholders (Leece, 2007). There are concerns that commissioners may not have the right skills to make markets work and to respond to the additional uncertainty that such a commissioning model creates (Needham and Duffy, 2012; Meagher and Szebehely, 2013). For example, problems with costing and pricing services were reported in England, and commissioners were not always capable of mapping local provider markets (OPM, 2008). There is a risk that care markets could actually decrease in scale as user-led commissioning expands if the latter leads to less predictable and more fragmented patterns of demand that undermine the business plans and financial stability of existing providers. As providers move from wholesale to retail markets, the associated financial and organisational risks need to be effectively managed (Needham and Duffy, 2012; Szebehely and Meagher, 2013). While in England some local authorities have contingency funding for

market failures, such action adds pressure on resource pools that are already under growing pressure (Needham and Duffy, 2012).

Assessment of the changes

Different commissioning models and arrangements have an impact on the way resources are deployed with consequences for the cost and quality of care together with the nature of services provided. By shaping the nature and extent of competition, the characteristics of contracts, the allocation of risk and the flows of information between providers and purchasers, the selection of commissioning options can define the degree of success or failure in the care sector (Knapp et al, 2001). In the next section, therefore, we discuss the impact of commissioning arrangements on the cost-effectiveness of the LTC sector, and we also consider some of the macro-level changes in the system.

Are services more cost-effective? Prices and quality of care

Despite market enthusiasts' initial expectations that the purchaser-provider split, outsourcing of services and provider competition in the LTC sector would provide effective measures to contain costs, the evidence to support these beliefs is rather mixed. Several studies in the Nordic countries illustrated mixed results regarding cost-savings (and quality improvements) following the introduction of competition and choice into the LTC sector. Moreover, transaction costs were generally not included in the comparisons, even though they can be substantial (Szebehely and Meagher, 2013). Evidence from the US showed that there are some, albeit small, positive price effects from competition in the nursing home sector (Mukamel and Spector, 2002; Mehta, 2006). Conversely, substantial cost containment was achieved after opening the home help sector to competition and for-profit providers in the Netherlands in 2007, when €200 million was saved compared to the previous year (Glendinning and Moran, 2009). There may, however, be trade-offs between costs and quality of care and/or stability of the care market. The cost savings in the Dutch home help sector were reported to be achieved to the detriment of providers and care staff who incurred reductions in wages. In 2007, over 30 per cent of providers in the Dutch home and residential care sector experienced losses, and many companies withdrew from the market.

There are also possible consequences for the quality of care as care workers in the Netherlands were replaced by less skilled home helpers (Da Roit, 2013) although according to early evaluations, users' satisfaction

remained unchanged (Tjadens, 2008). Recent research in English care/nursing homes found that increased competition pushes prices down while also leading to decreased quality of care as providers have to reduce standards. This is likely to occur if commissioners are more concerned about costs than quality, at least beyond a minimum level (Forder and Allan, 2014). In another study, public commissioners in England were reported to depress profit margins to very low levels which, combined with private payers' weak market power, encourages a system of cross-subsidies from private to public payers that has become widespread in the English residential care sector. These developments were reported to jeopardise market sustainability in England, particularly in less affluent areas, with fewer cross-subsidies from private payers (Laing, 2014). Overall although the relationship between the type of provider, their costs and quality of care remains a hotly debated subject, the existing body of evidence in a range of countries tends to demonstrate that for-profit providers provide inferior care relative to other organisations, although some studies have also demonstrated that for-profit facilities have lower operational costs (Comondore et al, 2009; McGregor et al, 2010; McGregor and Ronald, 2011; Grabowski et al, 2013; Harrington, 2013).

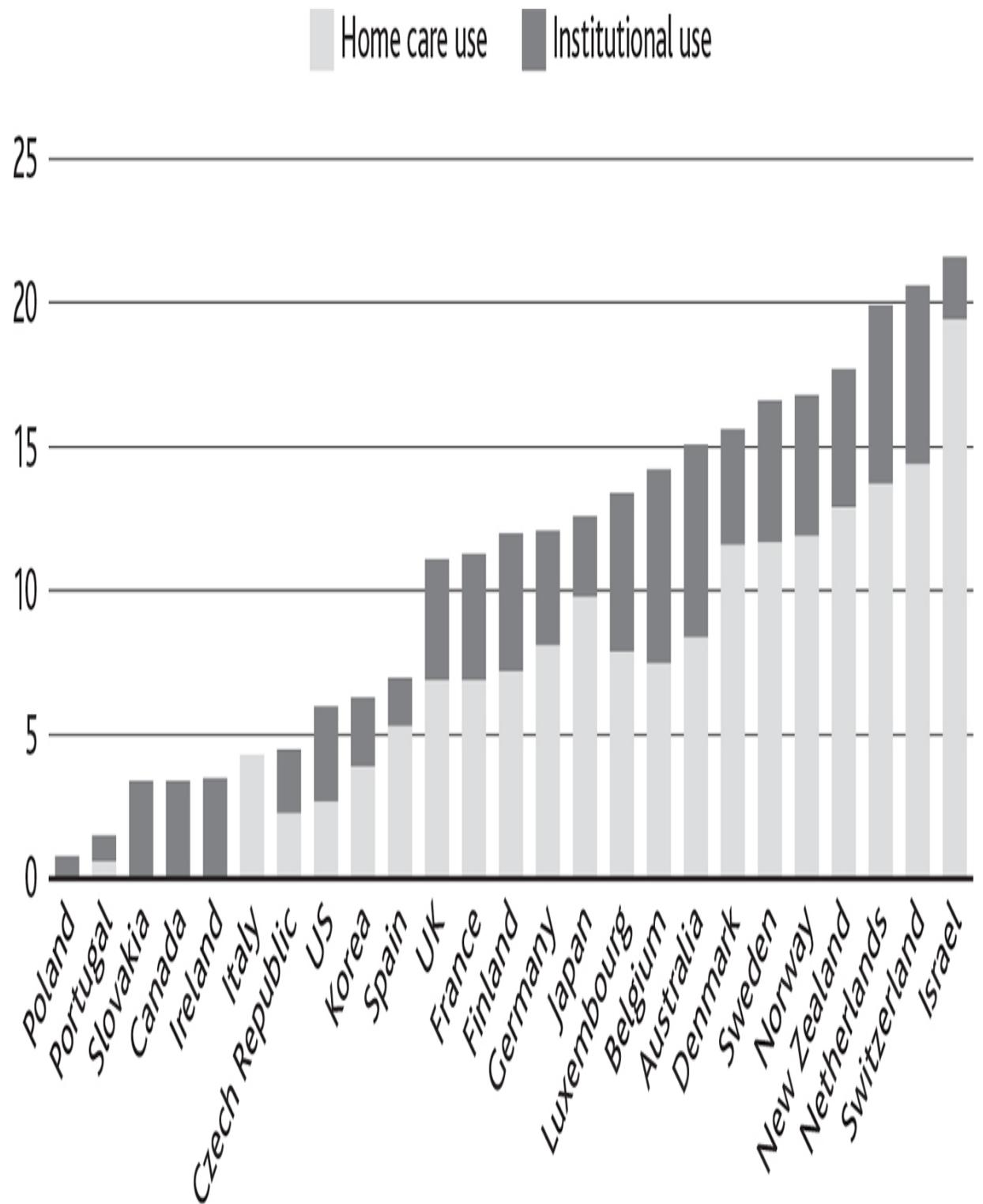
Home care and residential care: do we commission the right mix of services?

In the face of rising demand for LTC combined with cost containment and reduction pressures in an age of fiscal austerity, many countries have turned towards the expansion of care at home to reduce reliance on apparently more expensive institutional care. This growing emphasis on purchasing home care is also partly related to individuals' preferences to be cared for at home, which is believed to increase users' quality of life compared with care in institutions (Bettio and Verashchagina, 2010; Rostgaard et al, 2011; Lipszyc et al, 2012; OECD, 2013).

Overall, although a higher proportion of total LTC expenditure in OECD countries is devoted to care in institutions rather than at home (Colombo et al, 2011), recipients of the latter are greater in number (see Figure 6.1). Switzerland, Australia and the Netherlands have the highest rates of recipients of residential care, at just above 6 per cent of the population aged 65 and older, while Sweden, Norway, Finland, Luxembourg and New Zealand closely follow, with rates at around 5 per cent. At the bottom of the

ranking are Portugal and Poland, with rates below 1 per cent. Despite the overall policy emphasis on shifting resources from purchasing care in institutions towards care at home, the latter services are still limited in several Eastern and Southern European countries as well as Canada, Korea, Ireland and the US. On the other hand, Israel is at the top of the ranking with home care received by nearly 20 per cent of people aged 65 and over, followed by Switzerland, several Scandinavian countries and New Zealand.

Figure 6.1: Long-term care recipients at home and in institutions as a percentage of the population aged 65 and over in selected OECD countries in 2012 (or latest year available)



Source: OECD (2014)

Governments increasingly target home care services on users with the highest care needs (Rostgaard et al, 2011). In the US, a higher proportion of funding has been dedicated to purchasing home and community-based services (HCBS) (Doty, 2010; Kunkel and Lackmeyer, 2011), while the use of nursing homes has been declining (Wiener et al, 2009; Wiener, 2013).⁴ The recent shift towards managed care and capitated payments creates further incentives to develop the market for HCBS and to simultaneously shrink the more expensive residential care sector (Musumeci, 2014). Yet the evidence that home care is indeed less expensive is mixed. Although some studies from Canada illustrated that home care is less expensive than institutional care (Hollander and Chappell, 2002), the shift from institutional care to expanded HCBS in the US was not found to be associated with aggregate-level public cost-savings (Doty, 2010). A reduction in institutional care may be more than offset by higher home care use, including by users who would have not entered an institution (Miller and Weissert, 2010).

Moreover, in some circumstances, institutional care may be more appropriate and/or more cost-effective (for example, for high-need users requiring round-the-clock care, those living alone or in areas with limited home care availability) (Wiener et al, 2009; Colombo et al, 2011; OECD, 2013). Colombo et al (2011) noted that waiting lists for residential care in OECD states can vary from seven weeks in the Netherlands to up to three years in Japan. Government incentives in Japan have intentionally skewed the entry of private providers into the home and community care sector where profit-making has been allowed while forbidding profit-making in the residential care sector (Curry et al, 2013). Consequently, although the Japanese system is considered to be very successful in terms of stimulating the volume and scope of home care services, the supply of residential care is very limited (Curry et al, 2013; Kubo, 2014). On the other hand, following the LTC reforms in Germany, providers are eligible to be contracted by the LTCI funds independent of existing market capacity (Theobald and Hampel, 2013), and as a result, local authorities were reported to lose control over local care service planning with the consequential emergence of surplus residential care facilities (Allen et al, 2011; Rodrigues et al, 2014a).

Has competition increased?

Generating competition was a key reason for introducing market mechanisms into the care sector to ensure cost-containment, stimulate a wider choice for

beneficiaries and improve quality of care. The entry of diverse providers and the existence of a mixed provision of care in the LTC sector can be seen as indicators of a higher degree of competition compared with the non-market arrangements that existed previously. However, there are variations in the extent of provider pluralism, and thus the potential for market competition appears greater in some countries (for example, England, the US, Japan or Germany) rather than others (particularly in the Nordic nations). Furthermore, across the OECD, competition in LTC markets is not unrestricted or unproblematic. For example, the presence of different private providers in Australian markets suggests a higher degree of competition and choice than actually exists due to restrictions on private supply in a highly regulated and risk-averse system (Brennan et al, 2012). To address these limitations, the Australian government began a series of large-scale supply-side reforms in 2012 with a 10-year programme to, among other things, encourage new market entrants and a more diversified provider system to increase the range and scope of LTC services available (Australian Government, 2011, 2014).

In Germany, competition was reported to be restricted in the LTC market where charitable providers were given preference over for-profit providers through, for example, entitlements to tax breaks and eligibility for charitable donations (Allen et al, 2011; Rodrigues et al, 2014a). By contrast, it is for-profit providers that were given competitive advantages in France, following the passage of legislation imposing a ban on advertising by not-for-profit organisations (Joel et al, 2010). The creation of competition in the Netherlands through the 1995 introduction of personal budgets was also reported to be limited by the near-monopoly position of traditional home care providers and limited opportunities for new market entrants. In fact, a trend towards mergers financed by the LTCI scheme (general law on exceptional medical expenses known as AWBZ) resulted in a decrease in the actual number of providers operating on the home care market (Rodrigues et al, 2014a).

The extent to which different systems operate a ‘level playing field’ in which different providers are able to compete on equal terms is a perennial concern in LTC markets, as is the question of whether a growing role of large private corporations in service provision is a restriction on competition. Mergers, takeovers and closures have generated new challenges for commissioners to establish and retain a sufficiently competitive environment while simultaneously ensuring stable care markets and continuity of supply

(Rodrigues et al, 2014a). For example, in Sweden nearly half of private nursing homes are run by two corporations (Szebehely and Meagher, 2013). Similarly, in the US, large for-profit corporations have become the dominant providers, and nursing home chains increased their market share from 39 per cent in the 1990s to 55 per cent in 2010 (Harrington, 2013). As some large corporations provide residential care services internationally (Szebehely and Meagher, 2013; Schneider, 2014), this development restricts potential competition between care sector providers in more than one country.

The underlying idea behind allowing large corporations to operate in the care markets was their potential to bring more professional management practices and cost-efficiency gains through economies of scale (Harrington, 2013). Conversely, when large providers fail, significant numbers of individuals can be left without care unless there are robust plans to manage such failures. For example, the bankruptcy of Southern Cross in 2011, the largest provider of care homes in England which had 9 per cent of the market nationally, and a much greater market share in some geographical areas, jeopardised the care of 30,000 elderly residents across 750 care homes (NAO, 2011; Brennan et al, 2012). Recent changes in English law aim to prevent future provider failures. The Care Act 2014 established that from April 2015 the Care Quality Commission (CQC), as the independent regulator for health and social care services in England, would be responsible for evaluating the financial sustainability of care providers that would be difficult to replace in the event of failure, because of their scale or other factors (HM Government, 2014).

Transaction costs

Although the existence of competitive markets might bring savings through more efficient or effective service delivery, the outsourcing process itself incurs additional costs for tendering, accreditation procedures and quality assurance which, in principle, could be greater than gains from competitive markets (Knapp et al, 2001; Rodrigues et al, 2014a). For example, following the first years of competitive tendering in Sweden, there was little evidence that costs of services fell (Brennan et al, 2012), while the costs of procurement support were reported to have more than doubled between 2009 and 2011 (Erlandsson et al, 2013). The question, thus, is whether and in what circumstances commissioning can be a cost-effective solution. The administrative costs associated with tendering, reaching and monitoring

agreements and contracts vary depending on contract type and the degree of specifications considered necessary. For example, spot contracts⁵ tend to be most expensive from an administrative point of view for both purchasers and providers, yet still they have been very popular in England (Matosevic et al, 2008; Fernández et al, 2012).

Information asymmetries between providers and purchasers can also lead to higher transaction costs for the latter associated with gathering information to meet the risks of providers exploiting their market position and misinforming buyers about the level, cost and quality of services delivered. These costs can lead to the preference of certain providers over others based on perceived provider trustworthiness.⁶ Overall, the introduction of market mechanisms and competition in the English LTC sector triggered more adversarial relations between purchasers and providers, and such distrust may lead to higher transaction costs as more resources are needed during contract specification and monitoring processes (Knapp et al, 2001; Lonsdale, 2012). In one English study, less than half of sampled care home managers reported trusting in the information provided by local authorities (Matosevic et al, 2008).

Relations built on trust and a more relaxed approach to commissioning were reported to be gradually developing in England (Knapp et al, 2001; Glasby, 2012), and the Care Act 2014 further highlights the importance of collaboration and information transparency between local authorities and providers (HM Government, 2014). Nonetheless, the imperative to contain costs in the climate of financial austerity in recent years has encouraged more detailed specifications of the nature and timing of services to be provided in the contracts. For example, the increase in commissioning of home care time units of 30 minutes or less in recent years was reported to have triggered antagonism and complaints from providers, care staff as well as clients (UK Homecare Association, 2012; UNISON, 2012). The trend could hamper the development of more collaborative relations between commissioners and providers in the future.

The transaction costs associated with tendering procedures also have implications for the type of providers and services that enter the market. For example, tendering practices in Canada were reported to favour large organisations since the bidding processes required significant amounts of time, expertise and capital, access to which few small organisations had (Armstrong, 2013). In England, it has been suggested that commissioners should support small providers to develop their contracting skills and

expertise so that provider diversity can be sustained (see, for example, Matosevic et al, 2008).

Outsourcing prompted the development of performance and quality regulations that, in turn, introduced further costs into LTC systems for the establishment of institutions to monitor, control and enforce quality standards. For example, marketisation of services in Sweden was reported to lead to the proliferation of regulatory institutions to oversee the mixed economy of service provision, although the transaction costs associated with their operations are unknown (Szebehely and Meagher, 2013). Attempts to solve marketisation challenges through extensive regulations led to a so-called ‘regulatory trap’ in residential care in Canada where the level of regulation was reported to add to the transaction costs for both regulatory bodies and providers as well as increasing staff workloads (Banerjee, 2013). On the other hand, although less regulation may reduce transaction costs, it can lead to low and/or arbitrary service standards, as was reported in CEE countries (Golinowska and Sowa, 2013).

Conclusion

The different starting points and legacies of the countries analysed in this chapter conditioned the trajectory and pace of market-oriented reforms and commissioning arrangements within them (OECD, 2005). Commissioning processes are inextricably interrelated with the overall design and features of the LTC systems. In turn, the latter results in country- or region-specific variations in the organisation and operation of commissioning functions. For example, we have identified a mix of strategies for organising and delivering LTC services based on greater or lesser policy support for producing services in-house or purchasing them from external organisations.

In spite of these differences, OECD countries have essentially utilised variations on a small number of similar themes in their attempts to improve cost-effectiveness through the introduction of market mechanisms. The basic building blocks for promoting competitive forces include greater consumer choice, the purchaser-provider split and outsourcing service delivery to public, voluntary and private organisations. Several countries have also involved users directly as commissioners. However, as users acquire more leverage in purchasing care, it becomes more challenging to map and manage care markets to ensure an adequate match between demand and supply. It also necessitates that commissioners acquire new skill sets. Nonetheless, it is

important to emphasise that voucher schemes and direct payments have not yet turned to be a popular option, despite their potential for greater choice and cost-containment.

The international evidence on the financial and quality impacts of outsourcing services to private and public providers is rather mixed. Although there is some evidence that services produced by private providers have cost advantages, it is not always clear what their impacts are on the quality of services or such factors as market sustainability. If competition is pushing prices down at the expense of lower quality, as was suggested in England, the question is whether governments or the public are willing to accept this trade-off. Relying mostly on private providers can also lead to shortages of certain services, such as nursing homes in Japan (Curry et al, 2013), or in certain geographical areas, for example, residential facilities in Southern France (Joel et al, 2010), if the services are not profitable. Where LTC services are organised and delivered mostly by the public sector, as is the case in Nordic countries, the system can involve higher public spending, although it can give public authorities better opportunities to manage care markets and better control over the quality of care.

Even in countries with extensive public sector care markets, such as the UK, the US or Canada, competition is not unconstrained. In particular, the trend towards large chains dominating some care markets brings concerns about maintaining diversity of supply while also managing the consequences of provider failures. The feasibility of governmental monitoring of providers' financial situations and intervention where provider failure seems possible, as introduced recently in England, is likely to assume increasingly important dimensions to meet the risks of market instability in LTC systems in which continuity of care is so essential. Last, but not least, commissioning requires spending on tendering, accreditation and quality assurance, information-gathering as well as training of commissioners, providers and regulators. Such transaction costs are an important part of the debates around cost-effectiveness in LTC sector, although relevant cost data is often missing. It is therefore vital that countries keep better account of the resources used to make commissioning work (Knapp et al, 2001).

Notes

¹ Private not-for-profit providers (for example, charities, non-governmental organisations [NGOs], various organisations affiliated with churches or political parties) have a long history of delivering

social care services in Germany (see Polacek et al, 2011).

² The data can vary slightly depending on indicators used; for example, the data for Finland quoted above refer to percentage of staff and the data for Norway to percentage of expenditure (Szebehely and Meagher, 2013). Other sources use different indicators with slightly different results.

³ Accommodation and catering costs are covered for users who are social assistance beneficiaries.

⁴ However, a number of studies found mixed evidence for the association between the expansion of HCBS and the decline in nursing home use (Wiener et al, 2009; Doty, 2010).

⁵ In spot contracts, fees are based on the actual use of services and prices are agreed case by case. They offer flexibility to local authorities, but providers tend to bear more of the risk (Knapp et al, 2001; Polacek et al, 2011).

⁶ An English study demonstrated that public and not-for-profit providers tend to be perceived as more altruistic, and for-profit organisations as more concerned about profit-maximising (Matosevic et al, 2008).

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SEVEN

Cash-for-care benefits

Barbara Da Roit, Blanche Le Bihan and August Österle

Introduction

In response to increasing care needs, the development of long-term care (LTC) systems has become a prominent policy concern across the OECD (OECD, 2011). At the same time, since the 1990s, but even more so with the economic crisis started in the second half of the 2000s, cost containment has become a major preoccupation of governments. Policy measures in LTC have therefore progressively aimed at facilitating care arrangements combining formal and informal care and/or fostering market-based provision of care. In this context, the development of cash-for-care programmes – which provides people in need of care and/or their family caregivers with cash transfers so that they can organise their own care arrangements – is a common trend in many OECD countries, whatever the initial care model. This chapter analyses the development of such programmes, exploring the ideas behind the programmes, providing an overview of the different options for this type of intervention, and, by looking at the context in which cash-for-care schemes are embedded, discusses the realities of the different programmes.

The chapter first discusses different conceptualisations and ideas behind cash-for-care programmes, with specific attention paid to the ideas of choice, consumer direction and family support, leading to three ideal-typical logics of cash-for-care programmes: a market-based approach, the citizen perspective, and a conservative-familialistic perspective. Different policy designs on which cash-for-care schemes are based are subsequently presented. Following a set of criteria that distinguish cash-for-care programmes, we delve into the LTC programmes of various OECD countries. In particular, we look at the situation in Austria, the Czech Republic, France, Germany, Italy, the Netherlands and the UK, with some

information on the US. These countries were chosen for the significance of cash-for-care programmes within their LTC systems and for their belonging to different welfare and care regimes. The reality of the different approaches to cash for care is then discussed in the broader context in which the programmes have been established, and with a view to the objectives underlying cash for care. It is argued that context, timing and the specific regulation of the schemes entail different visions of care and of care work. The discussion focuses on effects in terms of users' satisfaction, on informal caregivers, on care workers and care labour markets, and on public LTC expenditure. The concluding section summarises the main policy messages emerging from the previous analysis.

Logics behind cash-for-care benefits

Cash-for-care benefits entail the provision of monetary transfers that enable recipients to receive care either through the purchase of services or the compensation of informal caregivers. They represent a break in the organisation of LTC traditionally based on the provision of in-kind services, either at home or in institutions, mainly supplied by public or not-for-profit organisations (Ungerson, 1997, 2003). Cash-for-care programmes have various names and forms, including direct payments, care allowances, attendance allowances, individual budgets, personal budgets or self-directed care. The actual 'filling' within the cash-for-care structure is open to each country's interpretation and allows large variations, ranging from general national cash allowances to marginal experimental programmes. In most cases users are provided with cash benefits or vouchers. Tax benefits are an additional or alternative option, a route, however, that is not followed up here.

A number of studies on the development of LTC systems have shown a move towards cash-for-care benefits, and more generally, towards policies allowing more individual choice for older people receiving publicly funded LTC at home (see, for example, Ungerson and Yeandle, 2007; Österle and Rothgang, 2010; OECD, 2011; Rostgaard and Zechner, 2012; Ranci and Pavolini, 2013). Choice is a major argument in favour of the development of cash-for-care schemes: introducing more flexibility in terms of how to receive care is presented as a way to increase the user's and/or the informal carer's self-determination. Instead of being provided with services in-kind,

care receivers and/or their family members are given the possibility of arranging their own care package. When looking at the most significant cash-for-care programmes, choice is often explicitly stated as a policy goal, yet, as underlined by Rostgaard and Zechner (2012, p 98), choice is also ‘a buzzword for many policy changes (...) under the rubric public care’, and it needs to be specified.

Moffatt et al (2012, p 727) suggest that the concept of choice in social policy has different political and ideological underpinnings, and they distinguish choice ‘linked with neo-liberal and new managerialist movements in public policy’, which means the introduction of markets and quasi-markets in public care services, and choice ‘linked to increasing bottom up demands from services users for more responsive, user-centred services’ (p 727). In both of these perspectives, choice is an instrument of empowerment. Yet the empowered actor is, in the first perspective, a consumer – being able to make choices between providers within more or less regulated markets puts LTC users at the centre of the market mechanism. In this framework cash-for-care schemes can be conceptualised as consumer direction, that is, ‘the ability of consumers to exercise autonomy and control over how, where, when, and by whom they receive their personal care and assistance’ (Batavia, 2002, p 67). In the second perspective, the LTC user is a citizen empowered ‘against’ a paternalistic welfare state, providing standardised care services to passive care recipients, but possibly also ‘against’ marketisation that ‘...is only one means of offering choice and, as examples of LTC policy show, it does not work perfectly to support autonomy’ (Rummery and Fine, 2012, p 337) of all carers and care recipients. So in the first perspective, empowerment and self-determination are pursued through markets, and in the second, through social participation. Yet these two perspectives are often intertwined, and care users are therefore placed ‘between citizens and consumers’ (Bureau et al, 2007, p 149).

In addition to the consumer direction and the social participation perspectives, the conservative or familialistic approach adds a third perspective to the meaning of cash-for-care schemes and choice. Here, the creation of care markets and individual empowerment are of less importance. The crucial idea is that public authorities do recognise the need and legitimacy to support older people in need of care and their family, but the latter remain in charge of arranging care and also of making the

necessary choices that public money sustains. The introduction of cash-for-care schemes may reflect a shift in care policies from ‘implicit’ to ‘explicit’ familialism (Leitner, 2010), or from ‘familialism by default’ to ‘supported familialism’ (Saraceno, 2010; Saraceno and Keck, 2010). Furthermore, cash-for-care benefits appear as the inheritance of the cash-based logic characteristic of the familialist care model. Family remains the main care provider, and public measures aim at supporting family in their caring responsibilities.

Most cash-for-care policies formally address people in need of care and give them the status of either consumer or citizen to whom a social right is granted. However, there are three limits to this individualistic choice logic. First, not all people in need of care are equally equipped to assess their situation and make individual choices. Second, the design itself of the cash-for-care schemes as well as more general features of the welfare regime might support different degrees of involvement of family members or informal caregivers. And third, professionals might be more or less involved in the making of care packages and in related choices. Informal or formal caregivers could then be regarded as co-consumers or co-beneficiaries of citizenship rights insofar as they have to make decisions about providing or managing LTC. As a result, decision-making concerning the care solutions may imply a varying degree of involvement of and different relations between three main actors: the person in need of care, the informal caregivers and the care professionals. Rummery and Fine (2012) argue that choice for carers implies being free to choose whether or not to care and how to provide care, and that choice for care recipients implies being free to choose what type of care to receive and from whom to receive it. Following this perspective, we suggest that these choices are interdependent to degrees that differ depending on the circumstances of the person in need of care and his/her family configuration, on the specific design of the cash-for-care scheme and on the context in which decision-making is embedded.

To deepen the analysis on this notion of choice, Batavia (2002) identified different domains of choice: choice about how, where, when and by whom. The *how* question refers to the ways in which care is provided. In family/informal-led models, family members or friends provide care. In service-led models, professionals decide about, manage, provide and supervise care. Under cash-for-care schemes, to varying degrees, the user is

given choices in managing the necessary care and in making decisions about the provision of care. In terms of *where*, cash-for-care benefits often emphasise home care (see the Special Issue on home care in *Health and Social Care in the Community*, 2012). It is promoted by direct financial support for informal carers or by payments or vouchers for care users, allowing them to pay for informal care or to employ care labour in their private home. One of the limitations of the service-led care model is the lack of flexibility in the organisation of the care arrangement, the *when* of care provision. Giving users a budget to pay for care can give them stronger power to negotiate the schedule of service provisions. Finally, the *by whom* question, the choice of provider, is a major distinguishing factor of cash-for-care policies, as some approaches limit choices to competing formal care providers while in other approaches money can also be transferred to informal carers.

Against this background, specific policy designs related to the general feature of care and the welfare systems might keep the choices as open as possible, or conversely, set limits to the responses to the four questions of *how*, *where*, *when* and *by whom*.

Policy designs

The analysis here refers to selected countries that have national cash-for-care programmes, in particular, Austria, the Czech Republic, France, Germany, Italy, the Netherlands and the UK, and some information on the US where plans for a nationwide programme have been repealed. These countries represent different welfare regimes and have been following different approaches to cash-for-care. In the Netherlands, the UK and the US, cash-for care benefits were introduced in the 1990s–2000s as a way to flexibilise LTC supply, and as an alternative to traditional in-kind services (Da Roit and Le Bihan, 2010; Comas-Herrera et al, 2011). The three countries differ, however, with respect to the policy context in which the reforms have taken place. While the Dutch system is traditionally very generous and universalistic (Da Roit, 2012), services in the UK system are also relatively well developed, but, just as in the US, the accent on market provision came earlier than in other European countries (Glendinning, 2012). It should also be noted that the Dutch LTC system has recently undergone a profound reform inspired by cost savings and by an attempt to

further involve family members in care provision. This policy shift is associated with the reduction in scope of the existing national LTC scheme and the decentralisation of responsibilities to municipalities (for home care) and private health care insurance. While it is difficult to assess the actual consequences of this policy, and the attempt to shift more responsibility to the family, personal budgets are available in all sub-sectors of the newly designed LTC field. In the three continental European countries (Austria, France and Germany), LTC services were traditionally little developed. The LTC reforms that have taken place since the 1990s have introduced or substantially extended social rights for people in need of LTC, and were substantially based on the provision of cash instead of services for care (Le Bihan and Martin, 2013; Österle, 2013; Theobald, 2012). In Italy, which can be considered an extreme case of a conservative-familialistic welfare regime, a national cash-for-care programme directed at adult disabled people had already been introduced in the 1980s, and has unintentionally become the most important LTC intervention. Among Central Eastern European (CEE) countries, the Czech Republic stands alone in the development of a comprehensive LTC policy in the mid-2000s by introducing a cash-for-care system, similar to the Austrian one (Barvíková and Österle, 2013).

Based on different categorisations in the literature (Lundsgaard, 2005; Timonen et al, 2006; Burau et al, 2007; Ungerson and Yeandle, 2007; Da Roit and Le Bihan, 2010), it is possible to identify a set of criteria that distinguish cash-for-care programmes. These are organised around four main questions: is cash for care a choice? Who is the budget holder? How can the benefit be used? And who is eligible and how is the benefit calculated? Different answers to these questions allow for a wide range of options, which are illustrated here by means of national examples. In addition, there is a discussion as to what extent different features of the programmes reflect the logics discussed earlier. Table 7.1 offers an overview of the different national programmes and how they score with respect to the four mentioned criteria.

Is cash for care a choice?

The first crucial difference is that in some countries there is a choice between cash for care and services, in others, cash for care and services are

two separate pillars, while sometimes cash for care is the only possibility for receiving public support. In Germany, the Netherlands, the UK and in some states in the US, it is possible to choose between services in-kind or cash-for-care benefits, or even sometimes a combination of the two. In countries such as Italy, Austria or the Czech Republic, cash for care and services in-kind are not directly connected. Here, the cash benefit cannot be replaced by services in-kind. Recipients can use the money to buy services, but access to cash benefits and access to services are organised as two separate paths. The availability and affordability of services in these countries is very much determined by social service policies. France is in an intermediate situation as the cash allowance is allocated to finance a specific care package defined by the family and the professionals.

Table 7.1: Cash-for-care benefits: characteristics and policies

Country	Name of programme ^a	Calculation of benefit	Level of benefit (2014)	Cash for care as a choice	Primary budget holder	Use of the benefit
Austria	Pflegegeld	7 levels of care needs	€154.20–€1,655.80	Cash for care as a separate benefit, not as an alternative to in-kind services	Care user; implicitly often family members	Free use of the benefit
Czech Republic	Příspěvek na péčí	4 levels of care needs	CZK800–CZK12,000 (€29–€437) (those below 18 years of age: CZK3,000–CZK12,000)	Cash for care as a separate benefit,, not as an alternative to in-kind services	Care user; implicitly often family members	Free use of the benefit
France	Allocation personnalisée d'autonomie	4 levels of dependency	Level 1 : up to €1,312 Level 2: up to €1,125 Level 3: up to €843 Level 4: up to €562	Cash for care as a benefit allocated to finance a specific care plan defined by the professionals and the care users	Originally care user (implicitly often a family member) but in more and more departments the benefit is directly delivered to services in case of high levels of dependency	Use of the benefit is controlled (but non-professional, informal, care can also be purchased)
Germany	Pflegegeld	3 levels of care needs, plus an extra level 0 for considerable limitations in daily living skills	€235–€700 (level 0: €120)	Users can choose between cash for care, service provision or a combination of the two	Care user; implicitly often family members	Free use when opting for the cash benefit

Country	Name of programme ^a	Calculation of benefit	Level of benefit (2014)	Cash for care as a choice	Primary budget holder	Use of the benefit
Italy	<i>Indennità di accompagnamento</i>	1 level	€504.07	Cash for care as a separate benefit, not as an alternative to in-kind services	Care user; implicitly often family members	Free use of the benefit
Netherlands	<i>Persoonsgebonden budget^b</i>	Personal budget is allocated according to the required/assigned care	No pre-defined amount	Yes	Care users, implicitly often family members; possible support of ad hoc organisations	Use of the benefit is controlled (but non-professional, informal, care can also be purchased)
England	<i>Personal budget</i>	Personal budget is allocated according to the required care	No pre-defined amount	Choice between direct payment, managed personal budget, or mixed package	Direct payment: care user; managed personal budget: relative, unpaid carer or local authority team	Use of the benefit is controlled

Notes:

^aThis table covers a major national cash-for-care programme for each country, not necessarily all cash-for-care programmes for the respective country. In many countries there are other programmes in place, for example, regional programmes, programmes addressing specific groups of the disabled or programmes addressing care givers. And there might be additional payments to the benefits mentioned in the table recognising specific needs.

^bAs a consequence of recent policy development, the Dutch LTC system is now divided into sub-sectors that fall under the responsibility of different institutional actors – the national LTC insurance (high-need cases), health care insurances (home nursing) and municipalities (home care). Personal budgets are available in each of these, but the rules that apply to them vary. The table reports the general and common orientation of these different provisions.

Who is the budget holder?

In general, the person in need of care, a family member or a professional can act as the budget holder. In most systems, the budget holder is formally the person in need of care. However, in cases of more severe dependency, family members formally or informally move into the role as the budget holder. This is the case in the cash-for-care schemes in Austria, Germany (when opting for the cash benefit) or Italy. In other systems, professionals can play a key role in budget-holding. An example is the UK, where as an alternative to direct payments, the commissioning of services can be left to councils (personal budgets) or to a care provider (individual service fund), while the service user can still choose how the money is spent. The situation is similar in the US: the second component of the US cash-for-care programme is counselling and gives the recipients the possibility of being supported in their management task and even to transfer their employer status to an agency. There are, however, also examples where specific cash benefits are directed at family carers, such as the carer's allowance in the UK (Burau et al, 2007) or in a number of CEE countries (Österle, 2011).

How can the benefit be used?

The regulation of the schemes varies, enabling resort to different types of care providers. In some systems, benefits are paid as contributions to care-related expenditure, without pre-defining the actual use. This is the case in Austria, the Czech Republic, Germany or Italy. As a result, cash benefits can be employed to purchase care in the market, from any kind of organisation or from individual care workers, and to informally compensate family members or other caregivers (Da Roit and Le Bihan, 2010; Barviková and Österle, 2013; Österle, 2013; Theobald and Hampel, 2013). Consistently with the approach, in all four cases, the users do not need to justify their expenses and there are no systematic controls of the use of the benefits. However, according to Austrian legislation, cash can be replaced with services in the case of misuse. This option best represents the aforementioned conservative or familialistic logic of cash for care. In other systems there are more explicit limits to the use of the benefit. There are tighter regulations in France, the Netherlands and the UK. The benefit is meant to finance a specific care package – defined as a number of hours per type of care – according to the needs of the recipient as defined and controlled by the social service system. In the UK, for instance, the basic principle is that the payment must be

sufficient to purchase services to meet eligible needs, and that it must be spent on services that meet those eligible for care. This does not exclude the right to choose one's personal assistant, who may be a professional but also a relative (except for a spouse in France). However, the relationship between the budget holder and the informal care provider paid through a cash benefit is formalised. In the Dutch case, a formal agreement establishes the employment conditions of the informal caregiver, and provides the informal caregiver paid through the personal budget with some (even if not full) employment-related social rights (Grootegeod et al, 2010). The logic is the same in France, where the allowance can be used to pay a relative (except a spouse), and where a working contract is established. Finally, in Sweden the attendance allowance is conceived as a symbolic payment to informal carers; however, measures have been introduced to relate the payments of informal carers to labour market wages and to make it possible for informal caregivers to be employed by municipalities as social care workers. These systems reflect more a liberal, market-centred logic or a citizenship-based empowering logic. There are, in fact, explicit incentives for the creation and support of care markets in which the budget holder is the key actor whose choices are supposed to ensure efficiency, flexibility, cost containment and effectiveness. But at the same time, the formalisation of informal care relations reflects an attempt to regulate family relationships in a way that strongly contrasts with conservative-familialistic systems.

The cash-for-care schemes in Austria, Italy and Germany are intended to provide rather implicit and non-formalised support for informal care, without the establishment of a direct link between the benefit and compensation for the caregivers. The benefit tends to represent additional income for the user, while the possible financial arrangements between the beneficiaries and their caregivers are left to intra-family negotiation (Costa, 2013; Österle, 2013; Theobald and Hampel, 2013). In these contexts, even more implicit mechanisms are at work. For instance, in Germany, where users can choose between cash and care services, there are, in practice, financial incentives for employing a family caregiver (Keck, 2008): because the system aims at covering basic needs only, social services delivered are insufficient to cover all needs, which makes additional family resources necessary. Families therefore often opt for cash and for self-made solutions.

In England, informal care is explicitly considered as the pivot of social care and eligibility for public support takes into account the availability of informal care. The introduction of cash payments with the creation of direct

payments at the end of the 1990s and the experimentation of personal budgets and individual budgets in 2007 reinforced this rationale by extending individual consumer choice in the public sector (Comas-Herrera et al, 2011). Personal budgets are an individual allocation of funding to enable care users to make choices about how best to meet their needs. The personalisation logic goes even further with individual budgets, defined as a new system that aims at bringing together the different possible resources care users are entitled to (Glasby et al, 2006; Glendinning et al, 2008; Netten et al, 2012).

Closely related to the choices opened up in terms of use, and to the issue of formalisation of unpaid informal care is the question of employment strategies and professionalisation. Although in most of the countries studied it appears as a consequence of the characteristics of the cash-for-care programmes (see page 153), the link between employment and older care policy is explicitly put forward in the policy-making process in the French configuration only. Here the-cash-for-care scheme introduced at the end of the 1990s aimed both at meeting the needs of older people in need of care and creating new jobs in the service sector (Le Bihan, 2012).

The possibility of choosing between cash and services also has an impact on how the benefit is used. In systems where this choice exists, the cash option is mostly taken up when users intend to use the benefit within family or other informal networks (as in Germany), or when users intend to make their own choices in the market for care services (as in the UK). In some systems, as in the Netherlands, opting either for cash or for services is also determined by the willingness to exercise the particular choices the cash system opens up, also considering the administrative requirements involved. In other systems, as in Germany, the relative economic value of services in-kind is larger than that of the cash option (Cuellar and Wiener, 2000). Therefore, users might opt for services (or combine cash and services) if they are happy with the service provided in the respective provider network. In systems with stand-alone cash-for-care schemes without pre-defined use, there is no pre-defined limitation in terms of what type of care provider is used.

Who is eligible and how is the benefit calculated?

The fourth main criterion in distinguishing cash-for-care schemes is eligibility and the calculation of the benefit. In terms of eligibility, there is a trend to not only address the older population or younger adults with

disabilities in cash-for-care programmes, but to make users of all age groups eligible. Concerning LTC schemes, there are, however, large variations in defining the population concerned, as well as care needs and the different levels of care needs. While many countries such as France or Germany apply a list of pre-defined categories or levels of dependency (in France) or care needs (in Germany), the level of the cash benefit is individualised in the UK or the Netherlands. The assessment of needs is also varied and might involve different actors (for example, doctors, nurses or social workers), and it might also consider or not consider the availability of informal care resources.

In terms of benefit level, the cash-for-care benefit is flat rate in Italy (€504.07 per month in 2014). In most other countries, in the case of cash benefits to users, there is a link between the level of care needs and the amount of cash provided. In Austria, in 2014, the benefit varied according to seven levels of needs between €154.20 (level 1) and €1,655.80 (level 7). In Germany, the benefit (when opting for cash) is between €235 (level 1) and €700 (level 3). In addition, level 0 (€120) introduced in 2008 is aimed at people with dementia who do not qualify for level 1. In the Czech Republic, care allowances range between CZK3,000 (about €109) for those aged up to 18 and CZK800 (about €29) for those aged beyond 18 in level 1 and CZK12,000 (about €437) in level 4. In France, it ranges from €1,312 (level 1, the highest) to €562 (level 4).

There are, however, important differences in the way in which the amount of the benefit is calculated. In Austria, the Czech Republic, Germany and Italy, the benefit is understood as a universal contribution to care-related costs. Benefits are lump sum compensations that leave financial management of the provision to individuals and their families. In none of these cases is the benefit means tested. However, when using services there might be co-payments referring to the cash benefit, as is the case, for example, in Austria. In other systems, including the Netherlands and the UK, the benefit is meant to cover all or the bulk of care needs. In the Netherlands, the need assessment is used to define a package of necessary care together with its economic value (calculated as about 75 per cent of the costs of equivalent in-kind services). The amount of the cash transfer reflects this evaluation, but might be diminished in relation to the economic capacity of the care receiver (via a system of means testing or co-payments). This is also the case in France where the maximum amount attributed to the four different levels of dependency is reduced according to the level of income of the recipients (Le Bihan and Martin, 2010). Means testing also applies to the situation in the

UK, where it has become a key issue in the policy debate. Indeed, although the Royal Commission on Long-Term Care indicated that there should be free personal and nursing care, at home as well as in institutions, in England, the government only accepted the application of this recommendation for nursing care in nursing homes. Means tests for personal care are set up by the different local authorities, leading to territorial disparities. As part of the Medicaid system, the US cash and counselling programme is also means tested and concerns only the poorest section of the population (Frolik and Brown, 2009; Kraiem, 2011).

As summarised in Table 7.2, it is possible to identify a pattern in the policy design of cash-for-care schemes according to the different logics (consumer, citizen and familialistic) that they represent.

Schemes based on a market and citizenship logic share many features as opposed to schemes based on a conservative logic. The major difference between market and citizenship logics is a stronger emphasis on autonomy and social participation in the citizenship logic involving, for example, stricter regulation of services or formalisation of informal care.

Discussion of the policy options: policy design, context and outcomes

Cash-for-care programmes are connected with manifold objectives, some of which are more explicitly expressed in policy debates – such as choice, empowerment or support for family care – while others often remain implicit – such as cost containment considerations. The policy evaluations available so far have mostly been concerned with users' satisfaction and to a more limited extent, with the quality of care (OECD, 2013). Less, even if increasing, attention has been paid to the effects of cash-for-care programmes on the profile and working conditions of care workers. Moreover, available studies deal with a huge variation in policy design and follow very diverse approaches. They include comparative studies as well as single-country or single-region studies (see references below).

Table 7.2: Cash-for-care policy options in consumer, citizen and familialistic logic

	<i>Market-based logic</i>	<i>Citizenship logic</i>	<i>Conservative/familialistic logic</i>
<i>Is cash-for-care a choice?</i>		yes	no
<i>Who is the budget holder?</i>		person in need of care	explicit: person in need of care implicit: family
<i>How can the benefit be used? Who?</i>		funding of care package; justification of expenses; controls	no pre-defined use; no justification of expenses; no controls
		formalization of informal care	
<i>How is the amount of the benefit calculated?</i>		commisurated to costs of the care package	lump-sum contribution
<i>Means testing</i>	yes	yes (co-payments)	no

A systematic review of the implications of cash-for-care programmes on the main single objectives as referred to above is beyond the scope of this current section. Rather, we discuss the possible implications of cash-for-care benefits in four key areas – effects (1) on the users; (2) on informal caregivers; (3) on the care labour market; and (4) on social expenditure – by taking into account a number of key issues in policy design and the role played by the broader context for the outcome. In fact, how cash-for-care programmes are perceived and how they work is not only determined by the varying design of these schemes, but also by the broader context in which they are embedded. The national (and often sub-national) context that determines the implementation of cash-for-care programmes includes the broader LTC policy and welfare state context, the cultural environment and the socioeconomic context.

First, in no country are cash-for-care programmes the sole approach to care and caregiving. Programmes are more loosely or more strictly linked to other care policies and are implemented at a certain stage of development of the entire care system (Da Roit and Le Bihan, 2010; Ranci and Pavolini, 2013). It is important to take into account different starting positions and policy contexts to understand the impact of the different policy measures. Even where similar schemes seem to have been developed, the underlying policy goals may have been different. Moreover, apart from the broader LTC policy context, individual choices are also shaped by the cultural context, by perceptions of obligations and rights in care and caregiving and the reality of managing care in families. Many studies have shown the huge variety in perceptions and realities, between countries but also within countries (see, for example, Pfau-Effinger, 2005, 2012; Eurobarometer, 2007). In that context, Pfau-Effinger (2012, p 153) emphasises the ‘complex and often contradictory context of institutional, social and economic factors as well as the specific “care culture”, all of which combine to frame senior care in the specific care arrangement of a country.’

Users' satisfaction and quality of care

There is a strong policy assumption that cash-for-care programmes make users happier or at least not less happy than service users. In general, this assumption is confirmed by evaluation studies (Foster et al, 2003; Clark et al, 2004; Wiener et al, 2007). A recent review of case-managed, integrated and consumer-directed home and community care services for older people (Low

et al, 2011) does identify higher levels of consumer satisfaction with care and service use. However, some caution is necessary in order to interpret these results. First, the heterogeneity in the programmes studied, in the methodologies applied, in the operationalisation of concepts such as ‘satisfaction’ or ‘empowerment’ leads to some inconsistency in the results (Low et al, 2011). Second, it has been shown that the users of LTC are not a homogeneous group in terms of needs and expectations: what might work out for adult physically disabled people might not work out for older people with mental health problems. A recent study on personal budgets in England, for example, emphasises differences in expectations and wants between younger adults and older people (see www.sscr.nihr.ac.uk/news.php#4Feb15). Third, it is well known that levels of satisfaction are strongly influenced by expectations and by (the perception of) available alternatives. As a result, the availability of in-kind services, their (perceived) quality and organisation can be expected to be important in determining the level of satisfaction of the users of cash-for-care schemes. Furthermore, US research shows that the level of satisfaction of users of consumer-directed services varies across types of services purchased by means of cash benefits (relatives, individual workers, organisations, and so on) (Heller et al, 2012). This implies that it is not just choice per se that matters in enhancing satisfaction, but also the nature of available and affordable choices. In countries like Italy or Austria, for example, satisfaction also arises from the fact that the cash benefit is seen as a major financial support in the case of care needs and as recognition of care work provided informally. Finally, although increasing choice and control can be perceived as positive by users, cash-for-care schemes have also caused anxiety about the responsibility of organising one’s own support and managing one’s budget, as shown by Moran et al (2013) in a recent study on the English individual budget pilot schemes.

A second strong policy assumption embedded in cash-for-care schemes is that enabling users (and/or their families) to make their own choices enhances the quality of services. However, there is so far little evidence that cash-for-care benefits enhance clinical outcomes (Low et al, 2011).

Effect on informal caregivers

As shown above, some cash-for-care schemes allow for compensating informal caregivers. This gives rise to specific types of ‘commodification of care’ (Ungerson and Yeandle, 2007) and new forms of care relationships,

which are neither fully formal nor fully informal. ‘Semi-formal care work’ (Pfau-Effinger et al, 2009; Pfau-Effinger and Geissler, 2005) entails care ‘provided by family members or within social networks in the context of welfare state programmes, such that it is no longer informal, but has some formal features in that it is registered and may also be connected with some kind of pay and social security’ (Pfau-Effinger, 2009, p 212; 2012). However, not all cash-for-care schemes support the same types of care relationships, while policies to provide family or other informal care workers with social security rights (and hence establishing semi-formal care work) are not necessarily linked with cash-for-care programmes. In fact, some cash-for-care schemes are explicitly meant as an informal compensation for relatives, others explicitly allow and regulate employing one’s relatives as caregivers, others implicitly allow for compensating one’s informal caregivers, and others forbid it in most cases. These different arrangements will have an effect on the labour market participation of potential paid caregivers, on their social security position, but also on the claims and pressures that the ones in need of care will be able to put on them. A Dutch study found, for instance, that paid caregivers – with whom, according to the personal budget regulation, the budget holder must have a formal employment contract – felt that their work was recognised, but also that more pressure and demands were put on them by the cared-for. At the same time, their labour market and social security position was not completely equivalent to that of a ‘normal’ employee (Grootegeod et al, 2010).

The relationship between cash-for-care benefits and (particularly women’s) paid employment is an important and not adequately investigated issue, which is very likely to be influenced not only by the features of the cash-for-care schemes, but also by the institutional and cultural context. For example, strong incentives for later retirement and attractive labour market conditions will limit the willingness and opportunity to provide long hours of family care, while high unemployment or low benefit levels in the case of unemployment create incentives for informal caregiving, even more so if this provides access to some financial recognition via cash-for-care programmes. Quantitative analysis led by Bolin et al (2008) suggests that the relationship between informal care provision and labour market outcomes differs between Northern, Central and Southern Europe. Investment in informal care decreases the probability of working for men (not for women) and reduces the number of hours of work for both men and women more in Central Europe than in Southern Europe. The caregiving role reduces the number of

hours worked more for men in Northern than in Southern Europe. The authors explain these results by the different cultural contexts: ‘outcomes might be less severe in countries where norms favouring family loyalties and intergenerational support are stronger, since more acceptance will exist among employers and employees, when caring for one’s older parents’ (Bolin et al, 2008, p 735). The link between informal care provision and employment of caregivers is a key issue in Europe, through the development of conciliation policies, to facilitate juggling work and care for the adult children of older people in need of care (Le Bihan et al, 2013).

The evolution of the role of informal care is another important effect of the development of cash-for-care schemes. Facilitating the externalisation of care work from the family, cash-for-care schemes have also strengthened the role of informal carers as ‘care managers’ (Da Roit et al, 2007). Family members are those responsible for taking decisions concerning the care responses and, for instance, for choosing care workers, supervising care activities, managing the working contract, taking appointments at the hospital, visiting the GP or dealing with a situation in case of emergency (Österle and Hammer, 2007; Da Roit and Le Bihan, 2011). It has even been observed that care arrangements in the private sphere of the care recipient are viable only in the presence of an informal carer who acts as a care manager, and who also provides complementary care activities during the daily, weekly and yearly leaves of the paid care worker.

Effects on care workers and the care labour market

The second path towards the commodification of care rests on the possibility of hiring one’s own carer (besides relatives and informal caregivers). This has important consequences on the position of care workers under cash-for-care schemes as they will be, at least in principle, employed directly by the person in need of support. Cash-for-care schemes can have an impact on the availability, profile, qualifications, working and living conditions of care workers, both within organisations and through direct payments. However, the actual organisation in this case also differs greatly per context and can have diverse effects.

It has been shown that unpaid overtime work, caring for several older people, low levels of job stability, of social control and support considerably reduce job satisfaction among agency workers in consumer-directed schemes (Delp et al, 2010). As a result, cash-for-care benefits that recognise an

adequate number of hours of care to be provided that limit the fragmentation of care provision, that support organised instead of individual labour, that provide an adequate level of job security are likely to enhance the satisfaction of workers and their ability to make sense of their demanding work. In the UK, for example, personal assistants report higher job satisfaction and less stress than traditional care workers (d'Aboville, 2006).

The evolution of the care market must also be questioned. The care sector – traditionally dominated by not-for-profit providers in most countries and by public ones in a few others – has been opened to private for-profit providers in the past two decades. In that context, consumer-directed care often goes along with developing competition between providers. However, the degree to which this process has actually taken place differs greatly across countries: the creation of care markets is not an obvious outcome of the introduction of cash-for-care programmes. In the UK, where the marketisation rationale is particularly pronounced, the price of services, traditionally negotiated between local authorities and the providers, can now be negotiated directly by recipients and care providers (Wilberforce et al, 2011). People can purchase services directly from private providers, with no public sector mediation. The expansion of the private care sector is, in turn, strongly associated with the increasing importance of migrant care work within care organisations, both in institutional and domiciliary settings (Cangiano et al, 2009; Da Roit and Weicht, 2013). Hiring migrant workers solves the problem of care labour shortages, which is mainly due to unattractive working conditions and pay. Analyses led in the US also underline the negative impact of cash-for-care programmes: having the beneficiary serve as the employer can reduce the ability to organise for better wages and working conditions (Kraiem, 2011).

At the other extreme, in France, LTC policy has always been closely related to employment policy. In the last 15 years not only has the number of home care workers more than doubled (Bressé, 2003; Marquier, 2010), but the composition of the workforce has changed in favour of more qualified profiles, despite persisting professionalisation problems, such as low wages and insufficient qualifications. In the Austrian context, the extension of formal care services in the past two decades has also contributed to the professionalisation of the care sector. At the same time, new migrant care workers arrangements in the private home (see below) are linked to only minimal or no qualification requirements, and entails potentially highly

precarious work conditions. This has created considerable risks in terms of de-professionalisation (Österle and Bauer, 2012).

Cash benefits are often associated with the rise of unregulated and undocumented (migrant) care work within households. It is widely recognised that a private care sector extraneous to social and labour regulations has emerged in Southern European countries, in Austria and Germany. According to recent estimates, there are currently between 700,000 and 1 million (that is, 6-9 per cent of the population aged 65 and over) immigrant care workers in Italy (Gori, 2012; Da Roit and Weicht, 2013) and 100,000 in Germany (Theobald 2009). In Austria, before regularisation in 2007, there was an estimated number of about 30,000 migrant care workers. A comprehensive regularisation effort in 2007 has largely eliminated the grey migrant care economy. By the end of 2013, more than 44,000 migrants have been working in private households on a self-employed basis, a figure coming close to the total number of care workers in full-time equivalents in the traditional LTC service sector (Österle and Bauer, 2015).

In these countries, the externalisation of tasks from families to paid care workers is at least partly based on the availability of relatively cheap and partly undocumented immigrant labour coming from various countries. In Austria and Germany, migrant care arrangements are usually based on fortnightly or monthly shifts, that is, with two care workers replacing each other in a care arrangement (Österle, 2013; Theobald and Hampel, 2013). In Austria and Germany, these ‘care work commuters’ are mostly from neighbouring Central European countries, but increasingly from more distant Eastern European countries; care workers from Eastern Europe and South America are both present in Italy. However, not all types of cash-for-care but *unregulated* cash-for-care benefits are a relevant factor for the development of (unregulated) migrant care work in private households (Da Roit and Le Bihan, 2010; Gori, 2012; Da Roit and Weicht, 2013). The control exercised on the use of the benefit implemented, for instance, in France and in the Netherlands, has major consequences on the organisation of care work: even if the users can choose their carer, the latter must be officially hired. By contrast, in Italy, Austria and Germany, cash-for-care schemes – the use of which is free – tend to favour the growth of a grey market in the care sector. Moreover, the existence of a large underground economy and of undocumented migration even in the absence of cash-for-care benefits can produce similar results, that is, the creation of a large unregulated and often migrant-based care market. Where these two conditions are simultaneously

present, the extent of migrant care workers in private households becomes even more relevant (Da Roit and Weicht, 2013).

If cash benefits have not directly ‘caused’ the rise of the grey market in LTC, they have certainly supported its development, because of three interconnected factors. First, for families, this solution is a more cost-effective alternative to family care and to social service provision. Immigrants can provide 24-hour care that would not be available from social services or would be too expensive (Da Roit, 2007). Second, the arrangements yield better incomes to those providing care compared with the income opportunities in their home countries, even more so when a live-in arrangement provides free board and lodging (Österle, 2013). And third, migrant care in private households reduces the pressure of increasing demand for social services. For all these reasons, a well-established and recognised migrant-carer model tends to appear as *the* solution to increasing LTC demands. This can be seen in various attempts to regulate the migrant care market in the three countries. In Austria, by allowing self-employment and by introducing an additional means-tested benefit, it was possible to legalise the previous grey care economy arrangement while at the same time keeping the main features of the work arrangement (live-in, two to four weekly shifts) and limiting the additional costs to users (Österle and Bauer, 2015: forthcoming). Attempts to regularise grey market arrangements have also been made in Italy and in Germany, but with more short-term regularisation effects.

Effects on social expenditure

The extension of LTC systems over the past two decades has occurred as welfare state provisions in many other sectors have been faced with retrenchment (Österle and Rothgang, 2010). But cost-containment efforts have also been at the core of developments in LTC, either as explicit policy objectives or as implicit conditions in policy design (Glasby et al, 2006; Ranci and Pavolini, 2013). Besides other policy approaches (such as favouring community care over residential care), cash-for-care schemes are generally believed to be cost-effective or able to keep costs under control (Zarb and Nadash, 1994). The mechanisms underlying this assumption are manifold: cash benefits as a contribution to care-related costs, competition between providers enhanced by choice and consumer direction, the use of less expensive forms of care, or an activation or re-activation of informal

(family) care resources. The use of migrant care labour in private households (see above) is just one example that combines these mechanisms for a potentially ‘cost-effective’ way of covering LTC needs.

In reality, however, the assumption of cost-effectiveness is often misleading if it does not consider the manifold implications cash-for-care schemes may have for users, informal care and for care workers (see above), and the interconnectedness with other elements of a care regime. First, the exact definition of eligibility rules and the actual accessibility to both cash benefits and services defines the options users have. As outlined above, cash benefits are either universal or more selective, they contribute more or less to covering LTC needs and might, in different ways, be linked to the use of in-kind services. For example, the extent of family care is not only determined by the extent and character of the cash benefit, but also by the availability and affordability of services (including the employment of care workers in the private household) and the sociocultural meaning of family care (Da Roit and Le Bihan, 2011). Second, privatisation and creating competitive markets can have very different meanings, leaving more or less room for the development of market prices and flexibility in defining quality standards. In many countries, the employment of care workers in private households allows most flexibility in terms of prices and quality. This can, however, create substantial negative spillover effects in terms of working conditions and pay. When low pay and precarious working conditions are silently accepted in a grey economy of care, or if they are even part of the regular LTC system, this creates pressure on both the quality of care work relationships and the quality of care work beyond these particular arrangements (Bauer et al, 2014).

Key challenges for the future

The development of cash-for-care programmes in LTC is a common trend across many OECD countries. A major commonality of these programmes is that they emphasise choice for users. However, as shown in this chapter, the context in which the programmes are embedded, the actual design of the cash-for-care programmes and the understanding of choice vary hugely. This results not only in diverse cash-for-care systems, but also in large variations in the outcome of these systems. With regard to the choice idea behind cash-for-care programmes, this chapter distinguishes three perspectives: market orientation, empowerment orientation and family orientation. While the actual design might include more than one of these perspectives, the relative

weight given to the perspectives has important implications for the outcome of the different policies. In that respect, how much choice for whom, the emergence of migrant care work and the risk of de-professionalisation and cost containment are three major challenges that can create substantial trade-offs for policy-making in LTC.

The market-oriented perspective emphasises consumer choices, although major limitations in this perspective arise for financial reasons. Cash-for-care benefits can extend the purchasing power of users, but the choices users can make will largely depend on other available income. This is even more the case for tax credits, which only can be used by consumers beyond the taxable income threshold. Hence, strong market orientation, for many, will limit access to alternative provisions of LTC. This limitation is also one factor determining the development of migrant care work in private households. Such arrangements have developed as a relatively cost-effective response to increasing demand for LTC when family care is not available, and when social services are either not available or not affordable. Apart from financial reasons, the particular arrangement with live-in or live-out care workers spending long hours in the home of users also comes closer to a family care arrangement than any other social service provision. Hence, cash-for-care programmes allowing the employment of migrant care workers in private households combine the market orientation with the familialistic orientation.

However, migrant care work arrangements are often illegal or semi-legal arrangements. And even in situations where the arrangements have been regularised, migrant care work tends to be highly precarious (or, for many, no longer affordable). In addition, it can contribute to a process of (de-)professionalisation. The same can apply to situations where family members can enter into a regular employment relationship with users. In the empowerment orientation, choices are extended beyond consumers to citizens, establishing choices as a social right. While this reduces the earlier problem of limiting choices because of financial reasons, and might also reduce dependency on family care work or low-cost migrant care work, it often collides with cost-containment considerations that are high on the agenda across all OECD countries. Taken together, cash-for-care programmes signify much more than simply a choice orientation in LTC policies. The design of the programmes and the way they are embedded in the broader care and welfare regime is a continuous challenge of balancing often conflicting interests and objectives. Cash-for-care programmes are often put forward as a measure that strengthens the user's choice and autonomy. In reality, cash-for-

care, in combination with limited public coverage and limited social rights in terms of services and individual ability and willingness to pay, can lead to refamilisation and create considerable risks for professionalisation, for the quality of care work relationships and for the quality of care. These issues should not only be treated as potential effects; they also have to be brought to the centre of debates about the future of cash-for-care schemes.

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EIGHT

Policy instruments to promote good quality long-term care services

Juliette Malley, Birgit Trukeschitz and Lisa Trigg

Introduction

In ageing societies it is not simply access to long-term care (LTC) that is important, but also its safety, effectiveness and responsiveness. This is not least because good quality LTC should help maintain the health and functional status of people for longer, but also because poor quality care can cause serious harm and has the potential to be life-threatening. Indeed, concerns around the quality of LTC services are the second highest priority area for LTC reform across OECD countries, just behind the fiscal and financial sustainability of LTC systems (Colombo et al, 2011).

The political debates about ensuring the quality of LTC services are largely driven by three issues. First, scandals around abuse and neglect arise frequently enough across OECD countries to ensure safety is a relatively constant political concern. Second, the effectiveness of LTC is of interest since OECD countries tend to invest a significant amount of public resources in LTC (Colombo et al, 2011). Politicians are accountable to the public and need to demonstrate the value of these services to show that taxpayers' money has been spent wisely. And third, the responsiveness of services to their users is a concern, an issue that is linked to the lack of both information about the quality of providers' services and incentives to develop services that are right for users rather than easy for providers to deliver. Despite underlying similarities in problems experienced, a variety of policy solutions are found across OECD countries to promote quality.

The aim of this chapter is to describe and compare the policy instruments and approaches used by selected OECD countries to promote the quality of LTC services. Since the way in which each country promotes quality is inextricably linked with the overall design and features of the system, we have chosen to illustrate the policy options using six countries – Australia,

Austria, England, Finland, Japan and the US – whose LTC systems differ on a variety of characteristics. These countries vary according to the degree to which the management of different aspects of the LTC system is centralised or decentralised, how the system is financed, the eligibility criteria and the make-up of the LTC market in terms of private and public provision, as shown in Table 8.1.

In discussing efforts to promote LTC quality in these six countries, we draw heavily on a number of recent publications. These include Wiener et al's (2007) study on approaches to quality improvement; the country chapters¹ included in Mor et al's (2014) book on regulation and quality assurance, and the country reports from a special edition of EuroHealth on LTC quality.² We also make use of outputs from two Europe-wide research projects: the ANCIEN (Assessing Needs of Care in European Nations)³ and Interlinks⁴ projects.

This chapter is organised as follows. LTC quality can be understood and positioned in a number of different ways, so in the next section we briefly set out the critical issues. The third section describes and maps the different instruments in place in the six OECD countries using a conceptual framework for evaluating policy instruments. We then discuss the success and failure of these instruments, drawing on general economic and management theory, as well as evidence from implementing interventions within different LTC systems. The chapter concludes with observations and recommendations for future policy development in this area.

What is quality in long-term care services?

In defining the quality of LTC, it is useful to start with the carer–cared-for relationship, which constitutes the basic caregiving unit. Understanding the nature of this relationship is critical to developing relevant measures of quality for LTC. Additionally, by focusing on the carer–cared-for relationship we can usefully exclude aspects such as equity, efficiency and accessibility from our definition of quality, since these only make sense at the aggregate service or system level, and may therefore be more usefully understood as aspects of performance (Reerink, 1990).

Table 8.1: Characteristics of national long-term care systems in six countries

	Australia	Austria	England	Finland	Japan	US
Degree of centralisation (policy, funding, provision)	Mainly centralised	Mixed	Mixed	Mainly decentralised	Mixed	Mixed
Source of public funding	Tax-based	Tax-based	Tax-based	Tax-based	50% contributions; 50% government	Tax-based
Eligibility criteria	Universal	Universal LTC allowance; public support for LTC services	Public support for LTC means- tested; universal nursing care; means tested	Universal coverage within a single system	Universal coverage within a single insurance system	Public support for LTC means- tested (Medicaid); universal for seniors (Medicare)
Type of providers	Mainly private, not-for-profit	Mixed, with private mainly not-for-profit	Mixed, mainly private, for-profit	Predominantly public, with private, mainly not-for-profit	Mixed, with for-profit providers not-for-profit	Mainly private-for-profit

Source: Adapted from Colombo et al (2011)

Considering the nature of the care relationship, it is important to recognise that although some users of LTC may require specialist equipment and medical expertise, most care consists of help with activities related to daily living. Since most care is help with daily living, care is ongoing and is a prominent feature of the cared-for person's everyday experience. Many of the activities are intimate tasks such as washing and dressing, which require close collaboration between the carer and cared-for person, such that the 'consumer' of care is said to 'co-produce' his/her own care, even more than is the case for health care. These characteristics have two corollaries for developing relevant measures of LTC quality. First, measures of the quality of care need to reflect its relational and experiential character. This means that non-clinical aspects and aspects related to the process of caregiving, such as the behaviour of carers, the responsiveness of services and the cared-for person's quality of life, are just as important as clinical characteristics, such as the incidence of pressure sores or use of restraints, and end results (Malley and Fernández, 2010). Second, the quality of care is not solely influenced by the care provider. Self-care abilities and the commitment of the care recipient also determine processes and outcomes (Trukeschitz, 2011).

There are various frameworks for measuring LTC quality (for a review, see Murakami and Colombo, 2013b), which broadly fall into two approaches. Perhaps the best-known is the production process approach forwarded by Donabedian (1988), which distinguishes structural (input) from process and outcome indicators. Structural measures focus on aspects of the care environment, such as staff-to-patient ratios and room size, and do not capture the quality of the caring activity. By contrast, process measures focus on the way care is delivered and outcome measures on the results or impact of caring. Another approach, which is common among frameworks developed and adopted by policy-makers, focuses on dimensions of quality, selecting those that have the greatest policy relevance. A good example of this is the OECD framework, which distinguishes (clinical) effectiveness and safety, patient-centredness (including the experience of care), and care coordination and integration (Murakami and Colombo, 2013b).⁵ While frameworks help to conceptualise quality for measurement, developing appropriate measures of quality, particularly those reflecting processes and outcomes, is far from straightforward. Measurement is plagued by barriers to data capture, reporting errors and attribution of the effect of care. Although not the subject of this chapter, these issues are important since measurement and assessment is a central element of any quality promotion strategy.

Types of policy instruments to promote good quality long-term care services

Instruments to promote good quality LTC might do so *directly* by addressing specific quality-related concerns, or they might aim to influence quality in a more *indirect* way by matching needs to resources through assessment or redesigning (parts of) the LTC system. System-level redesigns, such as the introduction of consumer-directed care or marketisation, intend to change allocative and/or distributive LTC outcomes in general – the promotion of quality might be one of many goals. In this section, however, we focus on the description and analysis of instruments designed to directly affect LTC quality.

We describe these instruments in terms of two dimensions: the *type of intervention* and the *implementation characteristics*. Following Bemelmans-Videc (1998), we group them as one of three types: regulatory, economic or information-related instruments. In a more visual language, Bemelmans-Videc speaks of ‘sticks’ (regulation), ‘carrots’ (economic means) and ‘sermons’ (information) to characterise the underlying aims of these interventions. By implementation characteristics, we refer to both the direction of implementation (‘top-down’ versus ‘bottom-up’) and the binding force of an instrument (‘high’ or ‘low’). Highlighting the direction of implementation and binding force helps to demonstrate the fact that not all instruments are developed by government (‘top-down’) or consist solely of mandatory requirements (‘high’ binding force). As we show, some are, in fact, developed by providers or by external stakeholder groups (‘bottom-up’).

Regulatory instruments

Regulatory instruments influence actors ‘by means of formulated rules and directives which mandate receivers to act in accordance with what is ordered in these rules and directives’ (Bemelmans-Videc, 1998, p 10). According to Bemelmans-Videc, the defining property of regulation is an authoritative relationship. Most regulation of LTC services gains its authority through legislation, and there are generally powers (sometimes delegated to arm’s-length bodies⁶) to enforce compliance with the regulations. While such regulations are by definition implemented in a top-down fashion and have a high binding force, regulation can also be implemented from the bottom up

or entered into voluntarily, through self-regulation. Commitments from self-regulation can be strong but by definition are not enforced by law.

The variation in regulatory instruments across six OECD countries is shown in Table 8.2, according to the implementation characteristics and three core elements of regulatory instruments described by Hood et al (1999). The first element is a method for setting standards, which we refer to as *directions*. Directions are designed to influence different parts of the production process. While the US has a mix of structure-, process- and outcome-focused standards, Austrian and Japanese standards assess mainly structural aspects of quality, such as workforce requirements (for example, qualifications and staffing ratios), the living environment (for example, room size) and care technologies (such as care plans). By contrast, in Australia and England, standards focus on ‘outcomes’, although often these standards actually describe processes, such as plans and protocols, and may differ somewhat from an academic understanding of outcomes (Australian Government, 2011; Malley et al, 2014).

The second element of regulatory instruments is a method of *surveillance* for detecting compliance with the directions. England, Australia, the US and Austria use inspections, which involve on-site observation and frequent interviews with service users, relatives and staff, to uncover instances of non-compliance. By contrast, Japan and Finland use inspections primarily to follow up complaints and not as a form of surveillance. Instead, both countries have ‘desk-based’ approaches to surveillance: Japan relies on auditing and Finland on performance reviews to survey quality. Data is gathered from records and documentary evidence, including forms of self-assessment; there are no site visits.

A method for *enforcing* compliance, should instances of non-compliance be detected, is the third element of regulation. Australia, England and the US have a range of sanctions of varying severity to apply to providers that fail to meet standards. At the lower end are remedial action plans, while penalties, such as fines and termination of business, are reserved for more extreme cases or repeated failure to comply with standards. The range of sanctions is less diverse in Austria, Japan and Finland. However, in practice, there are often differences between what is available, the intentions of the system and the extent to which sanctions are used. Thus, despite the range of available sanctions, the Australian regulator operates more at the remedial end, trying to work with providers to find solutions, reflecting the dual orientation of the regulator towards assuring safety and quality improvement. By contrast, in

the US, although the regulator is focused more on identifying and reporting non-compliance, sanctions are rarely applied in practice (Braithwaite et al, 2007).

Table 8.2: Summary of the forms of regulatory interventions to promote quality long-term care services across selected OECD countries

Direction of implementation	Top-down	Bottom-up	
Type of intervention	High	Low	High/low
Directions for LTC, providers, the workforce, or the rights of users and dependent people, for example, standards, targets, codes of conduct, charters	AUS, AUT, ENG, FIN, JPN, US	AUT, FIN, JPN, US (accreditation and certification)	AUT
Modes and rules for surveillance of commissioners, providers or the workforce, for example, inspection, audit, review	AUS, AUT, ENG, FIN, JPN, US	AUT, FIN, JPN, US (accreditation and certification)	
Rules and powers for enforcement of directions	AUS, AUT, ENG, FIN, JPN, US		

Key: AUS = Australia, AUT = Austria, ENG = England, FIN = Finland, JPN = Japan

Although the binding force of regulatory instruments is generally high and implementation top-down, there are examples where the character of regulation is more voluntary. This is particularly the case in Austria and Finland, where the setting and implementation of regulations is devolved to lower levels of administration. In Finland, for example, there are national guidelines for standards and surveillance, but municipalities have a high degree of autonomy in how they are implemented within their own quality management systems, so guidelines at the national level have little force. Self-regulation is also common, with many countries having quite high usage of voluntary accreditation and certification schemes. These include the International Standards Organisation (ISO) system, national schemes such as the National Quality Certification (NQC), which is popular in Austrian residential care, and the Joint Commission Accreditation Programme in the US. Additionally in Austria, as an example of bottom-up self-regulation, the main LTC not-for-profit providers have a document of understanding about the quality of domiciliary care services, which is a self-binding agreement.

The design variations discussed are illustrated in Table 8.2, but countries also differ in the target of the regulations. Thus the regulated entity in England and Australia is the provider; Japan and the US focus on both providers and the workforce; and in Finland and Austria the workforce is regulated. Regulation in all countries, except England, is much more developed for residential (and in particular nursing) homes. While many countries have directions and surveillance for home care agencies, standards are usually fewer and surveillance activity less frequent. It is only in England where home care agencies are subject to the same standards, surveillance and enforcement regime as care homes. However, countries are often aware of this difference in the intensity of regulation of residential and home care and, for example, recent legislation in Australia has narrowed the gap between the two regimes (Australian Government, 2013).

Economic instruments

Economic instruments set incentives or disincentives to induce actors to change their behaviour. Although most economic instruments aim at incentivising more efficient LTC provision, some are specifically designed to promote LTC quality. These economic instruments comprise at least two types of interventions. First, financial incentives, such as quality-related subsidies or reimbursement systems, reward providers for extra efforts in

promoting quality. Second, economic incentives are used to increase competition based on the quality of LTC through, for example, setting quality-related criteria for selection of providers for public procurement. The expectation behind this policy is that market forces will lead to better performance and thus to higher quality LTC.

Financial incentives to improve LTC quality can be grouped into (1) quality-related subsidies, (2) quality-related payment schemes or price regulation and (3) quality-related procurement modes (see Table 8.3). More generic approaches tie the eligibility of providers for public funding to the adoption of quality management systems. LTC providers need to implement at least some quality monitoring and quality improvement strategies to qualify for public funding, for example, in Austria. On the other hand, more sophisticated incentives reward providers for specific behaviour that is supposed to lead to LTC quality improvements such as their investment in staffing levels or in skill development. Across our six OECD countries different types of financial instruments are in place to incentivise providers to invest in such quality improvements.

Quality-related subsidies can be found, for example, in England. Providers investing in staff can apply for workforce development funds from an independent organisation, Skills for Care, which receives funding from government to develop a better skilled care workforce. These funds are accessible to all eligible providers as they are not linked to a particular funding mode or provider–purchaser relationship.

Quality-related reimbursement intends to influence either the standards of staffing in particular or more generally the characteristics of LTC service provision. Examples in the first group of quality-related reimbursements can be found in Japan and Australia. In Japan, additional reimbursement is available for providers that exceed the minimum standards of staffing in nursing homes. In Australia, the Conditional Adjustment Payment (CAP) encourages providers of residential care to improve corporate governance and financial management practices. The basic public reimbursement per resident is topped up (CAP) if workforce reforms are implemented (Australian Government, 2013). The second type of quality-related reimbursement seeks to tie public means to certain LTC service characteristics. Different types of pay-for-performance (P4P) exist with the goal of encouraging ongoing improvements and rewarding high quality care. P4P is comparatively well developed in Australia for care home and home care services. P4P is increasingly used in some parts of the US and England, primarily in the care

home sector. In England, both the criteria for a quality premium over and above the basic fee and the level of this premium vary between the local councils. Similar variations in programme characteristics are found across states in the US (Briesacher et al, 2009; Werner et al, 2010; Allan and Forder, 2012).

Table 8.3: Summary of the forms of economic instruments to promote quality longterm care services across selected OECD countries

Type of intervention	Direction of implementation
Quality-related subsidies, for example, for investments in quality infrastructure; for certifications; for projects aiming to improve quality	Top-down ENG (workforce development subsidies)
Quality-related price regulation, payment schemes, for example, P4P, mark-ups on reimbursement rates for over-fulfilment of standards	AUT (funding linked to adoption of quality management schemes) JPN (mark-up on reimbursement) AUS (CAP) ENG, US (P4P – care homes) AUS (P4P – care homes and home care)
Quality-related public procurement, for example, quality criteria and their weights in public procurement	AUS (call for tenders on quality criteria only possible) ENG

Key: AUT = Austria, AUS = Australia, ENG = England, FIN = Finland, JPN = Japan

Public procurement can also be used to incentivise providers to focus on the quality of their services. The public purchaser can increase competition on quality by putting higher weights on pre-defined quality criteria and asking providers to compete on both price and quality. Examples of such schemes are found in some areas in England and include a ‘preferred supplier ranked list’, where the provider’s position on the list is determined through a quality assessment. In its extreme, public purchasers set both the price and output quantity (for example, care hours provided) and call for tenders on quality criteria only. An example for such quality-focused competitions are the tenders for stated-funded aged care packages for home and residential care in Australia (Davidson, 2011; Australian Government, 2014).

Information instruments

Information instruments are implemented to influence the behaviour of actors ‘through the transfer of knowledge, the communication of reasoned argument, and persuasion’ (Bemelmans-Videc, 1998, p 11). We interpret information in its broadest sense here, and include four categories of information: education and knowledge management; quality management systems; public reporting; and feedback on quality from users, staff and other members of the public. The use of these types of information instruments is illustrated in Table 8.4. Although the binding force of information instruments is usually relatively low, there are exceptions where they interact with regulatory or economic instruments.

In the six OECD countries, *education and knowledge management* involves a number of actors, many of whom are not formally part of government or operate at arm’s-length from government. For example, in England, the regulatory standards provide basic guidance on care processes, but these are supplemented by guidance on best practice from an arm’s-length body, the National Institute for Health and Clinical Excellence (NICE), and two independent, but partly government-funded, organisations, the Social Care Institute for Excellence (SCIE), focusing on social care processes, and Skills for Care, focusing on the workforce. For residential care in Australia, education and knowledge management are more explicitly embedded in the regulatory system. The regulator has responsibility for the dissemination of better practice approaches alongside its inspection and audit role, which it fulfils by holding courses and conferences on continuous improvement and

on achieving accreditation standards, as well as recognising good quality providers with Best Practice Awards on an annual basis.

Another source of information is advocacy groups that, in addition to campaigning for better care, are also active in defining, disseminating and educating providers on best practice, particularly in residential care. Although such groups are found in all countries, they are particularly vocal in the US, where several approaches to the redesign and improvement of residential care to achieve better quality of life outcomes have emerged under the banner of the ‘culture change movement’ (Rahman and Schnelle, 2008).

Quality management systems and quality improvement tools, such as the generic ISO system or the care home-specific E-Qal in Austria, are adopted by providers for a variety of reasons. Many of these tools (for example, the ISO system) may be considered self-regulation (see page 172); however, they also act as information-related tools to increase providers’ awareness and skills in monitoring and improving the quality of LTC. Benchmarking is another way of using information to support quality improvement goals. In England, the popularity of benchmarking in public sector organisations and the availability of data on social care at the local government level has enabled the emergence of Adult Social Care Benchmarking Clubs. These are often run by specialist benchmarking firms that assist local commissioners in sharing and comparing performance information, to identify opportunities to transfer learning for more effective commissioning and quality monitoring.

Table 8.4: Summary of the forms of information interventions to promote quality long-term care services across selected OECD countries

Direction of implementation	Top-down	Bottom-up	
Binding force			
Type of intervention	High	Low	High/low
Education and knowledge management (excluding professional and clinical staff)	JPN	AUS, ENG, FIN, US	AUT, AUS, ENG, FIN, US
Quality management systems and improvement tools		AUT, JPN	FIN, US, ENG
Public reporting			
Publication of inspection reports, compliance and sanctions	AUS, ENG, JPN, US, AUT (partial)		
Provider performance data	AUS, US	FIN (partial)	FIN
Collaboratively produced information from stakeholders including users		ENG	AUS, ENG, US
Complaints channels	AUS, AUT, ENG, FIN, JPN, US	AUS, AUT, ENG, FIN, JPN, US	

Key: AUT = Austria, AUS = Australia, ENG = England, FIN = Finland, JPN = Japan

A more recent development involves care users and other members of the public in improving care provision. The *public reporting* of quality information aims at directly addressing the lack of information about quality in LTC markets, which undermines the ability of consumers to make effective choices about their care and creates market inefficiencies. Information on quality is available in three different forms (Fung et al, 2007). The first type is the publication of *right-to-know* information, where users are made aware of compliance with regulatory requirements and major provider failings. This is achieved by publicising the outcomes of regulatory inspections and reviews for residential care in Australia, and for residential and domiciliary care in England, Japan and the US, with a focus on online information. In Austria, only the part of the NQC assessment that covers structural indicators and management reports is accessible online. The second type, *targeted transparency*, consists of structured and formally provided information that sheds light on provider quality. The most comprehensive example is Nursing Home Compare and Home Health Compare from the US, which enable the comparison of nursing home and home health agencies on a range of quality indicators derived from the national minimum dataset for providers. There is a less-developed version in Finland (see www.palveluvaaka.fi) and one in development in Australia (Australian Government, 2012). A more recent development is the emergence of a third type of information – *collaborative transparency policies* – where users and other stakeholders contribute to the production of published quality information. In other sectors, users and consumers are able to post reviews of products and services on the internet, for example, via sites such as TripAdvisor. In England, the government is actively supporting the development of similar feedback and comparison sites for LTC providers (Trigg, 2014). The end goal of these initiatives is to empower care users to make informed decisions in selecting providers, although the ability of the frailest care users to act as consumers is questionable (Braithwaite et al, 2007; Eika, 2009).

For instances of very poor care, there are usually more formal two-way channels for users, family and staff members to raise concerns about care received. Top-down regulations normally dictate that providers should have complaints processes in place and act as the first port of call for complainants. In Australia, England and in each state in the US, there is a single independent body that deals with complaints that are not satisfactorily resolved at the provider (or commissioner in England) level, while local bodies are in place in Austria and Finland to resolve complaints. In Japan the

escalation process is slightly different: complaints are made first to the care manager and then to the LTC insurer. In all countries there may also be a bottom-up element with providers developing complaints systems that go beyond regulatory requirements, for example, to achieve external quality certification, for example, via the ISO scheme.

Critical assessment of policy instruments to promote good quality long-term care services

To assess the value of quality-promoting policy instruments it is necessary to view the instruments within a wider context. All quality-promoting instruments sit within a LTC governance regime, which structures the relationships between providers and their staff, government and service users. From the point of view of professionals and providers this might be described as the ‘external environment’. External environments will vary between countries and, where responsibilities are devolved to lower levels of administration, also within countries. It is therefore highly likely that similar policy instruments will have different effects depending on where they are implemented.

Provider characteristics will also be important in determining the chances of success of policy instruments. Factors such as the style and effectiveness of the leadership, the organisation’s vision, mission and strategy, and the level of engagement of stakeholders in the process have been shown to be important in determining the success of change activities (see, for example, the model developed by Burke and Litwin, 1992). Organisations may have very different goals to government and staff may be motivated by a range of factors, both altruistic and self-interested. It is therefore unlikely that the impact of each policy instrument will be uniform across providers or staff.

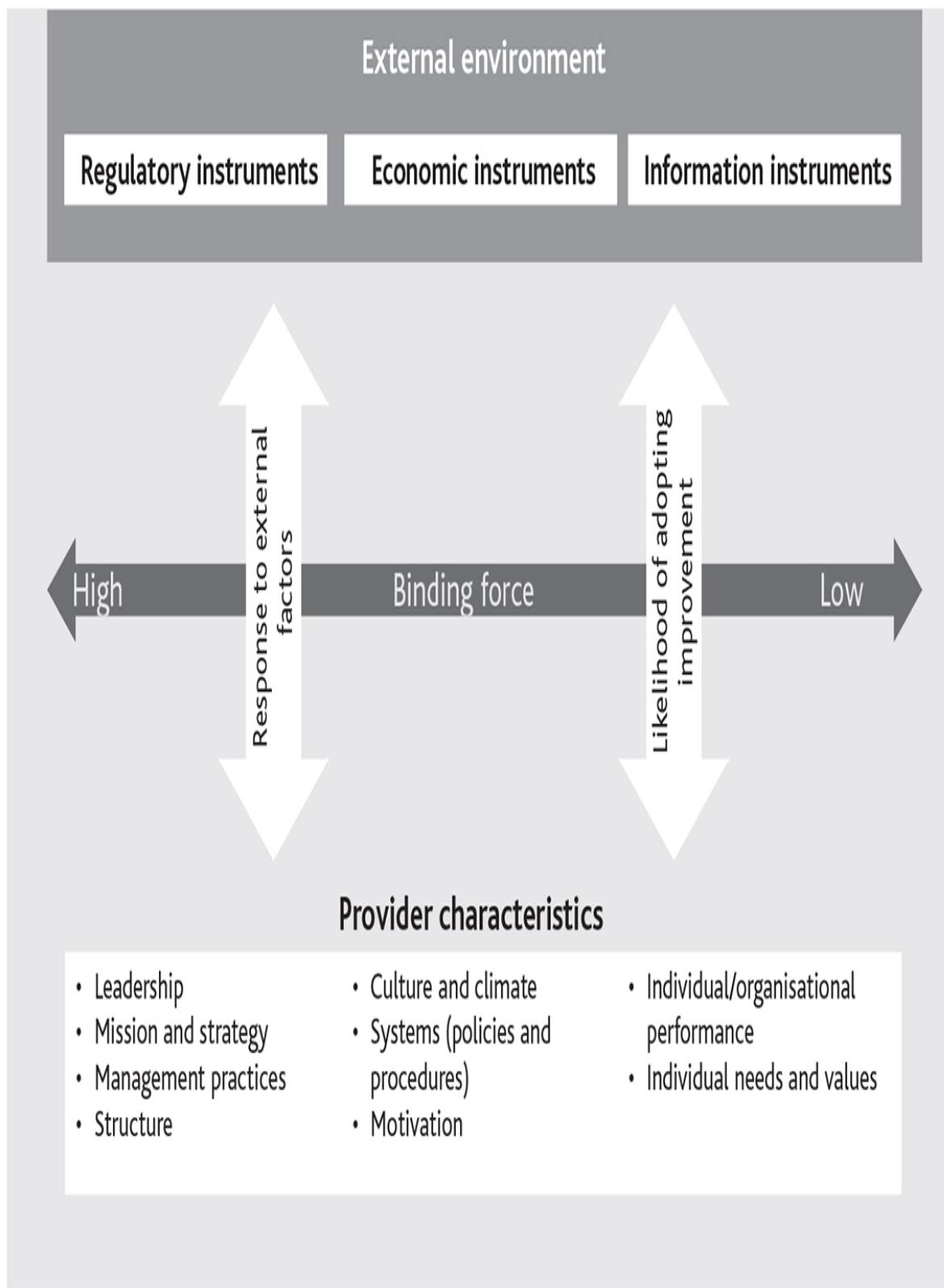
The implementation characteristics for each instrument, in particular the binding force, are therefore an important factor in understanding the impact of instruments. Where the binding force is low, we must consider why providers or professionals would adopt the instrument; conversely, where the binding force is high, a more important consideration is whether providers and professionals react in adverse ways to the instrument.

The interaction between the different instruments, providers (and their staff) and the external environment is shown schematically in Figure 8.1. In the following sections we assess the effectiveness of regulatory, economic and information instruments, paying attention to these relationships.

Assessment of the regulatory context for long-term care providers

The effectiveness of regulation is often considered through the lens of ‘regulatory failure’, describing situations in which the regulatory regime fails to have the desired effect. Causes of regulatory failure include resistance to the regulations, regulatory capture (where the regulated bend the regulations to meet their needs in place of the needs of those for whom the regulations were designed to protect), ritual compliance (where organisations go through the motions of compliance), lack of data (reflecting the difficulty of measuring aspects of quality), and performance ambiguity (reflecting the multivalency of performance and quality) (Boyne et al, 2002).

Figure 8.1: Key factors determining the likelihood of successful implementation or adoption of policies to promote formal long-term care



Source: Provider characteristics are taken from the model developed by Burke and Litwin (1992)

Partly as a result of measurement problems and performance ambiguity there may be a lack of alignment between regulatory goals and the goals of other actors within the LTC system. For example, a regulatory system that focuses on, say, workforce characteristics and the use of care technologies, implicitly sets these structural requirements as system goals. This may be appropriate if the goal is, for example, to professionalise the workforce (see page 180). However, if the goal of policy-makers and providers is to improve user outcomes, it is important to demonstrate how the structural standards specified promote user outcomes. Where standards do not support the system goals and are not aligned with providers' goals, they may be a barrier to achieving high quality care: providers may resist the regulations, perceiving them as burdensome and pointless, and poorly chosen indicators with no relationship to quality have broader system-wide effects such as distorting priorities and introducing inefficiencies.

Yet evidence about the relationship between structural aspects of quality and user outcomes is in most cases either equivocal or absent. An exception in this regard is staff-to-patient ratios about which there is fairly compelling evidence from the US context. Studies have shown higher staffing levels to be positively associated with high quality care in nursing homes (at least when measured using clinically oriented outcome indicators) (Spilsbury et al, 2011), fewer severe deficiency citations and an improvement in certain health conditions requiring intensive nursing care (Chen and Grabowski, 2004).

To better reflect system goals, some countries have developed standards that focus on aspects of process or outcome quality. However, process- and outcome-focused standards are generally much harder to define and measure than structural standards. Although some aspects, such as the use of restraints, may be monitored from care records, many, particularly those associated with quality of life outcomes, require assessment either through observation or interview with the service user. It is unlikely to be by chance, then, that inspections are used in the US, which has some process and outcome standards, and England and Australia, that focus exclusively on outcome and process standards, since this method allows the inspector to observe practice and engage with service users.

While inspections may allow for a more rounded assessment of quality and help to overcome the distortion and motivation problems associated with structurally focused standards, it is an expensive and complicated activity, particularly when compared to a desk-based review or audit of documents. Inspectors need to be skilled in inspection methods and knowledgeable

enough about care practice to judge compliance with consistency against what can be quite vaguely specified standards. Evidence from the US which finds wide variations within and across states in the number of deficiency citations demonstrates the problem of inconsistency in interpretation of the regulations (Miller and Mor, 2006). Data-based ways of surveying standards that do not involve inspections have been attempted, although unsuccessfully to date, in England, due to difficulties collecting comparable data (see Malley et al, 2014). In the US inspections are run in parallel with a highly standardised and very detailed data collection and quarterly reporting scheme (Stevenson and Bramson, 2014). It seems likely that process and outcome standards lead to higher surveillance costs and variability in the assessment of compliance with standards.

Enforcing regulation also raises challenges. Regulation scholars have proposed that regulators adopt a ‘responsive regulation’ approach to enforcement, which takes compliance through persuasion and education as its starting point (Ayres and Braithwaite, 1992). Underpinning this approach is the recognition that providers are motivated by a wide range of factors. Penalties and deterrence activity assume that providers are largely self-interested, potentially inducing ‘resistance’ to the regulations and crowding out more ‘knightly’ altruistic motivations (Le Grand, 2003). However, compliance through persuasion and education as a strategy on its own assumes that providers are largely knights, thus suffering conversely from problems of gaming and falsification where providers are, in fact, self-interested ‘knives’. For this reason, enforcement strategies must incorporate strong sanctions and deterrence to deal with the self-interested knaves (Braithwaite et al, 2007).

In practice, in countries that follow the responsive regulation approach, achieving such a balance is a challenge. Whereas the US regulator focuses, on paper at least, on detecting and enforcing compliance, the Australian regulator and its quality assessors explicitly have a dual quality improvement and enforcement role. Some commentators complain that this has led to a tension and blurring of roles, which undermines the regulator’s effectiveness (Australian Government, 2007). Thus, many countries seem to have come to the conclusion that regulation is not a silver bullet, but one part of the solution. Regulatory approaches based on controlling quality through inspection and enforcement need to be supported by other mechanisms, including self-regulation, quality management based on self-assessment or third-party certification (Leichsenring et al, 2014b), and data-based public

reporting (Leone et al, 2014), all of which have gained importance in recent years.

Assessment of the regulatory context for long-term care professionals and workers

The main aim of regulation aimed at the workforce is to ensure that workers have the right skills, experience and up-to-date knowledge. In countries such as Finland, Austria and Japan, that heavily regulate the workforce, this is explicitly associated with the goal of professionalisation (see Leone et al, 2014). Japan is particularly interesting in this respect since care workers have distinct qualifications and, highly unusually compared to other countries, many obtain their qualifications following a four-year university programme. Commentators speculate that it is for this reason that care workers have a relatively high status and are paid above the minimum (Ikegami et al, 2014). Professionalisation may therefore be one important component of improving the status of care work, which is important for a growing industry already suffering from recruitment and retention problems (Fujisawa and Colombo, 2009; Colombo et al, 2011).

However, a highly professionalised workforce is likely to be a more expensive workforce. More expensive workers, such as nurses, may be displaced by less expensive or unqualified workers, where substitution is possible. (Although this may not have negative consequences for the quality of care; see, for example, Chen and Grabowski, 2014.) Ikegami et al (2014) suggest that the reason nursing agencies in Japan have not expanded as fast as home help agencies is because nurses are three times as expensive as care workers. Indeed, in England there has been a debate for some time about introducing registration requirements for care workers, but one argument against this has been the effect this would have on the cost of care, which is already considered unaffordable for some people. There is a concern that, unable to afford the wages of professional care workers from home care agencies, people may turn in larger numbers to the grey ‘unregulated’ market. In the long term substitution would affect demand for professionals, and would likely lead to low take-up of training by workers, thus undermining the goal of professionalisation.

Professionalisation of the workforce therefore requires strict regulation of roles for different professions, and policing of the market to ensure there is not ‘inappropriate’ substitution. In this respect, one challenging issue that has

emerged in many European countries, particularly those with certain types of care regimes (cash-for-care regimes, substantial co-payments for home care services and an undersupply of home care services that oversee the dependent person for half a day and longer) and access to relatively cheap labour in Central and Eastern European (CEE) countries, is a growth of migrant care in private households (Österle and Bauer, 2012). Many people hire unqualified immigrants although this practice is often illegal. For example, in Austria, to protect the goal of professionalisation and also to prevent dependent people from being sued for illegally employing migrant care workers, migrant care work was regularised in 2007 by introducing, among other things, some qualification requirements and restrictions around care tasks to be conducted by migrant care workers in private households (Österle and Bauer, 2012; Trukeschitz and Schneider, 2012). The problem was therefore resolved by creating a new type of care worker.

Assessment of economic incentives to improve the quality of long-term care services

Although economic incentives are used across a number of countries, very little is written about the effectiveness of individual schemes in promoting quality, although one type of scheme, P4P, has received a lot of attention. The evidence for its effectiveness is limited, and interpreting the findings is complicated by the diversity of ways in which P4P schemes have been implemented (Briesacher et al, 2009). Much of the debate about P4P is focused on the way providers (or staff) may react to such schemes and the potential for negative consequences.

A variety of negative consequences have been identified. There is the potential for providers to focus on the aspects of quality that are measured, and on which the additional payments are allocated, at the expense of other aspects of quality. There are also concerns about the accuracy of performance measures, where they are collected by providers, since they may seek to manipulate or game the data to get a higher payment. Independent collection of the data may not necessarily overcome this problem as agents of independent organisations may be susceptible to bribes or inducements, thus requiring additional layers of regulation to assure the standards of independent data collection organisations. Providers may also engage in ‘cream-skimming’, where they select people who are easier to care for to make their performance appear better. All of these adverse consequences

have yet to be researched in the context of P4P schemes, and more information about whether, and the circumstances under which, they occur is necessary for P4P schemes to be evaluated (Konetzka and Werner, 2010).

A further issue with the use of P4P to reward ‘good’ performance is that it can redistribute funds from badly performing providers to good providers. Commissioners generally have a set budget to use to pay for LTC services. Unless additional funds are identified and ring-fenced to finance P4P schemes, then funds for the scheme will be deducted from the general budget, thus reducing the money available to pay providers their basic fees. This, in effect, diverts money to good performers, and could further undermine the ability of poor providers to improve, potentially hastening their exit from the market.

Finally, P4P mechanisms build on measurable LTC characteristics and aim to reward good quality LTC provision. This may be considered a good thing, since it improves market efficiency. However, particularly in the case of care homes, it may be viewed more negatively since relocation to a new home is a stressful event that potentially leads to poorer health outcomes and increased risk of mortality, although the evidence is equivocal (Jolley et al, 2011; Holder and Jolley, 2012). A scheme that increased the number of care home providers exiting from the market may therefore, paradoxically, lead to worse outcomes for users.

Assessment of information tools to support long-term care quality improvement

Underpinning the success of many information instruments, particularly quality management systems, is the rate of adoption by providers. It is perhaps for this reason that adoption of a quality management system is often embedded within regulations. For example, in Australia, providers have to show that their management processes and practices support continuous improvement to gain accreditation. Yet in the absence of a legislative imperative there is still extensive use of benchmarking, accreditation and associated quality management systems across countries. In addition, there are grass-roots movements, such as the culture change movement and the provider-led adoption of the resident assessment instrument (RAI) in Japan.

Many providers seem to participate in quality programmes to signal quality in a competitive market. Indeed, branding appears to be increasingly important, with institutions allied to culture change programmes using their

care philosophy as a selling point. In England, established companies from other sectors use their brand position when entering the LTC market. What is interesting is that even in countries with relatively low levels of service competition, such as Austria and Finland, there is still a desire on the part of providers to signal quality through participation in accreditation schemes. It is possible that this is a strategic response to what is, in all countries, a growing and evolving market, with many countries increasingly allowing entry from private providers. This development may equally be rooted in care worker shortages and the attempts of providers to attract skilled care workers.

Nationwide quality certification systems, which are voluntary by nature, may have other benefits, helping to establish uniform quality standards and overcome fragmented quality regulation in a federalised system. An example is the development of the NQC for care homes in Austria, which is noteworthy since Austria is characterised by regional autonomy in standard-setting, and currently focuses on structural indicators. The NQC defines nationwide standards, and while recognising the predominance of structural indicators, it also draws attention to both process and outcome indicators. Although there is room for improvement, this example shows that uniform quality standards can evolve even in a decentralised governance system.

Other facets of the LTC system, particularly the regulatory environment, can thwart the adoption of some voluntary measures. In the US, the emphasis of the culture change movement on quality of life is often in conflict with regulatory measures, which are preoccupied with minimising risk for users, and can inadvertently sabotage improvement efforts. For example, the Eden Alternative® model for residential care for older people involves developing more home-like and stimulating environments with, for example, soft furnishings and pets (Koren, 2010). The regulator itself has recognised the difficulties posed by its highly prescriptive requirements in environmental design, and training and information has been developed for providers to show them how to negotiate their way through regulatory requirements to implement culture change initiatives (Miller et al, 2010).

In addition to impeding quality-promoting efforts, regulations may be difficult to follow. Although standards are often intended to provide guidance to providers on how to deliver quality services, they may carry with them varying levels of clarity about what is required at an operational level to deliver the required level of quality or to improve quality over and above minimum standards. It is common for other knowledge and education instruments to be developed by a variety of independent and government

organisations to supplement standards. It may be challenging for providers, who may be small and lack resources to interpret and integrate information from a variety of sources. Organisations dedicated to supporting providers to change, such as the Quality Improvement Organizations (QIOs) in the US or from the culture change movement, could be of value.

While many governments are developing public reporting schemes, their effects are generally poorly understood. In particular, the mechanism through which public reporting schemes have their effect is unclear. Berwick et al (2003) suggested that public reporting might have its effect through either a ‘change’ or ‘selection’ pathway. The change pathway works through market position or reputation, where providers are ‘shamed’ into improving quality to ensure they remain competitive, whereas the selection pathway works through allowing people to make better choices about their care. Interestingly, the evidence from the US, and England to a lesser extent, provides more support for the change rather than the selection pathway. Thus Mukamel et al (2007) find that nursing homes in the US examine their report cards to address failures. While there appears to be low awareness and usage of reports among users (Castle, 2009; CSCI, 2009; OFT, 2011), reports may be used more widely by professionals and intermediaries in supporting older people to select providers (Shugarman and Brown, 2006; CSCI, 2009). Despite more evidence for the change pathway, new policies tend to emphasise the publication – usually online – of quality information to assist users to make choices, either consisting of data generated by providers and regulators (Australia) or reviews generated by users themselves (England).

Several issues have to be solved to ensure that publication of quality information can be used effectively to support decision-making. Users and their carers may not be using the quality information for valid reasons. All too often, LTC is a ‘stress’ purchase made under difficult circumstances. This is particularly the case for residential care where users are often seeking care following hospitalisation (Bebbington et al, 2001; Castle, 2003). Several problems compound this issue. The quality information available may not reflect what matters to service users, who may be more interested in the experiences of other users and carers; the user surveys in England and Finland are a step in this direction. Users of LTC have many difficulties interpreting data and quality information (Vaiana and McGlynn, 2002; Gerteis et al, 2007), and older people and those with disabilities are the groups that are least likely to have access to the internet (Dutton and Blank,

2011; Fox, 2011). Overcoming these problems is critical for quality information to be of real value as an aid to consumer choice.

Leaving aside the issue of whether the intended audience for the information is capable and motivated to use it, publicly reported quality information of all types may fail because of other implementation challenges. For example, user-produced reviews might be compromised by challenges in generating sufficient reviews, by whether reviews are genuine, and by issues associated with the confidentiality and anonymity of both users and staff (Trigg, 2014). Issues around confidentiality and anonymity also hamper the effectiveness of complaints and whistle-blowing channels, with the fear of retribution or hostility seen to be a disincentive for the reporting of cases of abuse and neglect (Australian NAO, 2012; Healthwatch, 2014), and better processes are seen as important (Cooper et al, 2008). In addition, the competitiveness of markets is important in determining the effectiveness of the public reporting of quality, as predicted by theory (Grabowski and Town, 2011).

How quality is measured is also a challenge for public reporting. Information reporting systems can only report on certain aspects of quality and unreported aspects of quality may suffer at the expense of reported aspects. Although opinion in the US based on the evidence from various studies is that public reporting has a modestly positive impact on the quality of care delivered (Konetzka and Werner, 2010), research has been limited to the effect on clinical quality indicators. Aspects of quality of life and user experience were not assessed. As Netten and colleagues (2012) show, the relationship between quality of life outcomes for service users and other quality indicators may not be straightforward. They found that the care home providers with better star ratings, where the star rating derived from inspection activity, were not necessarily always those with better quality of life outcomes for service users. In addition, although Werner et al (2009) found that unreported aspects of clinical quality improved in US nursing homes, the improvements were less than those for reported aspects, indicating that providers do focus on what is measured to some extent. The mix of indicators is also important to reduce the risk that providers will indulge in cream-skimming, as observed on an albeit limited basis by Mukamel et al (2009). Together these studies illustrate that, although a focus on certain aspects of quality may not completely crowd out improvement on other aspects of quality, high quality on one dimension does not necessarily lead to high quality on another dimension, and resources may become

concentrated on the reported aspects of quality. Consequently the choice of indicators to report is important since a poorly chosen indicator can unfairly reward or penalise organisations, and may affect the efficiency of the market.

Conclusion

This chapter has illustrated the variation across countries in their efforts to promote LTC quality. We framed our analysis by distinguishing between regulatory, economic and information-related instruments. Even at this very general level, different policy styles could be identified, with countries relying more or less on information-related or economic tools in addition to regulatory approaches; putting different emphasis on regulating the workforce, providers or protecting consumers; and varying in the regulatory methods, degree of enforcement and types of standards employed. Some analysts have seen in the combinations of instruments adopted a certain degree of path dependence, with the direction of travel moving from regulatory controls, to the standardisation of care practices, and finally stimulating quality through market-based incentives and competition (Murakami and Colombo, 2013a), while others see evolution in terms of selective borrowing and adaptation of elements from other regimes (Bode and Champetier, 2012). Whichever explanation comes closest to the truth, it is certain that the degree of variation observed means that there should be ample room for countries to draw on and learn from the experiences of others.

However, learning from other countries' experiences is complicated by the variety of ways in which LTC systems are organised. For example, many of the information and economic instruments we identified work by increasing competition on quality and therefore rely on competitive markets for services. The competitiveness of markets varies, however, both within countries, due to differences in local conditions, and between countries, due to political choices over the extent of marketisation. It is therefore very likely that the effectiveness of instruments will vary according to the external environment or LTC system. Thus, although countries vary in their use of the spectrum of information and economic instruments available, suggesting that there is room for countries to develop their approaches to quality promotion, the effectiveness of these policies may be limited by the features of the LTC market. Some 'competition-based' policies, such as public reporting, may have other benefits, such as promoting transparency and generating trust, but

this is not always the case. When designing policies to promote quality it is important that governments, or other actors, consider the full range of tools at their disposal and analyse carefully the interdependencies between other aspects of governance and quality-promoting instruments.

The multiple types of instruments act in different ways on providers and give policy-makers a variety of tools to guide the behaviour of people and organisations within the LTC system. However, the impact of each type of instrument is unlikely be uniform across providers. The complexities faced by organisations attempting to make either incremental improvements or transformational changes are described in an extensive body of literature on change management and organisational development (see, for example, Burnes, 2009). As well as the motivation of the provider organisation and its staff, which we have considered here, the capacity of the organisation to respond will also be influenced strongly by characteristics such as the skills of its leadership, the structure of the organisation and its existing processes and systems. The predisposition of the provider to the adoption of innovations – whether technological or otherwise – will also influence how quickly and enthusiastically the provider adopts new ideas about the delivery of care (Rogers, 2003). In addition to the design features of the instruments, the characteristics and nuances of organisations are therefore important to consider when analysing the likely chances of success of the instruments.

A further challenge for policy-makers is the lack of evidence over the relative costs and benefits of quality-promoting instruments, which compromises their ability to make strategic decisions regarding which instruments to implement. For example, evidence about the effects of regulatory instruments is particularly weak, yet regulation is relied on more extensively than other instruments (Murakami and Colombo, 2013a). Equally, evidence about the value of instruments that focus on professionalising the workforce is poor. However, a number of countries choose this route to quality improvement despite the fact that investing in the workforce is likely to increase labour costs and therefore the overall cost of providing care, since labour costs are the vast majority of costs for providers. Currently this choice seems to be informed more by the particular political and social history of a country than evidence as to the value of such an approach. Indeed, such a policy would be difficult to sell to organisations struggling with cash flow or profitability issues, particularly since the cost premium cannot be offset by reducing staffing ratios – staff may be highly motivated and skilled, but that will not matter if they are unable to devote

sufficient time to service users to ensure high quality care is provided. Interventions that facilitate immediate reductions in (or maintain) staffing costs are likely to be the most appealing for providers and cash-strapped governments, even if, in the long run, their benefits are small in comparison to the benefits of investing in staff. Research providing an evidence base for the social and economic value of different types of instruments will be invaluable in this regard.

Measuring LTC quality adequately is a key issue for quality-promoting policies since the success of most instruments depends on reliable quality measurement. As we have shown, many problems are associated with the choice of measure and how quality is measured. First, structural indicators, such as room size, staffing ratios and education levels, still dominate in the OECD countries. As making an informed choice between quality measures is far from trivial, it seems some public authorities stick to measuring what they are legally required to rather than investing in the wholesale redesign of quality measurement systems. While a small number of countries have invested in the development of process and outcome indicators – to reflect the continuous and long-term nature of LTC by the way care is delivered (care processes) and how the care provided relates to the purpose of the intervention (care outcomes) – these systems are still a work-in-progress. Second, as the quality of LTC cannot be measured in every detail, public and private purchasers rely, to some extent, on the intrinsic motivation of the LTC provider. Quality assessments that come with what is perceived to be irrelevant data collection or too much burdensome paperwork for care workers might crowd out such intrinsic motivation, leading to undesired and unintended results. Finally, the choice of measures needs to reflect what is important to care recipients. While the service user or care recipient's perspective is very important in other industries, it seems to be in its infancy in LTC as quality is often defined from an expert's perspective (providers, care workers, public authorities). As LTC can be considered as an experience good, user experience measures should have more importance in quality measurement frameworks. Although service user satisfaction surveys are quite common, they often do not measure the care recipient's quality of life. Measures such as ASCOT (ASCOT Social Care Outcomes Toolkit, see www.pssru.ac.uk/ascot) are leading the way in measuring quality of life in this area, but there needs to be more work to understand how experience measures can and should be used to direct or stimulate quality promotion.

Space did not permit us to expand on two important aspects, which we mention briefly here. The first is that a wide variety of actors were involved in quality promotion efforts within countries, including public authorities at all levels of government, from the local, through regional levels to the national as well as arm's-length bodies and more independent organisations. However, the extent of involvement of these actors and the roles they perform differed between countries. Understanding the reasons for this variation as well as the consequences for the success of policies to promote quality would be an interesting and valuable direction for future research. The second area is quality of informal care. Given that LTC provided by family members and friends is still the most important resource for dependent people, policies to promote the quality of informal LTC could play a crucial role in improving LTC quality more generally. Interestingly, the political debates about LTC quality mainly address professional LTC provision. Informal care policies still primarily aim at supporting family members in caring for their loved ones (Schneider et al, 2015, chapter 10, this volume), rather than enhance the quality of informal care. Only a few countries have also developed programmes to assure the quality of informal care in private households. These home visit and counselling programmes differ in their design and coverage. More systematic analysis is needed to map different policy options for promoting the quality of informal care and their impact on both maintaining the health and functional status and quality of life of people in need of LTC.

Notes

¹ Australia: Gray et al (2014), Japan: Ikegami et al (2014), Austria: Leichsenring et al (2014a), England: Malley et al (2014) and the US: Stevenson and Bramson (2014).

² Austria: Trukeschitz (2010), England: Malley (2010), Finland: Finne-Soveri et al (2010) and the US: Mor (2010).

³ Austria: Czypionka et al (2012), Finland: Böckerman et al (2011) and overviews of European countries: Dandi (2012); Dandi et al (2012).

⁴ Finland: Hammar et al (2010).

⁵ In fact, the OECD framework goes further, melding the dimensions with the production process approach to identify key inputs (workforce, living environment and technologies) that the authors regard as 'instrumental for good care' (Murakami and Colombo, 2013b, p 48).

⁶ Arm's-length bodies are administrative bodies that are not formally part of any government department, but are subject to ministerial direction and are usually financed by government.

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Part Three

CARERS

NINE

Developing a skilled long-term care workforce

Francesca Colombo and Tim Muir¹

Introduction: time to address the growing demand for long-term care workers

Long-term care (LTC) is a labour-intensive sector and a sufficient supply of LTC workers, with the appropriate skills and training, is critical to delivering high quality care. However, service managers and policy-makers across many OECD countries often find it difficult to recruit and retain LTC workers. Relatively low pay and difficult working circumstances discourage many from working in the sector. Turnover is high and retention is notoriously low, leading to shortages in some OECD countries.

With ageing populations and higher expectations driving increased demand for LTC, OECD countries will need to increase the number of LTC workers in the future. In this context, challenges around the recruitment and retention of LTC workers are set to become even more crucial to the availability of high quality LTC services, and to ensuring that people can expect to live a good life in old age.

In recognition of this challenge, several OECD countries have implemented policies to mitigate the risk of workforce shortages. This chapter looks at what they have done, and argues that, despite the hurdles, workforce challenges are surmountable, as long as policy-makers and employers take steps to improve the dismal image of caregiving as low-paid, hard, and low-skilled work. Ensuring an adequate supply of care for the future may well require a ‘new’ vision for LTC workforce policies, one that is about improving LTC job quality.

Better jobs will mean a better quality of care, but may also mean a higher unit cost. This could be offset by productivity improvements, and this chapter offers an overview of possible approaches to productivity and

discusses what options have been implemented to date. There is, however, a lack of robust evidence as to what works and a need for more research in this area.

Like the other chapters in this book, this chapter starts by presenting a brief framework that defines LTC care workers, and reviews empirical evidence on the supply of care workers across OECD countries. LTC workforce policies are then discussed, drawing from recent OECD analysis and other academic literature. The chapter presents the main policy options before discussing the merits of each and highlighting approaches that seem to be working successfully in countries – although the lack of systematic evaluation often limits the scope for generalisation. The chapter concludes by summarising policy recommendations for the future, including the need for better research on factors underpinning the successes and failures of country policies and initiatives.

Defining and profiling the long-term care workforce across the OECD

LTC means a range of services required by people with a reduced degree of functional capacity (physical or cognitive) and who are dependent for an extended period of time on help with day-to-day activities. Often this includes activities of daily living (ADLs), which are personal care tasks such as eating, dressing or moving around, and it may also include help with instrumental activities of daily living (IADLs), such as domestic errands, shopping or housework. LTC can also involve basic medical services, nursing care, preventive services, rehabilitation or palliative care, resulting in a complex mix of services. LTC is rarely delivered by a medical doctor. Instead nurses, lower-skilled care workers, family and friends, or a combination of the above are typically involved.

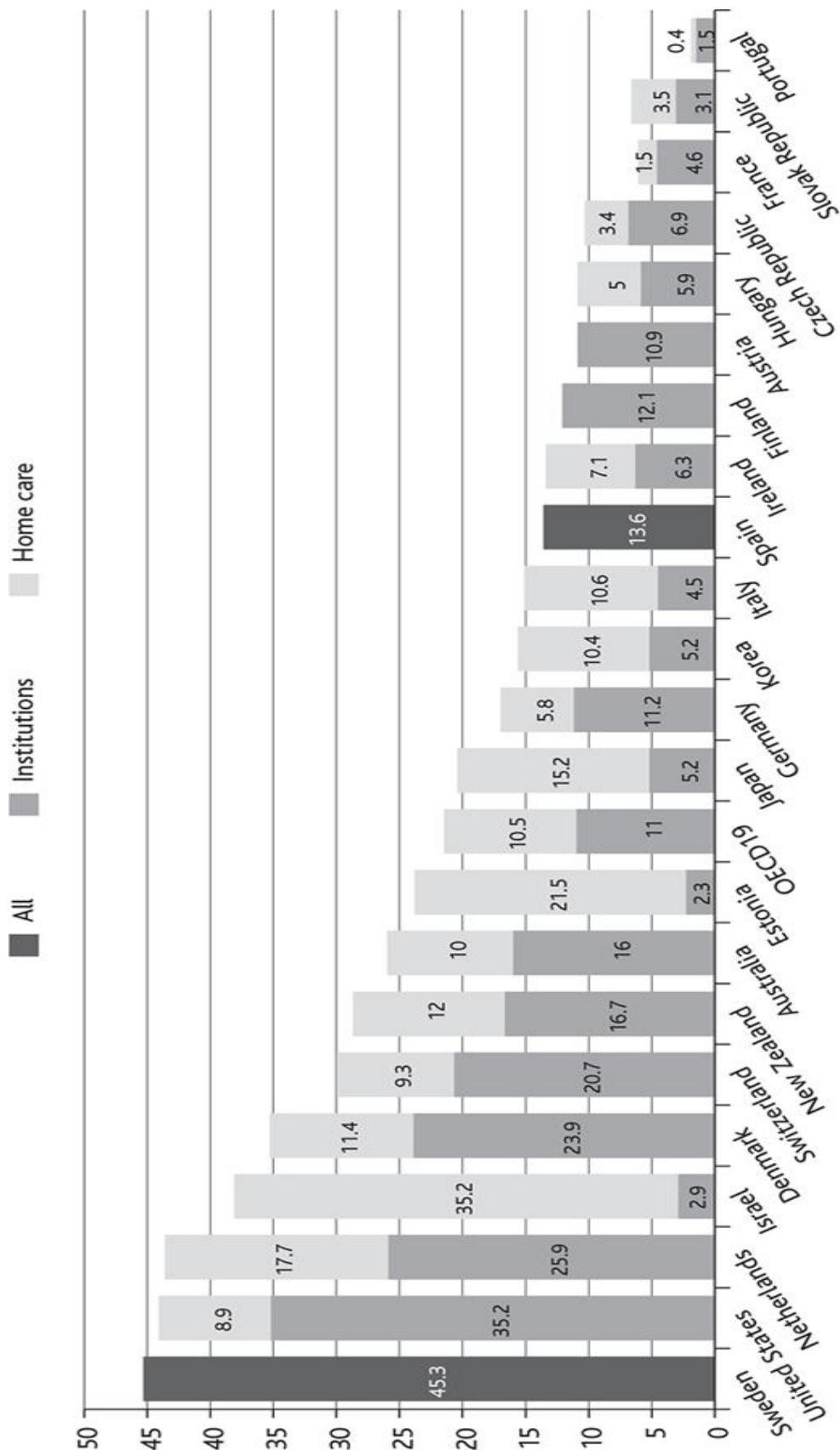
This set-up makes cross-country statistics hard to collect and interpret. Personal care workers are a heterogeneous category, including both trained LTC staff and workers with no care-related training or qualifications. Among the former, training duration, occupational status and job titles differ markedly (Colombo et al, 2011). Training requirements vary, so that untrained workers in one country can deliver a similar mix of services to qualified nurses in another. Several European countries – Italy, the Netherlands, France, Germany, Austria and the UK, for example – have

implemented cash-for-care schemes, which provide the care recipient with a cash entitlement to buy care services from whomever they choose, and this can lead to family and friends being employed instead of professional carers. This category of workers may not be captured in the statistics – for example, the data for Germany exclude people declared to social security systems as caregivers.

Despite these difficulties, and bearing in mind the limitations of the data, it is possible to collect information on LTC workers from government statistics or country surveys. These data show that in OECD countries there are on average around 24.5 LTC workers per 100 people aged 80 and over (who account for over half of all people receiving care). This ratio is the highest in Sweden, the US and the Netherlands, while France, the Slovak Republic and Portugal have the lowest number of LTC workers (OECD, 2013; see Figure 9.1). These figures indicate that the supply of formal care varies widely between OECD countries. In countries where there is less provision of formal care, the gap is often covered by families and friends providing unpaid care.

LTC workers represent a small share of total employment – around 2 per cent of the working-age population on average across selected OECD countries. Predictably, the lowest shares of LTC workers are generally found in countries where the formal care sector is small, for example, the Czech Republic and the Slovak Republic, while the highest shares are mostly in countries with long-standing and comprehensive LTC systems, such as Sweden, the Netherlands and Denmark. However, this share has increased over the past decade. In Japan, the number of LTC workers has grown by 8 per cent per year since the implementation of universal LTC insurance (LTCI) in 2000, even though total employment has been flat (see Figure 9.2). There is a similar, if less dramatic, picture in Germany. In contrast, countries such as the Netherlands and Sweden, which started with more care workers in the early 2000s, have seen changes in LTC employment roughly follow changes in overall employment.

Figure 9.1: Long-term care workers per hundred people aged 80 and over, 2012 (or nearest year)



Notes: In Sweden and Spain, it is not possible to distinguish LTC workers in institutions and at home. Data for Finland and Austria represent institutional care only, so may be artificially low. LTC workers refer to nurses and personal carers providing assistance with ADLs to people requiring care at home or in institutions other than hospitals. For other categories of workers assisting people with cognitive and physical disabilities, such as physiotherapists, dietitians, or social care workers, there is no systematic international data collection.

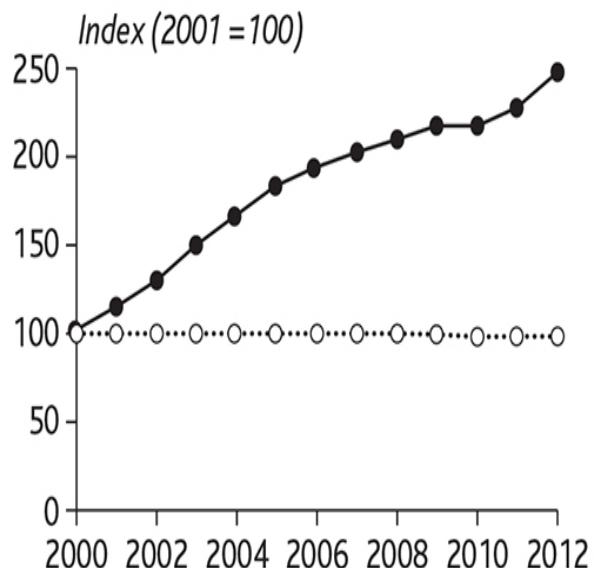
Source: OECD (2013); due to time lags inherent in collecting data at an international level, these are the latest data published by the OECD at the time of writing

Although in most OECD countries between half and three-quarters of the users of formal care are living in the community, the majority of LTC workers provide care in institutional settings (Colombo et al, 2011). This is unsurprising for two reasons: first, people in institutional care tend to have more intensive needs and require more hours of care; and second, formal care in the community is usually complemented to a greater extent by informal care from family and friends. However, low ratios of workers to users in the community may also represent large workloads, which can be detrimental to quality.

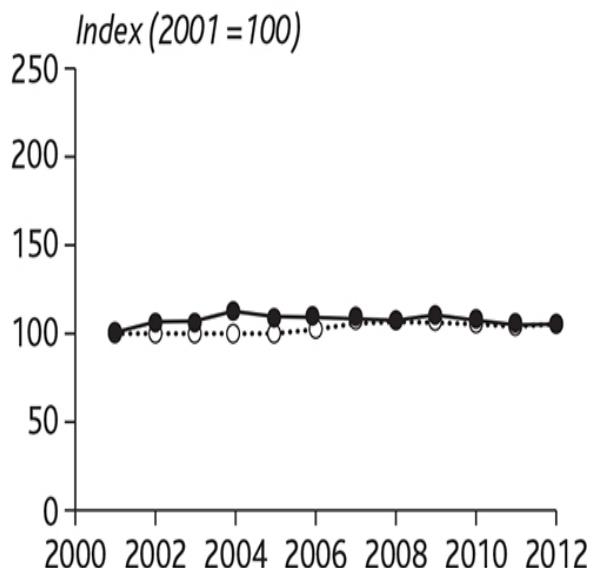
Figure 9.2: Trends in long-term care employment and total employment in selected OECD countries, 2000–12 (or nearest years)

.....o..... Total employment —●— LTC employment

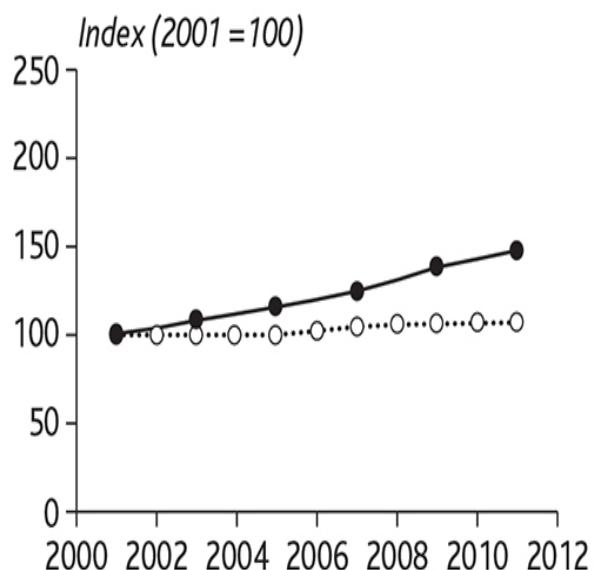
Japan



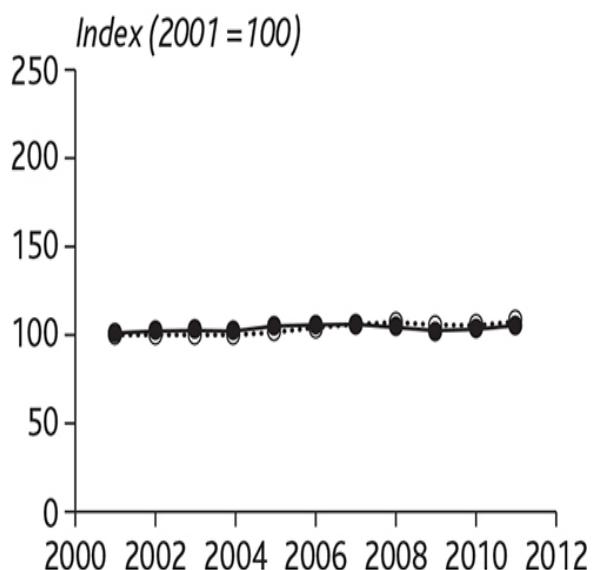
Netherlands



Germany



Sweden



Source: OECD (2013)

Unsurprisingly, the LTC sector is predominantly a source of female employment (Fujisawa and Colombo, 2009). In Canada, Denmark, Korea, New Zealand and Norway, over 90 per cent of LTC workers are women. In the Netherlands, one in every seven working women is employed in the care and welfare sector (van der Windt et al, 2009). There are also relatively high rates of part-time work, particularly in home care settings: in the US, over two-fifths of ‘direct care workers’ are employed less than full time all year round (PHI, 2007, 2010). A Japanese survey of institutional care employers suggests a similar part-time rate for institutional care workers (Hotta, 2010a).

LTC workers have generally lower qualifications than health workers (Fujisawa and Colombo, 2009), with those working in institutional care having higher qualifications than those in home care. About one in four is a nurse, which generally requires at least three years of targeted training including a significant practice component. The other three-quarters of the workforce consists of lower-skilled personal care workers, such as nursing aides, health assistants and home-based care assistants. A number of OECD countries are looking at the possibility of delegating some of the tasks currently provided by nurses to lower-skilled staff in order to reduce costs (see page 209).

Finally, while LTC workers can be motivated and committed in their work, LTC jobs can be demanding and burdensome, leading many to leave the profession due to stress and burnout (European Foundation for the Improvement of Living and Working Conditions, 2006). Work-related accidents and injuries are common. In the US, depression, accidents, and, due to heavy lifting, lower back problems are common (Gleckman, 2010). Low-skilled LTC workers in most countries earn somewhat more than the average for low-skilled workers. However, data from Germany, the US and New Zealand indicate that nurses in LTC earn lower wages than those in other health care jobs (Ministry of Health/University of Auckland, 2004; Rothgang and Igl, 2007). LTC workers in many countries lack job benefits, such as health insurance in the US (PHI, 2007, 2010), or have more limited benefits than most other workers. This is partly because there is an overrepresentation of part-time work in the sector and, in general, part-time workers tend to have fewer such benefits.

Poor working conditions can lead to recruitment problems and high turnover. Vacancy rates in social care in the UK are twice as high as in other sectors (Cangiano et al, 2009). In the US, the median duration of employment as a direct carer is five months, and two-thirds of those leaving an LTC job

leave the profession altogether (Baughman and Smith, 2012). Similarly, turnover in the Japanese LTC sector is higher than in other industries, standing at 27 per cent for non-permanent employees in institutional care (Japan Long-term Working Condition Survey, 2008; Japan Employment Situation Survey, 2008; Hotta, 2010a, 2010b). In Australia, the turnover rate – at 25 per cent – is higher than in other comparable sectors (Australian Government, 2012). High turnover rates increase the cost of providing care, and since a large proportion of LTC is publicly funded, this affects government budgets. The estimated cost of staff turnover for the US public programmes Medicaid and Medicare is US\$2.5 billion, based on a cost per replacement of US\$2,500 (Seavey, 2004). As well as increasing costs, turnover can have a negative impact on the quality of care – low staffing levels of registered nurses in nursing homes can lead to adverse resident outcomes, such as urinary tract infections, pressure ulcers and weight loss.

Addressing the need for long-term care workers²

OECD countries are using a combination of policies to respond to the increasing demand for LTC services. A simple way to conceptualise them is to consider three ways in which rising demand could be met:

- increasing the supply of workers by adding new inflows to the sector;
- increasing the supply of workers by ensuring that existing workers remain in their job; or
- maintaining the same supply of workers, but finding ways for them to provide more care.

The first set of solutions means *improving recruitment policies*. This has been approached in two main ways. Some countries have encouraged new pools of people that may not currently regard LTC as an option for employment (see page 203), while others have looked to migrant workers, leading to a rise in the recruitment of foreign-born LTC workers across the OECD, including a number of European countries (see page 204).

The second set of solutions seeks to address the high turnover of LTC workers. Focusing on improving retention can help make better use of existing human resources and reduce market exit. There are two broad approaches that OECD countries have taken to reducing turnover: improving job *quality*, through better pay and work conditions (see page 206), and

improving job *opportunities* through skill development and career building (see page 207).

The final set of solutions focuses on improving the productivity of LTC workers, so that more or better care can be provided with the same level of staffing. This can be approached by reorganising work processes or using new technologies more effectively. While an appealing option, there are few examples of policies that explicitly target productivity, and even fewer cases where the effect of these policies has been evaluated (see page 209).

The rest of this section describes these policy options in more detail, presents some country examples and offers an assessment of their effectiveness.

Improving recruitment by expanding the recruitment pool

Seeking new recruitment pools among groups that are underrepresented in LTC jobs or that may not consider a career in caring is, in principle, an appealing option. Countries have explored a range of policies that target younger workers entering the labour market, older workers who may have left the labour market, unemployed people, men and minority ethnic groups.

One approach to increasing the number of people working in LTC is to increase the share of new labour market entrants going into the profession. Targeted training programmes could attract young people to LTC jobs, and such programmes may be more successful if they include practical experience of the sector, for instance, through internships. However, although some countries (for example, Norway) have started to implement initiatives targeted at younger workers, there is little evidence of successful efforts to increase the number starting vocational training in the sector, or the number subsequently entering stable LTC employment. Perceptions of career opportunities (see page 207) may be an important factor in young people deciding to enter or stay employed in the LTC sector (Hotta, 2010a).

Other policies have sought to target older workers, including those who are re-entering the labour market. In the US, tax benefits have been used to help older LTC workers gain greater access to education and training, with additional federal funding available to those with lower incomes.

LTC jobs are mostly filled by women, and where men do work in the sector, they tend to be limited to technician and managerial roles, rather than direct care (Hussein et al, 2014). Encouraging more men to work in LTC may therefore be an opportunity to expand recruitment pools. In 2005, Germany

introduced a new policy (*Neue Wege für Jungs*, New Avenues for Guys), offering young men, among others, the opportunity to participate in caring work for older people or children.³ While 70 per cent of the participating young men surveyed were positive about ‘atypical’ professions (including child and elderly care), the numbers participating in such programmes may be too low to have a significant effect on the supply of LTC workers.

Several countries have experimented with programmes to direct the unemployed to the LTC sector, usually focusing on lower-level, unskilled care work. The UK, for instance, targets young people who have been unemployed for more than a year, while in Japan, ‘Hello Work’ employment agencies seek to recruit unemployed people to the LTC sector by providing vocational counselling, employment placement opportunities, seminars on work in the LTC sector and guided tours of social welfare facilities. Some of these programmes have led to promising results. For example, a work reactivation initiative in Helsinki (Finland), which encourages the long-term unemployed to re-enter the workforce by helping elderly people living at home with household management and errands, resulted in 40 per cent of participants moving on to paid work; and a programme in Turkey that trained unemployed women unfamiliar with the LTC sector to provide day care produced a shift in attitudes to LTC work (Hussein and Oğlak, 2014).

Other programmes aim to recruit people from minority ethnic groups, especially to care for people from the same ethnic groups – for example, the Dutch government intends to incentivise individuals from Turkish and Moroccan backgrounds to enter the sector (Ministerie van VWS, 2008). Australia (for nurses), Ireland and Germany have made efforts to re-recruit workers who left the LTC workforce; and there is some evidence that family members and friends, who successfully cared for a loved one as a paid caregiver under cash-for-care programmes, can be attracted to become part of the formal workforce.

However, on balance, the success of activation programmes and target group-based recruitment has been limited. Even where people are successfully recruited, many actually use LTC as a first step towards further employment elsewhere. Long-term evaluations are lacking and tend to focus on efforts to boost employment in general, rather than LTC employment specifically.

Improving recruitment by employing migrant care workers

Many OECD countries have a history of significant inflows of migrants, and international migration can provide a large source of new entrants to the domestic LTC workforce, so many countries find this an attractive option to address growing demand. As a result, some OECD countries have a significant number of foreign-born care workers operating in the sector.

In 13 of the 23 European countries that took part in the EUROFAMCARE study, migrant workers were being used to fill caring roles in the domestic LTC sector (Mestheneos and Triantafillou, 2005). The importance of migrant workers varies between OECD countries: while Germany has very few foreign-born LTC workers, in the US they account for nearly one in every four care workers (Colombo et al, 2011) and more than half of direct care workers are from a minority ethnic group (PHI, 2010). The importance of migrant workers is increasing, and between 2008 and 2009, over half of the 6 per cent increase in residential care employment in the European Union (EU) was accounted for by foreign-born workers. Patterns of migration for LTC workers show similarities to other health workers, notably nurses. Geographical proximity, ease of speaking the language and cross-border earning differences seem important, for instance, in Southern Europe, Germany and Austria. The enlargement of the EU to new member states in 2004 made migration easier for millions of people.

While in several OECD countries the share of foreign-born LTC workers is similar to the overall share of low-skilled migrants in the labour market, the care sector is overrepresented in some countries. This is the case in Italy, where over 70 per cent of all care workers are migrants, and Israel, where around 50 per cent are migrants. In Greece, Portugal, Spain and France, migrants are overrepresented in household services, which include home care. Similarly, in Greece, the Czech Republic, Poland, Austria, Ireland, Switzerland, Finland, the UK, Sweden and Denmark, foreign-born workers are overrepresented in health and community services (OECD, 2009).

Some countries target LTC workers through specific work permits or ex-post regularisation programmes. The Canadian Live-in Caregiver Programme (LCP) grants migrants permanent residence permits after two years of full-time work as ‘live-in carers’. LTC is the main route through which foreign workers enter Israel (almost all provide live-in care); and in Italy, inflows of LTC workers have been supported by ex-post regularisation of foreign workers. Care workers have been on shortage lists or part of bilateral agreements with source countries in France, Spain, the UK, Australia and Japan (Fujisawa and Colombo, 2009; Colombo et al, 2011).

But growing inflows have also required the management of irregular migration and black markets, where care workers are not declared to fiscal and social security authorities, are unregulated and have no work contract, as in some Southern European countries. Options for legal entry for lower-skilled jobs are few in the US, Italy and Spain, with irregular inflows exceeding regular inflows (OECD, 2009). In 2009, estimates of the share of irregular migrants in OECD countries ranged from 0.17 per cent of the population in Japan to 3.9 per cent in the US, with irregular migrants accounting for between 3.7 per cent (Austria) and 63.5 per cent (US) of all foreign residents (OECD, 2009). About 60,000 illegal migrants are estimated to be in Canada, most of whom are refugees (Bourgeault et al, 2009). Some countries have developed policies to discourage the use of irregular migrants or to provide them with paths towards regularisation. Germany issued special working permits for domestic workers arriving from countries entering the EU since 2004 (van Hooren, 2008); France has tax deductions and lighter administrative regimes for those hiring LTC and domestic workers; and in 2007, Austria developed a framework to regularise previously illegal LTC workers.

The migration of care workers can have benefits for both the receiving country and the migrant workers themselves. Receiving countries can respond to growing demand and fill vacancies relatively quickly. Migrants may be willing to accept posts that domestic workers will not, because of the hard nature of LTC work, and may come at a lower cost. With increasing ethnic diversity in many OECD countries, migrant workers may be able to contribute to adapting services to the needs of some care recipients. Meanwhile, migrants themselves benefit from jobs with better pay and conditions than in their origin country.

Nonetheless, there are questions about the sustainability of relying on migration to meet the increasing demand for care workers. In the longer term, countries that are currently sources of LTC workers will face ageing populations of their own and growing domestic demand for LTC. A multi-ethnic workforce reflects the increasing diversity in OECD countries' population, but overrepresentation of minorities in LTC jobs may point to the sector being unattractive to native-born workers. Given the size of the migrant care phenomenon in some countries, and the expected growth in the demand for care, the lack of reference to LTC in the migration programmes of many OECD countries is conspicuous.

Improving retention by improving job quality

Turnover of LTC workers is high, and this has a significant financial cost. A number of studies have looked at the reasons why many LTC staff plan to leave their jobs in the near future, and various aspects of job quality have been found to be important. Job satisfaction, workload, professional autonomy, relationships with colleagues and care recipients, pay rates and perceptions of the quality of care being provided are all factors in decisions about whether to leave an LTC job. Policies in OECD countries have sought to reduce turnover by addressing some of these issues.

There is some evidence that competitive wages can reduce turnover (Ministry of Health/University of Auckland, 2004; Hotta, 2010a, 2010b; Baughman and Smith, 2012; Butler et al, 2014). Belgium, Luxembourg, the Slovak and Czech Republics, France and New Zealand have recently implemented pay increases, in many cases beyond wage growth in the wider economy. In 2009, Japan increased LTCI fees after a long period of constant prices, enabling employers to remunerate workers better. In the US, the federal government provides financial aid to the states so as to increase wages, and research has found that a US\$1 increase in hourly wages could increase job tenure by 2.1 months (Wiener et al, 2009). Collective labour agreements in Belgium, the Netherlands and Sweden ensure that greater experience is reflected in higher wages. One-off financial incentives, such as bonuses, have been tried in the US, although with mixed success.

However, higher wages alone may not generate a sufficient supply of LTC workers to meet the growing demand for services. Even substantial and structural increases are likely to have short-lived effects on recruitment and retention if not accompanied by other measures, such as entitlement to work-related benefits. German, Swedish and Dutch data (BGW, 2007; Swedish Association of Local Authorities and Regions, 2007; van der Velde et al, 2010) and the US ‘Better Jobs, Better Care’ demonstration projects (Livingston, 2008; Engberg et al, 2009) indicate that when work-related benefits are provided, people have higher job satisfaction and a lower tendency to leave. Collective labour agreements in Denmark, Germany, Belgium and the Netherlands, as well as bilateral agreements between employers and employees in the US, set benefits including paid sick leave, entitlements to health insurance, paid travel to and from work or between work settings, extra pay for inconvenient hours and rosters and paid work meetings. Work-related measures that have been shown to improve retention

of nurses are applicable to the LTC workforce – such as overtime strategies, flexible work arrangements, family care initiatives, leave and compensation, health and wellbeing, safety practices, a supportive organisational culture, and union and management support.

High workloads and the demanding nature of LTC work mean that health and safety is an important aspect of job quality. The German Joint Labour Protection Strategy (*Gemeinsame Deutschen Arbeitsschutzstrategie*, GDA), a collaboration between the federal and state-level stakeholders, focuses on preventing musculoskeletal problems, reducing psychological stress and improving safety. It has online self-assessment tools for prevention, training for managers to implement risk assessments and regional information meetings to improve the culture of prevention and health literacy of employees.

Professional autonomy is important to LTC workers, but many have no say in the planning of care provision. Worker-centred policies increase the likelihood that workers feel valued and able to exert control in their work. Key aspects relate to organisation and communication patterns, but also worker recognition, especially merit recognition. Countries with well-developed social dialogue and a structured approach to the recognition of workers' needs, such as the Netherlands, Norway and Sweden, tend to manage better retention. The German New Quality of Work Initiative (INQA), jointly implemented by federal government, state governments and social partners, stimulates knowledge transfer and public debate, and draws media attention to examples of good practice. In Japanese nursing homes, mentoring opportunities at provider level, merit-based remuneration and opportunities to learn about providers' management principles or assignment of responsibilities led to lower stress levels among staff (Hotta, 2007, 2010a, 2010b). Other studies suggest that establishing staff appraisal mechanisms, promoting work–life balance (Suga, 2007) and involving staff in decision-making (Matsui, 2004) can reduce stress levels.

The perceived quality of care provided by an LTC facility and whether there are sufficient resources and staff can be important factors in determining whether LTC workers intend to stay in their jobs (McGilton et al, 2014). This indicates that efforts to improve quality may have a positive effect on retention, offsetting some of the cost, while cost-cutting measures may be counterproductive if they also undermine the retention of staff.

There is evidence of good results from such measures aimed at improving the quality of LTC work – or, in other words, valuing the care profession.

Paying workers better is important, but may not be enough. Access to workplace benefits, better working conditions, greater professional autonomy and recognition, and the provision of adequate resources and high quality care, can offer good returns on investment through lower turnover, higher job satisfaction and better outcomes for care recipients. However, many of these factors – and even whether someone *intends* to leave their job – may be less important to whether someone actually leaves their job than the personal circumstances of individual workers, such as whether they are the primary breadwinner in their family (Dill et al, 2013). This suggests that there may be a limit to the effectiveness of the policies outlined above.

Improving retention through skills training and career development

Improving the skills of the workforce through training and development can lead to higher quality care and a greater ability to deal with complex needs. Better training and development can also reduce staff turnover and so, although initial investment is required, it may at least partly pay for itself. However, training programmes for LTC workers are often short (a few weeks) and are not usually mandatory, although this varies depending on the job level and country.

Increasing educational requirements for LTC workers and improving access to training can help to raise the profile of LTC work and allow workers to build a career. Japan, Austria and the US have recently implemented measures to develop core competences for LTC workers and to assist those wishing to raise their qualifications (Hotta, 2007, 2010a, 2010b; Harahan and Stone, 2009). A few countries support career building through structured educational programmes, for instance, by means of scholarships (Australia) or modular educational pathways (Austria). Others have raised the professional standards of care workers by developing national profiles (Austria) or curricula (Germany), or by requiring workers to be certified (Japan and Korea) or to acquire targeted gerontological skills (Finland). Some countries provide targeted training in specific areas, such as improving leadership and management skills (England, the Netherlands and France) or dementia and abuse prevention (US).

The length of vocational education varies greatly, ranging from two weeks for home help aides in the US to three years for an individual carer in the Netherlands and up to four years for a social care worker in Japan (Colombo et al, 2011). Curricula show little development over time. For instance, in the

US, the minimum federal training requirement of 75 hours of training for nursing and home help aides has not changed in 20 years (IOM, 2008). Standardisation of training is often lacking and there is no consistent requirement for care workers to have relevant qualifications in order to work in the sector. In Australia, 30 per cent of community care workers have no relevant qualification (Martin and King, 2008), while in Germany fewer than half of the workers in home care have a relevant qualification. A range of short-term, on-the-job training schemes are available, often provided by employers. Across Germany, some 300 ‘care assistant’ qualifications existed in 2007 (Oschmiansky, 2010), and New Zealand has developed public–private partnerships, where employers provide mentoring and training.

While most LTC training is targeted at low-skilled workers, some countries also aim to retrain higher-skilled workers from outside the LTC sector. Older workers who have left other professions are one potential source, and Germany has recently increased public funding to cover the full three years of training for older workers who wish to change career into LTC. Australia has measures to rehire and up-skill associate nurses to work in LTC and qualify them as registered nurses. In Germany and the Netherlands, recognition of previously gained competences enables those with relevant knowledge, skills and experience to skip parts of vocational LTC education. The focus of education may be different when dealing with higher-skilled and lower-skilled workers. For example, lower-skilled workers are more likely to need encouragement and training to perform more complex tasks.

The characteristics of the LTC workforce can make improving career opportunities more difficult. Part-time and older workers are overrepresented in LTC jobs, but are not usually targeted by training and development. Women – also overrepresented – are less likely than their male counterparts to enter into targeted education or career-building initiatives. Lower-level care workers do not put themselves forward to participate in educational programmes. Nurses make up around a quarter of the LTC workforce, but wage and career differences with the acute care sector make LTC jobs less attractive, while educational curricula give little attention to the management of chronic conditions or geriatric care (IOM, 2008). Some countries have tried to increase the supply of nurses in the LTC sector by offering scholarships and internships (US; AAHSA and IFAS, 2007), providing funding for care workers to qualify as nurses (Australia), or introducing national educational requirements for elderly care nurses (Germany).

Improving productivity

With ageing populations requiring ever more care, many countries are seeking to improve the productivity of LTC services in order to contain costs. However, the labour-intensive nature of LTC means that opportunities to improve productivity are limited. Efforts must focus on either reducing the unit cost of labour, by delegating tasks that are currently performed by nurses to lower-skilled staff such as nursing assistants, or reducing the quantity of labour required, through the use of technology or the reorganisation of work processes.

Delegation of nursing tasks to lower-level workers shows potential. In a pilot in the Netherlands, lower-level care workers in nursing homes were made to work more independently with patients with dementia and depression, on the basis of nursing guidelines. Safety, quality of life of patients and staff satisfaction were high (Verkaik et al, 2010). In the US, several projects have encouraged such delegation. For instance, in the Nurse Delegation Pilot Program in New Jersey, voluntarily participating registered nurses delegate medication tasks for patients to certified nurse assistants. As nursing aides are often insufficiently trained in this field (IGZ, 2010), the New Jersey State Nurses Association developed guidelines to decide in which cases delegation would be possible and how to go about it, and a registered nurse instructs and supervises the lower-level care worker. However, using lower-skilled staff may not always lead to savings. Buurtzorg Neighbourhood Nursing, which started in the Netherlands, uses higher-skilled nursing staff to carry out all care activities. While this means higher unit costs, it has also led to a reduction in the total number of hours of care required. This counter-example highlights the need for careful evaluation of the costs and benefits of different care models.

Technology may have the potential to reduce labour costs and improve quality of life for the elderly and their carers (Haberkern et al, 2011). Remote training and supervision technologies could improve productivity; monitoring devices, such as glucometers and blood pressure monitors, could help to manage care without the direct involvement of a worker; and assistive technologies can promote LTC users' independence and safety. There are some success stories: for example, tele-homecare initiatives in Canada have shown a reduction in hospital admissions, while improving clients' self-management ability and staff satisfaction.

Another potential role for technology is to support the reorganisation of work processes. In home care settings, modern tools including smartphones can reduce administrative handling and enhance connectivity between users, their families and care providers. A ‘transition programme’ using screen-to-screen communication and monitoring through video and sensors, implemented in the Dutch health care innovation platform, led to better coordination (Ministerie van VWS, 2007). In South Korea, the introduction of electronic equipment for home care management was associated with better and more precise patient evaluation by nurses (Lee et al, 2009). Telecare technology adopted in Scottish community-based LTC services led to reduced pressure and stress on caregivers (Beale et al, 2009).

In nursing homes, there are several examples of how technological tools and smarter workplace organisation can help workers cope better with the demands of their work. A pilot voice communication system linking frail elderly people to their caregivers in Finnish nursing homes made it easier for LTC workers to complete their task without work interruptions, leading to improved work productivity and a 60 per cent decrease in the number of safety alarm calls (Valkila and Saari, 2010). Automation of administrative handling can reduce overheads. The implementation of electronic medical records (EMRs) in nursing homes in the New York area led to time savings, fewer medical errors, improved recruitment ability and better communication between employees and supervisors (Lipsky and Avgar, 2009). Again in the US, the Green House Project used computers, wireless pagers, electronic ceiling lifts and adaptive devices. Staff felt more empowered to assist residents and had greater job satisfaction (Kane et al, 2005; Cutler and Kane, 2009). A Swedish study demonstrated that the implementation of ICT in residential care for dementia can lead to improvements in personal development, reduced workload and higher worker motivation (Engström et al, 2005).

Despite these positive examples, the evidence that technology can replace human labour is mixed. The use of remote monitoring and reminders for taking medicine may not lead to a substitution of labour for people with dementia or intellectual disabilities (Söderlund, 2004; Depla et al, 2010). A recent assessment of the impact of five types of technology (supporting indoor/outdoor mobility, bed transfer, bathing, toileting and telephone use) found that, while they reduced the amount of informal care provided, they had no impact on the amount of formal LTC services required, and so did not reduce costs (Anderson and Wiener, 2013). Some therefore suggest that LTC

will remain a highly labour-intensive sector, with technological assistance being a help or supplement to human labour, rather than a substitute (Torp et al, 2008).

There are also questions about whether these measures are compatible with quality improvement goals. Technological developments can sometimes add to work pressures and workload (Evers et al, 2009), and care users see human interaction as an important part of the quality of services (Henderson, 2006). Slim and flat organisations can reduce overheads, but may sometimes be at odds with supervisory and clinical requirements. In the Netherlands, productivity developments in elderly care have been associated with reduced quality (van der Windt et al, 2009).

Unfortunately, there is still too little systematic evaluation of these initiatives, and evidence on the best approaches to enhance productivity in LTC labour markets remains sparse. The majority of the studies remain pilot programmes, and further systematic assessment is needed to validate their findings. There is a dearth of scientific evidence on the cost-effectiveness of most technologies used in LTC, which often do not undergo randomised clinical trials, particularly in home care settings (RAND Health, 2010). Given the rising demand for care and workforce recruitment challenges, this seems to be an area that requires more experimentation and empirical assessment.

Key policy recommendations and conclusions

In making policy recommendations on how to meet the increasing demand for care workers, it is first important to understand the size of the challenge that OECD countries are facing. While the share of the workforce employed in the LTC sector is still relatively small, it is set to increase significantly, assuming models of care (and hence the ratio of LTC recipients per worker) remain constant.

In most OECD countries for which information is available, the total number of full-time equivalent nurses and personal carers working in the sector is between 1 and 2 per cent of the total workforce. With the total size of the workforce in many OECD countries stagnating or declining,⁴ LTC would need to account for an increasing proportion of all workers if demand is to be met. The demand for LTC workers is expected to grow at an average rate of between 2 and 3 per cent per year, between 2010 and 2050 – with the exception of Japan, for which the projected demand is expected to slow down between 2025 and 2050. In absolute terms, by 2050, the demand for LTC

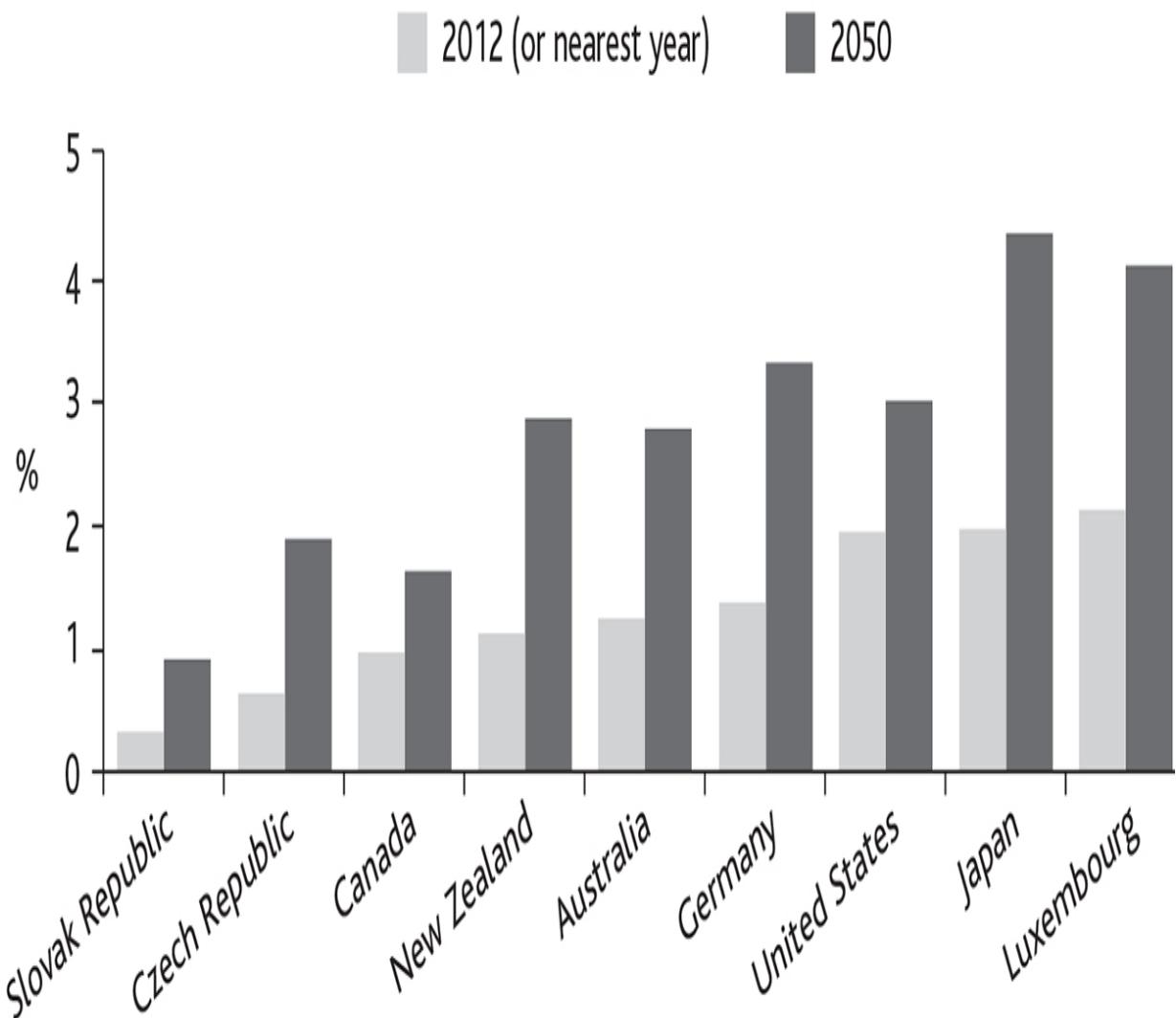
workers is expected to about double on a full-time equivalent basis in Japan, the US and Canada, and about triple in Australia, New Zealand, Luxembourg and the Slovak Republic (see Figure 9.3).

In light of these projections, recruiting and retaining LTC workers may become even more difficult, and the issues outlined in this chapter even more acute. Nevertheless, this need not result in future shortages, provided LTC labour markets are able to adapt to increased demand via, for example, higher wages and better working conditions. OECD countries have already implemented policies to address the growing demand for LTC workers, although not all can be regarded as entirely successful. Based on a review of these efforts and the academic literature, the following key conclusions and recommendations can be drawn.

- International statistics on LTC workers have only recently been collected systematically (see page 198) and the international comparability of data needs to be improved. Governments must require more systematic reporting of LTC employment data, especially in the private sector and in home care settings.

Figure 9.3: The demand for long-term care workers is expected to double by 2050

Full-time-equivalent nurses and personal carers
as a % of the total working population



Note: Projections represent the effect of ageing on demand for LTC services, assuming constant age-specific prevalence of disability. Data for 2012 was not available for all countries, so the latest available year was used for Canada (2006), the Czech Republic (2009), Germany (2011) and New Zealand (2011).

Source: Updated from Colombo et al (2011)

- As the number of people with dementia or other complex care needs grows, the demand for care workers may outstrip supply. Responding to this growing demand will require more effective recruitment, but current policies often fall short. Strategies to expand recruitment pools by targeting groups underrepresented in the LTC workforce (older workers, unemployed people, and men, as discussed on page 203) are in theory attractive, but in practice have had limited effects.
- International recruitment of LTC workers (see page 204) is a sizeable phenomenon in some OECD countries, ranging from around one in four care workers in Australia, the UK and US, to half or more in Austria, Greece, Israel and Italy. While international care workers accept relatively low wages today, this may well change due to pressure to recruit higher numbers and a need to upgrade skills. To meet future demand, countries may need to attract more migrants and pay them better. One proposal would be to extend work permits to care workers in immigration quotas, as happens in Australia and Canada. However, this may not be a sustainable strategy in the longer term, as countries that are currently sources of LTC workers will face ageing populations of their own and growing domestic demand for LTC.
- Working in the care sector is too often regarded as a dead-end job, with few opportunities for career building and strenuous working conditions (see page 198). This leads to high staff turnover, which increases costs to employers and governments. While higher wages can help, this may not be sufficient. Better working conditions, greater professional autonomy and a perception of providing high quality care are important (see page 206). Many countries are also investing in targeted training and career development – although applying this to a workforce consisting of many part-time or older workers remains a challenge (see page 207). In the long run, improving job quality seems to be an essential component of addressing demand for LTC workers. The current situation, characterised by high turnover, low job quality and low pay, is unlikely to be sustainable.
- LTC is a highly labour-intensive service and increasing demand will increase labour costs unless productivity can be improved. It may be possible to improve productivity through the reorganisation of work processes, greater use of technology and delegating nursing tasks to lower-

skilled staff (see page 209), but with insufficient evidence on what works best, there is a need for more research and analysis in this area, both at domestic and at international level.

Notes

¹ This chapter is based on the OECD report *Help wanted? Providing and paying for long-term care* (Colombo et al, 2011), as well as a review of the literature published since and the latest OECD data. Any additional opinions expressed or arguments employed herein are solely those of the authors and do not necessarily reflect the official views of the OECD or its member countries. The authors wish to dedicate this article to the memory of their dear friend and colleague, Frits Tjadens, who passed away in August 2012. Frits was the main contributor to the workforce chapters of *Help wanted?*. Other co-authors of this report are Ana Llena-Nozal and Jérôme Mercier.

² Unless a different source is indicated, the information included in this section is drawn from country replies to an OECD questionnaire on LTC workforce policies (2010).

³ See www.neue_wege_fuer_jungs.de/Neue_Wege_fuer_Jungs/Das_Projekt (German language only).

⁴ The total workforce is projected to grow at less than 1 per cent per year for most countries, to stagnate in Finland, and to decline in Germany, the Czech Republic, Japan and the Slovak Republic (after 2025).

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Policies to support informal care

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Introduction

Informal care – help and hands-on care provided by relatives, neighbours and friends – is a significant source of support for dependent younger and older adults. According to findings from the second European Quality of Life Survey conducted in 2007/08, close to a quarter of adults in the EU27 provide care for an older or disabled relative, and about 8 per cent do so on a daily basis (Anderson et al, 2009, p 35). Informal caregivers clearly outnumber the social care workforce and provide up to 80 per cent of overall care hours, even in countries with a well-developed social care infrastructure (Glendinning et al, 2009, p 5; Marin et al, 2009, p 5; Miller et al, 2009, p 2; Triantafillou et al, 2010, p 29). Based on a replacement cost approach, the economic value of unpaid care in 2011 was estimated at £119 billion for the UK, exceeding the annual cost of the National Health Service (NHS) (Buckner and Yeandle, 2011). Given the mainstay role of informal care in long-term care (LTC) systems, it can be expected to be an integral part of LTC policy approaches.

In fact, facilitating care in the community has assumed high priority in LTC policy in the past 15 years, putting informal care more or less explicitly on the policy agenda. Against the backdrop of austerity policies, in some countries there is an increased interest in informal care as a low-cost mode of providing help to dependent older people. Transitions to formal care and (early) nursing home placement have been shown to depend on access to informal care, stability of informal care networks and caregiver burden (see, for example, Allen et al, 2012). Thus, providing support to informal care seems to pay off from a public finance perspective. In addition, shared formal-informal care arrangements rather than either

state or family responsibility seem to meet the preferences of care recipients and their families (IMSERSO, 2004, 2006; Socialstyrelsen, 2004, 2012b; Sundström and Tortosa, 2006; Sancho, 2011). Against this backdrop, supporting community and informal care comes as a natural choice.

However, informal care also comes at substantial costs for both the care recipient and the carer. (Re)negotiating family care affects care recipients' perceived autonomy (Grootegeod and van Dijk, 2012). The care recipient also prefers formal care when family relationships are strained (Kröger, 2011). Furthermore, providing informal care adds to other roles and callings in daily life. As a consequence, informal caregivers can be confronted with role overload, emotional burden, physical strain, time stress, social isolation and financial strain. A growing policy problem is how to create a balance between informal care and paid work. The rising number of care-dependent older people in the community per working-age person implies that a higher share of workers will face dual work and family care commitments. Not surprisingly, then, informal caregiving may adversely affect caregivers' quality of life (see, for example, Rubin and White-Means, 2009). Thus, informal care is a two-sided coin, requiring policies to address its potential benefits *and* costs to care recipients, family carers and society at large.

Effective policies to support informal care are linked to LTC policies addressing formal care provision, require coordinated efforts across several policy areas (for example, LTC and labour market policy), and involve public and non-public actors. Policies need to cover both support for informal care and the provision of formal LTC services because both types of support are likely to interact (Colombo et al, 2011). A European survey shows that people everywhere prefer a good supply of services, rather than shouldering alone the whole commitment (European Commission, 2007). Work environments have to be adjusted so that informal care and employment can be reconciled more easily (UNESC and Economic Commission for Europe and Working Group on Ageing, 2012). Recent research shows that whether dual work and adult care commitments affect productivity at the workplace, absenteeism or job change intentions is co-determined by characteristics of the work and care arrangements. These issues need to be addressed not only by LTC policy, but also by labour market policy and human resource management (HRM) approaches designed at the company level (Schneider et al, 2013; Trukeschitz et al, 2013; Zuba and Schneider, 2013).

The purpose of this chapter is to inform and guide the design of policies that seek to support informal care. While the definition of informal care is still subject to academic and political debate, in this chapter the term relates to help by family and friends which is either provided unpaid or for a monetary reward that falls clearly below the compensation for an equivalent service purchased at the market. Informal care in our understanding may comprise a broad range of support activities, including help with household chores as well as personal care and supervision. However, what is counted as ‘informal’ may differ due to cultural patterns and national idiosyncrasies. Often policy measures offering substantial support to informal carers are restricted to family members.

Public support to informal carers can be divided into direct and indirect measures. Indirect measures comprise care services provided to care recipients but (also) with an explicit aim to unburden the informal carer. Direct support measures include, for example, economic remuneration or social protection granted to informal caregivers. We argue that the mix of specific support measures in a specific country is shaped by the degree to which informal caregivers are perceived as ‘co-producers’ or ‘co-clients’ in LTC provision.

The structure of the chapter is straightforward. The next section provides a conceptual underpinning of the discussion by way of classifying policy approaches to supporting informal care and introducing the major building blocks of such policies. We then make specific reference to illustrative country cases for how and why policies to support informal care were subject to changes, and in the fourth section we review the research conducted on the (cost-)effectiveness of specific measures to sustain informal care.

Conceptual underpinning of the discussion: policy stances towards informal care

What are the important similarities and differences among various approaches to supporting informal carers? As a first step towards answering this question, this section introduces the building blocks of policies in support to informal care on a conceptual level, focusing on (1) policy logics and objectives, and (2) policy instruments.

Care regimes and their implicit policy logic with regard to informal care

In order to reveal the underlying logics of policies to support informal care, it is helpful to start from the care regime literature (Anttonen and Sipilä, 1996; Bettio and Plantenga, 2004; Timonen, 2005; Saraceno, 2010), particularly by assessing the degree to which care to dependent adults is considered a public responsibility. The sharing of responsibilities between the state, the market and the family depends on a combination of factors such as tradition, legal responsibilities, health and social policy, and the economic context. In what follows we assume that a country's basic attitude towards public LTC responsibilities determines whether explicit policies in support of informal care are in place at all, and if so, the specific approaches taken.

If eldercare is not regarded as a public responsibility, policy-makers do not perceive a need to develop explicit policies providing for dependent older people or their informal caregivers going beyond 'end of pipe' entitlements to basic social assistance in case of impoverishment. The Mediterranean 'all in the family model', which has been identified in the care regime literature, illustrates this case. Italy, Spain and Greece come close to this analytical construct as public responsibility for eldercare is very limited, and where there are legal responsibilities of adult children for the welfare of their parents (and vice versa).

In care regimes that are characterised by mixed private-public responsibilities for LTC, the interrelationships between different modes of care, including informal care, need to be addressed. The LTC policies in the Anglo-Saxon means-tested care model, the Continental European subsidiarity model or the Central and Eastern European (CEE) model all constitute such 'mixed private-public' settings. In these care regimes, the state provides limited access to formal care, with no intention to completely substitute formal for informal care provision. This makes mixed formal-informal care arrangements more likely, creating risks (fragmentation) and potential gains (synergies) that affect care recipients, formal caregivers and informal caregivers alike. The challenge in these systems is to facilitate smooth interaction and a fair balancing of interests across all involved parties. This calls for explicit approaches to supporting informal care,

giving some choice to caregivers with regard to opting into informal care and regarding the types of help provided.

With systems that take almost full public responsibility for the LTC needs of older people, such as the ‘Scandinavian care model’ or ‘Nordic care model’ (often associated with Norway, Sweden, Finland, Denmark), families do not have to but usually do provide informal care. In the Nordic ‘shared care’ settings (Kröger, 2011, p 125), caregivers may be less likely to provide high-intensity care or to take on tasks that require expertise or training. Support to informal carers in this type of system may be less urgent than in other care regimes.

It is important to note at this point that the care regimes that have been identified in academic literature sketch out either core design principles or typical policy patterns to be observed. They point out basic political choice options, which is helpful for policy assessment and development. It is possible that shifts in policies and service supply in many European countries are blurring the earlier rather sharp distinctions between different care regimes. Traditional welfare states such as the Netherlands, Denmark and Sweden are cutting back on core services (primarily home help and institutional care) for older people (see, for example, van der Aa et al, 2014), while Spain is now less of a laggard in these services than it used to be (Andrés and Ponce, 2013; see also page 228).

Basic policy approaches to supporting informal care

A differentiated set of policies related to informal care can be derived from Twigg’s conceptual model (Twigg, 1992; Twigg and Atkin, 1994) that was adapted later on by Pickard (2001, p 444f) to conceptualise four policy approaches to informal caregivers. LTC policy can (1) consider informal care a given and thus fail to explicitly address it, (2) conceive informal caregivers as contributory (carers as co-producers), (3) address risks and needs of informal caregivers in their own right (carers as co-clients), or (4) work towards superseding informal care in the provision of help to older dependent adults.

As stressed by Pickard (2001), elements of these four basic approaches to policies supporting informal care could co-exist in current praxis. Informal carers can be both producers of care *and* consumers/clients of support services (Toffler and Toffler, 2007; Rifkin, 2014). Yet, for purposes

of analytical clarity, we discuss challenges and options for carer support policies from either a strictly co-producer and a strictly co-client logic.

Evidently, the first approach, which takes informal care as granted, matches with the ‘all in the family’ logic of (ideal-type) Mediterranean care systems. Yet even in these care systems policies could account for the imminent risks of informal care to caregivers and implement some elements of the carer as co-client approach. The Scandinavian-type care regimes obviously verge towards the ‘superseded care model’. Informal care is neither taken as given nor do informal caregivers attract much attention as co-producers of support services. Yet the emphasis of carer support policies could still be expected to lie on approaches viewing carers as co-clients. For all other care regimes with mixed private–public responsibilities in LTC, the type of policy approach taken is harder to predict. Any mix of the co-producer and co-client logic of support is conceivable.

Policy objectives emanating from the ‘carer as a co-producer’ logic

Viewed from a perspective that considers informal care integral to providing support for older dependent adults (which is denoted as co-production in economics), the logical objective of policies to support informal care is to maintain and develop informal care as an important resource (‘co-producer logic’). There are three specific challenges and according policy target areas to be discussed in this context, namely, (1) the availability of informal resources, (2) the stability of informal caregiving networks and (3) the quality of informal care.

Regarding the first issue of caregiver availability, one would expect countries that follow the co-producer logic in supporting informal care to take solid stock of the current and future supply of unpaid family care. However, hardly any country keeps track of this source of support in regular and representative surveys. Notwithstanding the lack of dependable data, experts assert a variety of demographic and socioeconomic factors to gradually wear away the overall supply of informal care to the older dependent population. They usually refer to increasing female labour force participation rates and changes in family and household structures (European Commission, 2008, p 34; Miller et al, 2009, p 5f; Colombo et al, 2011, pp 19, 67ff). While this reasoning seems plausible, there are hints at country variations as to the severity of the dwindling supply of informal care and in some cases even improvements, for example in Sweden

(Socialstyrelsen, 2004). A recent study shows that in Sweden it is indeed common that care provided by family and others overlaps with public services (and vice versa) and sometimes also with private services (Jegermalm and Sundström, 2013).

The second issue, the stability of informal care arrangements and networks, deserves close attention. Stable and reliable arrangements are essential for care outcomes and for avoiding care transitions including early nursing home placement (Szinovacz and Davey, 2007; Allen et al, 2012). According to the longitudinal study of adult-child care networks by Szinovacz and Davey (2007) for the US, more than half of all informal care networks (and about one-fourth of primary caregivers) changed within a two-year period. The authors voice concern that informal care arrangements will be even less sustainable for future smaller birth cohorts.

A third issue in policies to support informal care relates to the quality of care provided by informal caregivers. Care provided in an inadequate manner jeopardises the care recipient's physical or mental health. Also, excessive demands on informal caregivers may prompt harmful neglect or violent behaviour. A systematic review of empirical literature focused on support for co-resident family carers summarises evidence from seven studies on this issue (Stoltz et al, 2004, p 116). Caregiver burden and distress were found to be particularly high for dementia caregivers. One study in the review points to an association between carer burnout and abusive situations, that is, caregivers abusing an older dependent person or vice versa (Quayhagen et al, 1997). These issues also need to be addressed by LTC policy. When care responsibility is shared with public services, this provides a 'window' into the situation of both carer and care recipient.

Taken as a whole, these three challenges/policy targets from a 'carer as a co-producer' logic call for measures that (1) encourage potential informal caregivers to take on a caregiving responsibility, (2) stabilise given informal care arrangements by way of avoiding excessive care burden, and (3) support informal caregivers in delivering adequate support and preventing neglect and abuse. The unifying theme and aim of such policies is the wellbeing of older care recipients by ensuring that informal caregivers are able and willing to deliver care, reflecting the 'informal carer as co-producer' logic.

Policy objectives emanating from the 'carer as a co-client' logic

Following the ‘carer as co-client’ logic, informal help is not (only) to be viewed as a resource to the LTC system but as risk-taking behaviour: assuming caregiving responsibilities for families or close friends can be associated with a variety of social risks and challenges to the caregiver’s wellbeing. In this perspective carers appear as a vulnerable group. Thus, there is a need for social policy that effectively fends off these social risks and undue hardships. Approaches along this road could be labelled ‘caregiver support policy’ and are quite distinct from policies to support informal care from a co-producer perspective on informal care.

This second view on policies to support informal care can be backed by research on the hidden cost of informal care, which are well documented in research on the subjective caregiver burden (Aneshensel et al, 1995; Seltzer and Li, 2000; Etters et al, 2008; Roth et al, 2009; Hoefman et al, 2011). A solid number of studies reveal the adverse impacts of caring on the carer’s physical and mental health (see, for example, Brodaty and Green, 2002; Savage and Bailey, 2004), caregivers’ health behaviour (Hoffman et al, 2012) or health-related quality of life (Hughes et al, 1999; Jiménez and Vilaplana, 2007). Recent research also provides evidence for increased poverty risk for caregivers and economic and career opportunities lost to working-age caregivers (see, for example, Meng, 2010; Colombo et al, 2011, p 86; Nepal et al, 2011; Zuba and Schneider, 2013). Compounding the multiple hazards associated with informal care, taking on an informal caregiving responsibility is often unplanned and might not even be entered into by choice (Qureshi and Walker, 1989). Coping with caregiving responsibilities and/or negotiating one’s role in a caregiving arrangement can be very demanding, even in countries with extensive public services. Against this backdrop, policies to support informal care are about addressing care-related hazards to informal carers. Their task is to back and protect informal caregivers in their own right and to guarantee choice.

From the ‘carer as a co-client’ logic perspective support policies therefore need to (1) assess the risk profile of informal caregivers, (2) design appropriate interventions that mitigate these risks and (3) encourage informal caregivers to take up care relief services. While the first two approaches seem self-evident, it is important to mention that different groups of caregivers have different needs that can be best addressed with specific target group policies. With regard to (3), (non-)take-up of care services, the difficulty lies in the fact that caregivers often do not self-define

in the caregiving role (see, for example, Malmberg and Sundström, 2012), or do so only very late or in an incident of crisis. In addition, older care recipients and other family members may object to the use of social care services (Shaw et al, 2009, p 67). This is reflected in the poor utilisation – even when easily available – of both social care services offered to older dependent adults and services addressed at informal caregivers (Lamura et al, 2008; Shaw et al, 2009).

Policy instruments used to support informal care

The policy logic underlying the support of informal care will shape the specific policy interventions because each comes with a predisposition for certain types of instruments and measures and a specific focus in terms of content. It is certainly possible that both policy logics feed into a country's policy debates and policy implementation, yet necessarily to the same degrees or at the same point in time. Table 10.1 provides an overview of (1) instrumental categories and (2) potential differences in their implementation according to the basic policy logic.

Measures to support informal care can be categorised according to their overall aim as ‘information and counselling’, ‘education and training’, ‘respite care’, ‘care allowances/service benefits/benefits for home improvement’, ‘social/financial protection’ and ‘policies to support reconciliation of care and employment’ (see, for example, Pickard, 2004; López et al, 2007; European Commission, 2008; Colombo et al, 2011, pp 121ff).

In terms of their form and contents, support measures could also be grouped into service benefits, financial and social security benefits, or regulation: most service-based benefits can be provided at the individual as well as at the household level or in a group setting. By contrast, financial and social security benefits are generally targeting the individual. In some countries, various payment systems or economic remuneration for caring (including tax benefits) have been available for a long time. Regulation can be focused on the group of informal caregivers or extended to other societal groups and actors (for example, to employers of working caregivers).

Twigg (1992, p 60f), Pickard (2004, p 8) and Arksey (2007, p 169) emphasise that while some of the measures in caregiver support policies are mainly or exclusively targeted at caregivers (direct, ‘carer-specific’ approaches), carers also benefit from services provided primarily to care

recipients (indirect approaches). In some instances, interventions target carers and older dependent adults in a more or less even way (a ‘dual approach’). The latter is quite evident when the informal carers and the care recipient share a household. In this case, measures such as domiciliary care services, support for home improvements or interventions targeting the financial wellbeing of the household matter for carers and care recipients alike.

Table 10.1: Policies to support informal care – expected differences in policy focus according to the underlying policy logic

Category of instrument	Policy logic regarding informal care	
	Co-producer logic of informal care	Co-client logic of informal care
Information and counselling	Supporting care management and providing help with ADLs	Advice on legal entitlements and self-care
Education and training	Improving caregiving skills	Caregiver empowerment
Respite care (short holiday breaks, emergency care, adult day/ night care, in-home respite care)	Maintaining caregiver productivity	Protecting carers from the perils of informal care provision to their own health, maintaining their quality of life
Care allowances and service benefits; benefits for home improvement	Encouraging take-up of informal care; maintaining stability of informal care arrangement Cash benefits to <i>caregivers</i> (<i>caregiver allowances</i>), service benefits for care recipient Supporting home improvement to facilitate home care	Substituting formal for informal care Tax allowances, cash benefits (<i>addressed at the care recipient</i>), service benefits for care recipient (<i>shared care setting</i>)
Social protection/ mitigating financial risks of LTC	Accident insurance, health prevention, health insurance coverage and pension entitlements <i>targeted at full-time/high-intensity caregivers</i>	Accident insurance, health prevention, social assistance in hardship cases, <i>no incentives for working-age caregivers to specialise in informal caregiving</i>
Measures in support of reconciliation of care and employment	Not a policy priority Care leave for end-of life care Preference for (full) carer leave and carer leave for extended periods of time	Securing choice to family carers; protecting financial well-being and career opportunities Regulation on care leave for end-of-life care; entitlements to work part-time, short/limited leave entitlements Provision of home help services

Note: ADLs – activities of daily living.

As illustrated in Table 10.1, all general categories of instruments will be used irrespective of the underlying policy logic for supporting informal care. However, major differences by the dominant policy logic can be expected to emerge in the implementation of support measures in nearly all aforementioned categories. Information and counselling, as an example, if framed by a ‘carer as co-producer’ policy logic, is likely to focus on improving care management. By contrast, in the context of a ‘carer as co-client’ perspective it would centre on self-care and legal entitlements that are carer-specific. A major difference can also be found in the category of instruments that aim at reconciliation of paid work and informal care. The latter appears somewhat at odds with the ‘co-producer’ logic of supporting informal care.

Country cases and policy trends

Explicit LTC policies form a rather recent addition to social policy (Mestheneos and Triantafillou, 2005). In most OECD countries these policies emerged in the 1990s on a more visible scale. During the 1980s and 1990s, the discussion about the balance between formal and informal care appeared on the political agenda in many European countries. In the past decade European social care policy has committed itself to ageing in place and the postponement of institutionalisation, putting ever more emphasis on informal care. This, in turn, calls for increasing efforts to support informal care. In what follows, we provide a brief overview of such policies for the past 15 years for a selection of European countries that represent different welfare and care regimes.

As explained earlier, countries belonging to the ‘Anglo-Saxon means-tested care model’ acknowledge mixed private–public responsibilities for LTC. As a consequence they can be expected to address carers’ needs explicitly. In fact, the Carers (Recognition and Services) Act introduced in Britain in 1995 gave caregivers the right to an assessment of their needs but not to any services. Since the introduction of the Carers Act in the UK, legislation regarding caregivers has been amended on several occasions and in several different areas, for example, in social care, employment and pensions (see www.directgov.co.uk, 2010). In addition, personal (or individual) budget systems were introduced in the UK, where the *care recipient* could opt for cash instead of services (Carr and Robbins, 2009). The cash benefit option can benefit carers indirectly.

Countries in Northern Europe, especially the Nordic countries, have a long tradition of offering formal services to older people, to the (indirect) benefit of carers and the family. Among the Nordic countries, Denmark, Norway and Sweden have introduced support to carers in their social services legislation. Finland passed special legislation in 2006 covering informal caregivers, the Family Carer Act (see www.finlex.fi, 2010). This legislation regulates both care allowances and respite opportunities for informal caregivers as well as the provision of services such as home help and caregiver support groups (Johansson et al, 2011). The Netherlands offers a recent example of drastic shifts in LTC policy (van der Aa et al, 2014): public spending has been curtailed by de-centralising services to the municipalities and at the same time decreeing that care and nursing should, as far as possible, be provided by the family and others in the social network. Under the new legislation (Social Support Act, *Wet maatschappelijke ondersteuning* [WMO], 2015), public support is only granted if a person with care needs has insufficient financial and social resources.

Countries in Continental Europe whose social care policies reflect a ‘subsidiarity model’ (see earlier) offer flat-rate cash benefits to *care recipients* rather than carers. They partly cover benefits in-kind, training and counselling for family caregivers and respite services. Austria, for example, provides a cash benefit to care recipients to help households shoulder the cost incurred by LTC needs and which they can use at their own discretion (Trukeschitz and Schneider, 2012, p 188). In Germany care recipients have a choice between cash benefits and services in-kind. Cash benefits can be passed on to informal caregivers (Schneider and Reyes, 2007). Both countries provide social care services at the sub-national level. In Austria user fees vary across states and depend on household income. Furthermore, in 2007 Austria introduced financial support for live-in caregiving arrangements. These arrangements for the most part involve migrant care workers (Österle and Bauer, 2012; Trukeschitz and Schneider, 2012, p 190).

Policies addressing informal caregivers in their own right, especially social protection, evolved only slowly in Continental Europe. In Austria, a family hospice leave system was introduced in July 2002 and amended in March 2006, which supports informal care to terminally ill relatives. Family caregivers in paid work are entitled to reduce their work hours or take leave for up to six months. There is no replacement for loss in earnings except for hardship cases. As of 2004 informal caregivers caring for a relative with substantial care needs can obtain financial support for respite care.

Furthermore, Austria (and also Germany) provides social security benefits to family caregivers – on the condition that they are either not participating in the labour market or do so to a negligible extent. In Austria, family members caring for their frail relatives have health insurance coverage without contributions. Family caregivers who are not participating in the labour market and caring for a person with substantial care needs can self-insure in the statutory pension system at a reduced rate. As of July 2007, contributions have been waived completely for a period of 48 months if care is provided to a relative with very substantial care needs. Initiatives for caregiver benefits and caregiver empowerment have gained momentum following the launch in 2011 of the *Interessengemeinschaft pflegende Angehörige*, which is a membership association advocating caregiver interests.

In Mediterranean countries with less developed public services different types of respite services have been available for decades, but often scattered and with restricted eligibility. Spain exemplifies a combination of family obligations and rather extensive public services with widespread use of paid private help, often migrant labour (Vidal et al, 2011; Andrés and Ponce, 2013; Jiménez and Vilaplana, 2013). For example, 5 per cent of older people are institutionalised and 5 per cent use home help, although these services seem to be more highly rationed to those without close family, and primarily poor people (IMSERSO, 2010). About one in ten older people – primarily the well-off and more educated – use paid private help.

In Spain the new law on dependency (2007) has evolved into a system that frequently pays family carers: in 2012, 47 per cent of recognised cases were cared for by paid family members. This was unintended as the law was meant to promote services rather than cash to carers, but can be considered an effect of the economic crisis (León, 2011; Monserrat, 2014). The new government in 2012 established stricter rules for family carers to receive this cash support.

Looking back at the past 15 years, different LTC systems in Europe tended, until recently, to converge (Pavolini and Ranci, 2008). This also applies to their policies in support of informal care: countries that rely more heavily on informal care first focused on ‘co-producer’ approaches but gradually expanded the ‘co-client’ logic. By contrast, countries such as Norway and Sweden have cut down on some LTC benefits and have developed an interest in caregivers as co-producers of care, adjusting their policies of support to informal care accordingly (extensive hiring of family carers as pro forma home help in Norway and Sweden was previously a

response to logistic problems or difficulty in recruiting ‘ordinary’ staff in sparsely populated areas rather than explicit support to carers). As a result, several countries now apply dual approaches.

In several countries there are now associations lobbying for the interests of informal carers. In Sweden this led to legislation in 1999 that municipalities ‘ought to’ support carers. This was made mandatory in 2009, and in the same year government-funded caregiver research and information centres were established. One may even conclude that the best caregiver support is extensive public(ly) financed LTC services, as informal carers in those countries provide less care, or at least less ‘heavy’ informal care (Pickard, 2011).

Effectiveness of policy interventions

Challenges in assessing the (cost-)effectiveness of interventions

The design of policies in support of informal care can be informed by intervention studies, by way of identifying best practice models (see, for example, Toseland, 2004), through systematic reviews (see, for example, Glasdam et al, 2010; Fields et al, 2012), and meta-analyses (Sørensen et al, 2002). The last two options follow more rigorous and formalised procedures and aim to bear generalisable evidence. All of the aforementioned approaches have been taken in the last decade, with more than 20 reviews and meta-analyses regarding policies in support of informal care.

Yet, in spite of the large number of intervention studies and analytical efforts building on them, evidence on the effectiveness and cost-effectiveness of some (categories of) measures supporting informal care is still in short supply. The number of economic evaluations is particularly small, and those economic assessments available predominantly focus on respite care (see, for example, Gramain and Malavolti, 2004; Mason et al, 2007a; Selwood et al, 2007, p 7; Thompson et al, 2007; Goodrich et al, 2012; Jones et al, 2012).

The reasons for these gaps in knowledge are manifold: past caregiver support interventions have not always been designed and implemented with evaluation in mind (van Houtven et al, 2011). Also, many interventions that were initiated by research do suffer from deficiencies with regard to conceptual clarity, methods and data used: numerous intervention studies fail to specify the target, desired outcomes and specific content of the intervention. Intervention studies are not always designed as randomised control trials or do not adjust appropriately for baseline differences between

groups, or are based on small sample sizes. Many studies do not collect information on both caregiver and care recipient characteristics. Last but not least, only a few existing studies cover the cost of the alternatives to be compared in addition to intervention outcomes, rendering full economic evaluation impossible.

Evidence on the (cost-)effectiveness of policies to support informal care

This section summarises evidence on the effectiveness and efficiency of policies in supporting informal care drawing on systematic reviews and meta-analytical approaches that have been published since 2000. These studies allow mapping the terrain of empirical research in terms of geographical coverage, major avenues of research and rather uncharted territories.

With regard to *geographical coverage* it shows that existing studies mostly refer to interventions in (parts of) the US, Canada, the UK, Australia and New Zealand (Shaw et al, 2009). Only a smaller number of such intervention studies are reported for Continental Europe or Japan. Virtually no research-based evidence is available for lower-income countries in the OECD. At times, the limited geographical coverage of intervention studies is not even addressed in most reviews or meta-analyses. Notwithstanding, the geography of research findings is very important. There are notable cross-country differences in policy approaches and regarding the socioeconomic and cultural contexts (van Houtven et al, 2011, pp 3, 18), which are likely to affect the potential for policy transfer and policy learning.

Concerning the *major avenues of research*, a great number of intervention studies in the past two decades have investigated the effectiveness of service-based support. By contrast, there is less research on the effectiveness of financial benefits offered to support informal care or regulatory interventions. Furthermore, as pointed out by van Houtven et al (2011), there is little evidence on the impact of carer support policies on caregivers' economic outcomes (financial wellbeing, employment opportunities) and the quality of informal care provided. Overall, effectiveness studies still prevail, while there is a smaller body of full economic evaluations.

In their *meta-study of interventions supporting family caregivers*, Sörensen et al (2002) considered six types of interventions and six caregiver outcomes. They found that on average the interventions were effective and provided the expected (significant) impact on caregiver outcomes (Sörensen

et al, 2002, p 360). In the short term, the measured impact of interventions on caregivers' knowledge and skills were greater than on caregivers' depression and burden.

According to Sørensen et al (2002), the impact of support measures often depends on the specific characteristics of interventions. Similarly, some interventions were only effective for specific caregiver outcomes or specific sub-groups of carers. Therefore, we now proceed to a slightly more disaggregated discussion of research evidence. We first present evidence on the (cost)effectiveness of carer support policies by type of intervention, considering (1) training/education and counselling, (2) psychosocial support and (3) respite care/adult day care. We then focus on the effectiveness of support measures for the specific sub-group of dementia caregivers.

Effectiveness of specific services provided to support informal care

To our knowledge, no systematic review or meta-analysis has been conducted recently that (1) examines a broad range of informal caregivers and (2) exclusively focuses on *training/education and counselling*. However, the meta-analysis of 78 intervention studies presented by Sørensen et al (2002) covers six types of interventions including training and counselling targeted at informal carers. According to the authors, 'psycho-educational' interventions and psychotherapeutic treatments could be linked dependably to six different short-term outcomes (most of which concerned psychological wellbeing), notably on caregiving knowledge and ability (Sørensen et al, 2002, p 365). Measured effect sizes varied by intervention characteristics as well as characteristics of the caregiving arrangement. Unfortunately, their meta-analysis does not provide information on the cost-effectiveness of training/counselling. Studies on the effectiveness of caregiver education were also included in the systematic review conducted by Stoltz et al (2004) on support for family carers who share a household with the care recipient. They concluded that there is moderate evidence on caregiver education being an effective means of supporting family caregiving.

With regard to *emotional and psychological support*, Stoltz et al (2004) presented findings from four studies that family carers fear social isolation. In addition they pointed to moderate evidence from another three studies about family carers' strong desire to network in social support groups. However, none of these studies inform policies about how networking or social support groups should be best designed (Stoltz et al, 2004, p 117). One of the studies

quoted in Stoltz et al's review focuses on caregiving wives and daughters: Li et al (1997) showed social participation to reduce stress emanating from care recipients' problematic behaviour and – for caregiving daughters only – to diminish depressive symptoms. Similarly, López et al (2007) studied a single stress management intervention for distressed caregivers to physically impaired older adults. A setting with weekly group meetings showed the intended effect on depression and anxiety.

Respite care services form a third and prominent category of support for informal care. These services can be provided in the setting of private homes or in institutions (Mason et al, 2007b). Their explicit purpose is to provide informal caregivers with a temporary break from caregiving to improve carer wellbeing. While other caregivers step in for the usual informal caregiver, respite care is not primarily aiming at improving support for the care recipient in quantitative or qualitative terms (Shaw et al, 2009, p 5). There are several forms of respite care, including in-home respite care, host family respite, adult day care, institutional respite care and respite care packages (Pickard, 2004; Mason et al, 2007a, 2007b; Shaw et al, 2009). Mason et al (2007b) even mention video respite. Three recent literature reviews on respite care found that effectiveness studies on adult day care prevail, while less is known about alternative types of respite provision (Mason et al, 2007a; Shaw et al, 2009; Fields et al, 2012).

Stoltz et al's (2004) review of support for family carers found strong evidence that family carers desire respite care. Yet they also concluded from the 26 studies they reviewed that it is 'unclear whether they actually benefit from such (and other) services or how service provision should be attempted' and that 'service called respite does not necessarily lead to the experience of respite' (Stoltz et al, 2004, pp 111, 116). Evidence from Sweden (Socialstyrelsen, 1998, 2002) examined by Stoltz et al (2004) points to a high demand for in-home respite care, which was, however, difficult to access and/or not used when granted. Therefore they recommended negotiating rather than 'giving' this (and other types of) support to informal carers in order to make sure that services meet the demands of the target group (Stoltz et al, 2004, p 117). One US study in their review (Feinberg Friss and Whitlatch, 1998) found family caregivers to prefer consumer-directed respite services preferable over respite services that were administered by an agency. In a similar vein, the review by Shaw et al (2009) on respite care revealed that informal carers request a range of flexible services, and that information

about such offerings need to be conveyed more actively to increase service take-up.

The review of Mason et al (2007a, 2007b) also summarised findings on the effectiveness of respite services. There is tentative evidence that respite services reduce caregiver burden and depression. Furthermore, caregivers were found to be more satisfied with respite services than with ‘usual care’ when looking at 16 controlled trials comparing several support services. However, better controlled intervention studies showed positive impacts for specific subgroups of carers only. In terms of outcomes for care recipients, the review found no clear evidence on any harmful impacts for care dependents.

The cost-effectiveness of respite evidence remained unclear against the body of studies reviewed by Mason et al (2007a, 2007b). Only five studies selected for the review delivered an economic evaluation, all of which were focused on the specific case of day care respite services (see also Shaw et al, 2009). This brought the authors to the overall conclusion: ‘The existing evidence base does not allow any firm conclusions about effectiveness or cost-effectiveness to be drawn and is unable to inform current policy and practice’ (Mason et al, 2007a, p 297).

Fields et al (2012) focused their systematic review on adult day care services and studies conducted between 2000 and 2011. Adult day care comprises a bundle of services that may include rehabilitative and educational activities, entertainment and outings, transportation and specific caregiver support services such as counselling (Mason et al, 2007a, p 292). The body of studies reviewed by Fields et al provides evidence that informal caregivers experience respite when care recipients use adult day care. However, there are still blind spots with regard to carer benefits of specific services offered under the umbrella of ‘day care’ (Fields et al, 2012, pp 18, 26). In this context the authors highlighted an intervention study by Gitlin et al (2006), who compared caregiver outcomes for adult day care services in the narrow sense of the meaning to outcomes generated by usual day care services combined with additional caregiver support services (care management, education and training and other types of support). Day care centres offering such additional services generated better outcomes for caregivers in terms of reducing depressive symptoms and enhancing their ability to cope with care recipients’ problematic behaviours. Against this backdrop, Fields et al (2012) posited that day care for older adults can be considered as a ‘platform for innovative approaches to care’, and that each of

the service elements of the day care package should be examined individually in (cost)effectiveness evaluations (Fields et al, 2012, pp 18, 25).

(Cost)-effectiveness of policies supporting informal caregivers of people with dementia

Caregivers are a heterogeneous group with regard to their own personal characteristics, regarding their relationship with the care recipient and the care needs they are confronted with. Not surprisingly, then, studies point to differential impacts of standard support measures on different groups of caregivers. In particular, the meta-analysis by Sørensen et al (2002) found intervention effects to be generally smaller for dementia caregivers. Given the expected growth in the number of frail older people with cognitive impairments and the higher risk of caregiver burden and burnout for dementia caregivers, this group of informal caregivers deserves particular attention.

A systematic review by Jones et al (2012) summarised findings from 12 intervention studies focusing on dementia caregivers. Studies were selected in this review if they provided information on costs and caregiver outcomes. Altogether, the authors found 17 caregiver outcome measures to be used in one or more of the selected studies. Cost information was displayed as cost per patient or per caregiver-care recipient dyad, with different types of cost considered in each of the studies (cost of using specific health or social services, informal care hours).

Jones et al (2012) discerned three categories of measures to support informal dementia care, namely, pharmacological, psychosocial and service delivery interventions. All four selected studies on *pharmacological interventions* examined donepezil medication for care recipients, which is expected to improve care recipients' memory and their ability to accomplish ADLs. The four studies confirm the beneficial impact of this medication for care recipients. However, they found no significant impact of this intervention on caregiver outcomes as measured in terms of their general health as captured by the General Health Questionnaire-30 (GHQ-30), stress measured using a modified version of the Caregiver Stress Scale (CSS) or quality-adjusted life years (QALYs). They concluded that additional studies should extend the range of caregiver outcomes investigated in this context (Jones et al, 2012, p 15).

The second category of studies in Jones et al's (2012) review investigated *psychosocial interventions*, such as befriender schemes (with volunteers

regularly visiting the household over an extended period of time), occupational therapy (targeted at care recipients but with an intention to unburden caregivers) or education, counselling and problem-solving therapy sessions. The evidence for this type of support was mixed and weak. Jones et al (2012) emphasised that befriender schemes might be more cost-effective when implemented in an urban setting. They recommend extending the follow-up period in intervention studies, as was the case in a Finish psychosocial intervention study.

For the purpose of their review, Jones et al (2012, p 13) defined *service delivery interventions* as changes in the management or delivery of existing services. The studies selected covered case management interventions, care coordination between two different service providers, subsidised adult day care services and in-home respite care combined with education and counselling. Unfortunately, results for these studies – even though partly positive – were of limited value because of methodological deficiencies (for example, lack of results for the control group in one of the studies).

Overall, four of the 12 studies under review provided evidence for the effectiveness and three studies for the cost-effectiveness of the interventions. Jones et al (2012) concluded that the evidence base still calls for improvement. They stressed that studies need to account for the heterogeneity of dementia caregivers, and should (1) apply additional caregiver outcome measures, (2) collect better cost data, (3) increase sample sizes and (4) extend follow-up periods.

A second systematic review of intervention studies by Parker et al (2008) centred on measures that aim at supporting dementia caregivers in their role, in particular *psycho-education or multicomponent interventions*. The review included 40 published studies from 2000 to 2005, 34 of which were randomised control trials. These studies refer to depression, health, subjective wellbeing, self-efficacy and caregiver burden as caregiver outcomes.

Twelve out of 13 studies on psycho-educational interventions in Parker et al's (2008) review reported significant beneficial effects for caregivers on several measures. The meta-analysis conforms that there is a small but significant beneficial effect of such interventions, but with regard to caregiver burden only. Two out of seven 'support-only interventions' and 10 out of 12 multicomponent interventions also showed the intended effects. However, due to the heterogeneity of the multicomponent interventions, results for this group of intervention cannot be generalised. The systematic review also

presented evidence that caregivers reap health benefits from interventions that focus on nutrition and exercise.

Parker et al (2008) concluded that psycho-education as well as multicomponent interventions clearly reduce depressive symptoms among dementia caregivers. However, there is no secure evidence concerning the effectiveness of these interventions with regard to care burden. Parker et al recommended implementing measures that address both care recipients and caregivers. Interventions for care recipients should focus on the reduction of problematic behaviours. In addition, information should be provided on an ongoing basis and psycho-education offered individually rather than in a group setting.

This latter recommendation is in line with an earlier review by Selwood et al (2007) covering 62 intervention studies. Their review looked at the effectiveness of education, dementia specific therapy, coping strategies, behavioural management techniques and supportive therapy on caregivers' psychological health. Group interventions did not show the desired impact on the corresponding caregiver outcomes. According to the authors this can be explained by the fact that in a group setting there is less room for advice on how to cope with specific problematic behaviours the individual caregiver is faced with. Furthermore, there are limited possibilities in a group setting to include the wider family in the intervention (Selwood et al, 2007, p 86). Based on their review, Selwood et al recommended six individual sessions on behavioural management to effectively reduce caregiver depression. They also highlighted that 'education alone is inefficient' with regard to improving caregivers' psychological wellbeing.

Three other contributions to be briefly mentioned also consider education/counselling targeted at dementia caregivers: First, Corbett et al's (2012) review identified 13 randomised control trials on this type of intervention. Evidence from these trials show training and counselling to be effective in improving caregivers' quality of life and neuropsychiatric symptoms. However, no significant effects could be reported for care burden. In line with the latter result, a second review of 44 intervention studies by Thompson et al (2007) showed that psycho-educational support reduces depression for the target group of dementia carers.

Third, a Swedish systematic review focused on the effectiveness of educational and supportive strategies for enabling caregivers of people with Alzheimer's disease or frail older people. Studies were included if outcome measures for both informal caregivers of people with dementia residing in the

community and outcomes for care recipients were reported for an intervention. Only 17 studies of sufficient quality were identified out of some 4,000 that were carried out between 2003 and 2011. Outcome was measured primarily in terms of reduced burden, depression and behaviour problems. Results suggest that interventions that jointly engage people with Alzheimer's and their caregivers show moderate effects on carers' burden, quality of life and care recipients' problem behaviours. However, methodological problems and weaknesses reduced the quality of the presented evidence (Socialstyrelsen, 2012a).

A meta-analysis of 30 quantitative studies by Chien et al (2011) investigated the impact of *support groups for dementia carers*. They distinguished three categories of support groups (mutual support, psycho-educational, educational), and found significant and positive effects of support groups on psychological wellbeing, depression, carer burden and social outcomes. The authors indicated that length and intensity of support sessions (dosage) matter for the size of the effect as do caregiver characteristics (age, sex). Another narrative ('historical') review by Hornillos and Crespo (2012) looked at social support groups for caregivers of patients with Alzheimer's. They posited that while research on such support groups has a long tradition, it is still inconclusive, which they attribute to the 'black box problem': too little is known about how social support groups should in theory or actually do facilitate the sharing of caregiving experiences. Hornillos and Crespo (2012, p 164) recommended setting up long-term groups, to be led by peers (other caregivers) rather than professionals. As regards future evaluation of support group interventions, the authors suggested relating to the personal objectives of the participants in such groups when designing outcome measures.

Concluding this discussion of effective measures in supporting dementia caregivers, we would like to point to a review by Napoles et al (2010), which raised the issue of whether *ethnic diversity* in the group of dementia caregivers is or should be considered in developing caregiver support policies. Their review covered 47 studies published between 1980 and 2009. Less than half (18) of these intervention studies accounted for ethnic background in discussing caregiver outcomes, and just 11 reported that support measures were culturally sensitive. One Danish study has analysed ethnicity and use of social services for older people more generally, finding that foreign-born older people's service use is more similar to Danish-born

people the longer they have lived in Denmark and the less geographically distant their native country is (Hansen, 2014).

Summary and conclusions

Over the years, the need to develop policies to support informal care has become more and more visible on LTC policy agendas. Shared public–private responsibilities for the care of older dependents have called for systematic integration of informal care with other types of support to frail older people in order to maintain both the wellbeing of care recipients and of informal caregivers. There are still notable cross-country differences in the ways in which these policy aims are being addressed.

Policies to support informal care can be guided by two different logics. The ‘carer as a co-producer logic’ emphasises the role of informal care in providing adequate support to people with LTC needs. In fact, informal care is a substantial resource to all European LTC systems, even in countries with rather extensive public services. From this perspective, a key policy concern is whether the supply of informal care will keep pace with the growing care demand for LTC. In terms of policy priorities, the ‘carer as a co-producer-logic’ calls for measures that support informal caregivers in delivering adequate care and that contribute to the stability of informal caregiving networks.

Policies to support informal care are also called for in the informal carers’ own right. Informal caregiving can be associated with significant risks and burdens that make caregivers potential co-clients. Following the ‘carer as a co-client’ logic it is essential to assess the risk profile of informal caregivers, to mitigate care-related risks, and to encourage informal caregivers to take up care relief services.

Support programmes for carers can be an integrated part of the LTC policy, or an added-on policy. Special administrations to identify and support informal carers seem to be little effective, judging from the Swedish experience (Malmberg and Sundström, 2012). To use existing administrations and routines is a simple and cost-effective way to support carers in countries that have extensive services, rather than setting up new programmes that increase fragmentation of services. Risk assessment for caregivers is (or should become) part of the normal assessment procedures and monitoring of people in need of care.

Direct support to informal carers is difficult to design because caregivers are not easy to trace and do not form a homogeneous group. Special family care consultants in Sweden have trouble *finding* carers, and are even less successful in convincing them to use services such as support groups. Research has shown that informal caregivers do not often self-define as caregivers, or do so (too) late in their caregiver ‘career’. Some studies point to a gap between the support desired by informal caregivers and what is being offered to them. It appears that support services need to be tailored to the specific needs of specific sub-groups of caregivers.

Carers can also be supported indirectly by the routine community services for dependent people. It is known that service providers often have contacts with family carers of their clients. In Sweden, carers primarily demand good, ‘ordinary’ LTC for the cared-for person. Some ask for monetary compensation, but this is rarely granted (Jegermalm and Sundström, 2013).

Over the past two decades a variety of policy approaches to LTC in general and to supporting informal care has evolved in Europe, constrained by efforts to consolidate public budgets, but also increasingly pushed by carer interest groups. Most European countries have declared home care a policy priority, and seek to prevent or delay hospitalisation or transitions into institutional care. However, in spite of progressive rhetoric regarding support to informal and family carers, the efforts to contain spending on institutional care are not being compensated for by an expansion of supportive services in the community. This development may shift an additional care burden on to already burdened informal carers, especially when the intention is to delay or substitute for institutional care (Miller et al, 2009). For the future we surmise that organised patient and caregiver organisations will have an increasing influence on policies of support for carers. Financial restrictions and the flux of policies will, we conjecture, further the dual perspective of support policies and a general diversification of services, including greater variation of support programmes in all countries. This variation invites research on the relative effectiveness and efficiency of support policies taken, preparing a solid ground for evidence-based policy-making.

The cornerstones for evidence-based policy-making are the provision of adequate data for monitoring and research purposes, and the use of state-of-the art methods in intervention research and policy evaluation. There is an urgent need for regular and representative statistics on informal carers (their numbers, sociodemographic characteristics, the care hours provided and types of support offered). Furthermore, there is room for improvement in

scientific research on the (cost-)effectiveness of measures in support of informal care. The existing body of empirical studies is still insufficient because of methodological deficiencies, limited geographical coverage and several blind spots in data collection. Many effectiveness studies use small and selective samples. Studies refer to a limited number of outcome measures in general and caregiver outcomes in particular. Full economic evaluations are in short supply, because intervention studies fail to collect data on the costs of intervention. Goodrich et al (2012) report on 30 economic evaluations of LTC policies that included informal care. They find that including the costs and benefits of informal care changes evaluation results, in fact altering the key findings of some of the identified studies. Thus, the potential for informed policy choices and policy learning can only be realised if policy-makers invest in scientific research to facilitate high-quality, comparable studies on LTC policy outcomes for care recipients and informal carers.

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Part Four

INSTITUTIONAL ACTORS

ELEVEN

The relationship between social and health services in care for older people

Laurel L. Hixon

Introduction

For many years, there have been calls for developing integrated service delivery models to improve poorly coordinated, complex and inefficiently delivered social and health care to older people, yet few providers have moved successfully in this direction. Providing integrated health and social care for older people continues to be an important item on social policy agendas at the highest levels, including of the World Health Organization (WHO), European Union (EU) and individual countries. Take, for example, efforts around integrated care coming out of the WHO European Office for Integrated Health Care Services and research activities such as PROCARE (Billings and Leichsenring, 2005) stemming from the EU's Fifth Framework Programme 'Ageing Population and Disabilities'. Considerable work has been done to articulate policy initiatives and research to support this aim.

A large part of the literature has been devoted to *describing* the models of care, and significantly less to actually *evaluating* the evidence in terms of the clinical and cost benefits of these, or to articulating how to design policies that facilitate integrated care. In this chapter, all three topics are addressed. Integrated care is reviewed with an eye towards describing some of the common aspects of existing models and what they hope to achieve, evaluating the results, and making recommendations to policy-makers about how they might help remove barriers that exist so that generally small demonstration efforts might become scalable national models.

Integrated care and its rationale

No common definition of integrated care exists. Indeed, the terms ‘integrated care’, ‘coordinated care’, ‘continuum of care’ and others are often used interchangeably. Different authors emphasise different aspects of the design of integrated care. Yet integrated care is consistently seen by many as the answer to the fragmentation and inefficiency that characterise many health and supportive care systems. ‘Like a Rorschach test’, Kodner and Spreeuwenberg write, ‘integrated care has many meanings; it is often used by different people to mean different things. It is most frequently equated with managed care in the US, shared care in the UK, transmural care in the Netherlands and other widely recognised formulations such as comprehensive care and disease management’ (2002, p 1).

Grone and Garcia-Barbero (2001, p 7) offer this nicely general definition:

Integrated care is a concept bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation and health promotion. Integration is a means to improve the services in relation to access, quality, user satisfaction and efficiency.

These different definitions often reflect differences in context, particularly the community’s configuration of providers and payers, as well as the target group to be served, the broadness of services to be included and what they hope to achieve. The more ambitious the goals, the more important it is that the care system includes all, or most of, the components of integrated care.

Rather than distinct easily differentiated models emerging, what one finds is a set of overlapping integrating activities that are tailored to specific local circumstances. Burns and Pauly (2002) describe examples of what some models of integrated care look like in practice. These include: (1) care models that are integrated around specific diseases or individually tailored to address a complex set of conditions; (2) joint venture collaborations that rely on co-location of personnel to achieve coordination of activities and require changes in teamwork processes and delivery of care; (3) IT-integrated health care that relies principally on advances such as the electronic medical record, automated drug and supply dispensing, personal digital assistants and remote patient monitoring; and (4) patient-integrated

health care where the patient is empowered and given incentives to coordinate their health information and to serve as their own gatekeeper.

Lloyd and Wait (2006) add to this list a variety of initiatives that loosely fall under the umbrella of integrated care. They include: (1) greater sharing of patient information among professionals in different sectors; (2) standardised communication protocols to facilitate and improve communication; (3) single assessment processes with a central point of information from which to coordinate care; and (4) single access points to care.

Regardless of what array of services are included in the integrated care model, two key points hold: first, the lines between different aspects of care – general and specialist medicine, mental and physical health, social care and other supportive services – are blurred; and second, rather than the supply of services driving decisions, the organising principle of service delivery should be the patient.

Why is integrated care needed?

Policy-makers, planners, researchers and providers have long promoted integrated care as a goal, especially for people with complex, long-term problems. But why?

First, chronic health conditions such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes are becoming more prevalent. When chronic disabling conditions are found in people who are vulnerable because of frailty, social isolation, mental illness or any number of other social disadvantages (income, age, minority ethnic group), the health outcomes are highly dependent on these other social factors. In other words, one can't be adequately tackled without consideration of the other.

Second, among those complicating social factors, the changing age distribution in OECD countries has largely driven the increased attention to integrated care. Simply put, the rapidly growing number of older people are more likely to suffer from one or more chronic health conditions and more likely to benefit from health and social care systems that work together rather than being at odds with each other. And older people and others with chronic health conditions are increasingly voicing their preference for being cared for in the community rather than in institutions. Taken together, both

the volume and mix of services demanded has changed in keeping with demographics and preferences.

Third, these other demand drivers exist in an era of technophilia. While most technological advances are expensive, only some are beneficial. More attention is needed to understand how to do more with less and choose wisely which technologies and technological interventions meet the proper tests of cost measured against benefit and for which populations. This requires not only knowledge about best practice, but creating the right financial incentives and locus of responsibility. Medical technology as well as information technology (IT) should be included in these calculations. IT has the ability to increase the capacity of care systems to become more personalised.

Finally, people's needs change over time. It is often at certain critical times (for example, at hospital emergency departments or at the time of discharge from hospital) when the lack of integration is most acutely seen. It is at these pressure points where responsibility is often lacking for making sure that the care experience is seamless for the user. Bottlenecks and gaps in care often arise through poor coordination, poor planning or both. These are both costly and preventable.

Processes and mechanisms needed to achieve integration of care

In order for the array of services a person needs to be more than just a fragmented collection of services, certain processes or mechanisms are needed to integrate them. For the purposes of this discussion, the four integrating mechanisms suggested by Evashwick (2005) – care management, information sharing, financing, and management and structure – are used. Of course, these mechanisms all operate in an external context (policy and community) that can vary greatly and depend on factors such as leadership, shared values and other normative measures.

Each of four integrating mechanisms that are key to the success of integrated care delivery systems are discussed below. One of the most interesting aspects of what has been written about integrated care is the amount of agreement there is about both the essential components of integrated care systems and also that there is considerable need for all of these characteristics to be in place to achieve *true* care integration.

However, there is some disagreement about the *degree* to which some components – especially organisation and financing – must be integrated. The best explanation may lie in the conjecture that programmes ‘integrate different aspects of their programmes to different degrees, depending in part on opportunities’ (Leutz, 2005, p 7). In other words: ‘all integration is local.’

Figure 11.1: Integrated health and social care service systems framework

LEADERSHIP

(Normative mechanisms)

Inter-entity
organisation and
management

Care
coordination

Integrating mechanisms

Services in the continuum of care

Acute inpatient
Extended care
Sub- or post-acute inpatient
Ambulatory
Community care
Wellness and health promotion
Outreach and linkage
Congregate housing

Integrated
information
systems

Integrated
financing

Integrating mechanisms

↑
↑
↑

EXTERNAL CONTEXT

Source: Hixon (2015); adapted from Evashwick (2005) and Rosen et al (2011)

These opportunities for integration at the local level are hampered by the external context which, as Leichsenring (2012, p 2) suggests in Europe and, undoubtedly, exists more broadly, reflects ‘increasing marketization, lack of managerial knowledge (co-operation, co-ordination), shortage of care workers and a general trend towards down-sizing of social care services.’

Inter-entity management and structure

The first integrating mechanism is inter-entity management and structure. It has been suggested that ‘appropriate structure is a prerequisite for the other three integrating mechanisms to occur’ (Rundall and Ewashwick, 2005, p 187). These organisational arrangements for providers, however, may include a range of structures, from the most formal structure of ownership where they operate as a single organisation to strong, informal relationships between a group of organisations, with contractual affiliations between a series of networked organisations falling somewhere in between the two. These distinctions are sometimes referred to as ‘real’ (ownership) versus ‘virtual’ (networks and informal relationships) integration. There is disagreement about the degree of organisational integration that is needed to achieve clinical integration. Leutz (1999) suggests that the degree of organisational integration (linkage, coordination or full integration) should depend on a population’s characteristics including stability, severity, duration, complexity of condition(s) as well as capacity for self-direction. Certainly, at the very least, inter-professional working is facilitated by co-location, informal communication networks and knowing other professionals personally (Coxon et al, 2005).

In the past, integrated management and structure changes often came about when hospitals in some countries responded to reduced payments by expanding into residential nursing facilities, hospices, home care agencies and urgent care centres (Matsuda and Yamamoto, 2001; Ewashwick and Aaronson, 2006). Other integrated structures grew out of physician groups that purchased or affiliated with other institutional providers. In some instances, these expansions did not last because, either there was a failure to successfully integrate the financing of the structure, or the information systems failed (Ewashwick and Aaronson, 2006). Providers also became aware that expanding too far geographically could undermine their success. Hospitals often returned to their ‘core business’ of acute care.

A particularly striking example of hospitals responding to changes in payment policy occurred in the US. Hospitals expanded into a variety of sub-acute service areas when there was a financial incentive to find less intensive and expensive places to care for patients during their hospital stay. However, once the federal government instituted distinct payment mechanisms for these sub-acute services, there was a reversal of this trend.

Theoretically, there are a number of advantages that are associated with integrated service structures from both administrative and care delivery perspectives. The principal general benefits to organisations of integrated management are: increased efficiency, economies of scale, wider distribution of risk, greater bargaining power, expanded market via automatic referrals and product appeal to customers, improved customer satisfaction and enhanced quality and outcomes. There are a number of management techniques that providers can utilise to increase the likelihood of coordination across the continuum of services provided. These management techniques also produce efficiency advantages from shared central employment/human resource functions, joint education and training, shared care protocols and so forth.

Centralised purchasing can help reduce costs (economies of scale) across the system but can also ensure that IT is compatible across the system. Similarly, aligning human resource functions also serves several purposes: to standardise job functions, pay scales and benefits so that all staff will come to expect similar treatment across services, but also to ensure that there is commitment to integration by staff through appropriately written job descriptions and performance evaluations that build measures of integrated work into their metrics. Other mechanisms include creating a shared vision so that the parts of an integrated system have a common sense of purpose when working through day-to-day challenges, board education about organisational relationships and creating a management team that represents the different parts of the continuum, or different functions across these parts.

When services are linked together through common ownership, the normative integrative processes discussed by Rosen et al (2011), such as shared culture, consistent communication, skilled leadership and high trust relationships, are easier to develop. This is not to say that they are easy. In particular, leadership can be very difficult to find and retain when the system integrates across multiple service areas that historically have very different cultures – take the case of hospitals and nursing homes. Often, case studies of integrated care identify one or two people who are leaders with the vision and

communication skills fundamental to the success of the integration effort. When the integration is across acute and long-term care (LTC), it is particularly important that the organisation gets ‘right’ certain key positions. So, for example, the choice of physician leadership can be critical, since working with a multidisciplinary team when managing chronically ill patients is not always an environment physicians are comfortable in.

Integrated care management processes

Several terms often are used interchangeably with integrated systems of care: care coordination, care or case management, care or patient navigator and disease management. There is a lack of consensus regarding their definitions and use in actual practice (Schmitt, 2001; Wagner et al, 2001; Reid et al, 2002; Weingarten et al, 2002; Whellan et al, 2002; Huber et al, 2003). However, each of these integrated care models seeks to reduce fragmentation and to improve health care delivery through better coordination (Chen et al, 2000; Norris et al, 2002; Brown et al, 2004).

Attempting to answer questions about whether these different mechanisms improve quality and save money reflects the fact that the boundaries between these terms is blurry, and each of the models they represent has substantial overlap. Generally speaking, one can think of the term *care coordination* to represent the process of working with a population on specific disease processes and *case management* to represent the process of working with a specific person helping them with all needs (even as broadly as with insurance, transportation, housing), not just with a disease process.

Putting aside semantics, when studying these processes and the people who provide them, it is important to understand the context in which they operate. So, for example, it is essential that one knows if the person undertaking the management and coordination is an integral part of the treatment team, or has outsider status. Do they manage or coordinate only the disease processes, or are they also responsible for eligibility to services and resource allocation?

Clearly, both a structure and process for coordinating care are needed when organisational structures and payment systems are fragmented. Mechanisms for coordinating clinical care are widely recognised as essential, and have certainly progressed both in terms of sophistication and availability.

Take first the broader term of case management. Case management can be thought of as an integrative and collaborative process of coordinating

individual care. Case management as a separate and billable activity of dedicated personnel emerged in the 1970s, particularly in the context of the US National Long-term Care Channeling Demonstration (Weissert, 1988). Case management programmes are now widespread, yet the features and functions of case management, as well as cost, vary considerably from programme to programme. These features and functions include: periodic assessment of client needs; planning diagnostic, treatment and support services; provider referral and, if needed, assisting clients in making appointments; follow-up to ensure services are provided as planned; and regular communication between clients and providers to keep information on client status and their service plan up to date. They can vary by populations and settings, purpose, funding, duration and caseload size (White, 2005). Again, an important consideration is whether, in addition to care coordination, case managers are also given the responsibility of allocating an organisation's limited resources among a population, that is, when they are called on to act as gatekeepers. When case management involves both coordination of services and the administrative function of purchasing or allocating services, tensions can arise (Kane et al, 1991).

Who is responsible for clinical care coordination as well as the broader array of responsibilities also varies quite significantly by programme and can be controversial, as many people can carry out this responsibility. Again, who holds the position of case manager is determined, in part, by whether the role is primarily that of a gatekeeper, an advocate, or counsellor/mediator. Generally, the position is held by someone with a social work or nursing background. However, the job might also be done by a multidisciplinary team. For example, at the core of several exemplary models – for example, On Lok/PACE (Program of All-inclusive Care for the Elderly) in the US, and Northwest London Collaboration of Clinical Commissioning Groups – is the multidisciplinary team and considerable staff time (both professional and paraprofessional) is devoted to formal and informal exchange of ideas and information¹ about patient care.

Care coordination or disease management, where the focus is on the coordination and management of specific chronic medical conditions (for example, hypertension, diabetes, asthma), which lend themselves to a standardised approach, emerged from the more general case management idea, and tends to emphasise the role of the client in self-management, as well as the formal care system. More typically, care coordinators are qualified

nurses and may or may not be part of the treatment team. Many examples of these types of programmes exist.

The Te Whiringa Ora programme in New Zealand started as a collaboration of three physician practices focusing on chronic respiratory disease, and has expanded to include other chronic disease patient groups with high health care utilisation. Assessment, care coordination and telephone support are all features of the model, as well as telemedicine monitoring for self-management. Similarly, Regionale HuisartsenZorg Heuvelland in Maastricht began as a local organisation to redesign diabetes care management with multidisciplinary teams. The introduction of a national integrated payment policy ('disease treatment combinations') to improve care for people with chronic conditions triggered rapid expansion of the programme (Rosen et al, 2011).

In many instances, case management is not available to all clients of community aged care but, instead, it is built into the community care programmes that aim to delay, or reduce, nursing home placement, or when cases are particularly complex. The Community Aged Care and Extended Aged Care at Home programmes in Australia that are designed to delay or replace nursing home care (respectively) feature significant case management functions (Hixon, 2015). Government agencies sometimes specify for which client populations targeted case management is available and what services comprise targeted care management. Recent evidence of the effects of case management attached to community aged care was strongest for delaying, or reducing, nursing home placement and shortening nursing home length of stay, although there was no evidence of reduced costs or reduced use of medical services (You et al, 2012). This is consistent with other systematic reviews of case management (Grabowski, 2006; Pimouguet et al, 2010; Somme et al, 2012). It is worth noting that You et al (2012) excluded case management that is part of an integrated care model, because it is difficult to attribute the intervention effects to case management alone (Zwarenstein et al, 2009).

The main empirical findings on clinical care coordination are summed up in Ovretveit's (2011) comprehensive review.

1. Clinical coordination can improve quality and save money but it depends on which approach is used, how well it is implemented, and other features of the environment (for example, the financing system, regulatory schemes) in which the provider is operating.

2. Better clinical coordination improves quality and saves resources, but only some approaches save more money than they cost to operate and sustain.
3. Whether money is saved (or increased income generated) from reduced waste and improved quality depends on how the provider is paid.
4. The most cost-effective approaches to clinical coordination use reliable data to identify the type and conditions of patients/clients most at risk of deterioration and then make sure that those people get the right type of coordinated care and self-care services. Strategies that focus on ‘high cost and chronically ill patients’ who take up a disproportionate share of medical expenditures are ‘the most appropriate candidates’ (Burns and Pauly, 2002, p 136).
5. Models that focus on preventing hospital admissions and managing certain chronic conditions (especially congestive heart failure and depression; Mattke et al, 2007) are most likely to save money and raise quality.
6. Certain types of patients (poor, vulnerable, minority ethnic groups) tend to be underserved in terms of coordination of care.
7. Changes are needed in payment systems, regulation, professional education and codes of practice to counteract the increasing fragmentation and pressure to neglect coordination.
8. So that all players share in the financial costs and savings, arrangements (such as cost and saving sharing agent organisations) need to be put in place where one provider gains from another provider’s spending on coordination improvement efforts.
9. Cost savings depend on the type of coordination, how effectively it has been implemented and the timescale over which costs and savings are estimated.

In another comprehensive review, Davies and colleagues (2008) summarised the effectiveness of 85 studies of care coordination. The main features of these interventions ranged from coordination of clinical activities to supporting service users in accessing care. The impact of these on health outcomes, user satisfaction and cost savings was assessed. Positive patient health outcomes were seen in over 55 per cent of studies, 45 per cent had improvements in user satisfaction, but less than 18 per cent produced cost savings. In sum, both clients and providers benefit from care management when it is targeted towards clients with needs that are multiple and complex, as it facilitates the client seeing the right provider for the right problem at the right time.

Information-sharing processes

The ability of clinicians and managers to use individual and aggregate data to facilitate better outcomes delivered more efficiently is the overarching goal of an integrated information system. Ideally, the system should include a single client record that combines (1) financial, (2) clinical, and (3) utilisation information. It can be used by multiple providers and public and private payers and shared across multiple sites. An integrated information system might also be an information system that simply permits access and use of data from multiple distinct sources. Enormous public and private effort has gone into creating systems and processes for sharing information to help support both external accounting reporting and internal care-related decision-making (Shugarman and Zawadski, 2005), yet the ideal described above is still far from a reality.

In an excellent issue of *Health Affairs* (2005) dedicated to health information technology (HIT), many of the relevant general issues on this topic are discussed. At least two major themes central to the discussion of integration are found in the literature on HIT. First, it is important to consider all the pieces of the integrated care puzzle together, that is, information systems, care processes and financial systems are all interconnected. So, while information sharing is central to getting better outcomes more efficiently, one doesn't guarantee the other – information must be accompanied by redesigned care processes. Similarly, economic arrangements need to be set up so that the costs and savings associated with integrated information systems are fairly accounted for between stakeholders. The idea that information sharing is a necessary, but not sufficient, component, of integration is common to all the integrating mechanisms. Second, in working towards an information system that is both standardised and interoperable (two universally desirable characteristics), there is a ‘delicate dance’ between the important role of government as the primary payer for health care and the innovativeness of market-based solutions (Iglehart, 2005, p 1100).

In a sophisticated modelling exercise, Hillestad and colleagues (2005) attempt to quantify the benefits of HIT in terms of improvements in efficiency, safety, prevention and management of chronic diseases. Basing their estimates of productivity gains on evidence from other industries, they suggest that widespread adoption of electronic medical record systems (generally the first component of an integrated information system) would

yield large savings and HIT-enabled prevention, and management of chronic diseases would yield even more. They admit, however, that these savings are ‘unlikely to be realized without related changes to the health care system’ (Hillestad et al, 2005, p 1103). The authors list a number of barriers including acquisition and implementation costs, as well as uncertain or slow financial payoffs, and argue for a significant government role in overcoming those barriers.

There are several reasons for disputing the claim that savings made from HIT will be anywhere near what proponents hope. They include challenging whether efficiency gains derived from other industries (and indeed, some efficiency losses) are applicable to health care, agreement on some very complex operational issues such as standardisation and interoperability, insufficient evidence that disease management programmes can generally reduce the overall cost of health care services, and a host of other unproven assumptions (Goodman, 2005; Himmelstein and Woolhandler, 2005; Walker, 2005). Although assumed that sooner or later HIT will pay for itself through savings from increased efficiency, better outcomes and reduction of waste and duplication, the difficulty is that this benefit will tend to accrue to a different group of stakeholders (payers and patients) than those who make the upfront investment (providers).

Again, the need to consider the various integrating mechanisms together rather than separately is evident. HIT needs the support of appropriately designed reimbursement and payment systems. Specifically, there are two issues at play here. First, the ways health and aged care are paid for in many countries are not set up to reward quality outcomes but instead to reward outcome volume, or cost-shifting. Consequently, one priority is to align economic incentives so that they support the goals of integrated information systems. Second, the issue of who pays the upfront costs and to whom the benefits accrue must be addressed. For example, should governments directly pay for clinical IT, or use reimbursement policy to reward quality outcomes and let providers determine how to achieve those outcomes? Who should assume the risk of strategies that do not achieve their goals?

Interestingly, in the same way that case or care management is not uniformly beneficial to all clients, Dey and colleagues (2013) suggest that committing resources to more sophisticated electronic medical records capability may not be uniformly beneficial to *all* providers. In both instances, appropriate targeting is needed to produce benefits that outweigh costs.

Finally, other than the financing role that governments play, there is much discussion about other ways that government could or should promote HIT adoption. Explicit instructions about what IT capabilities it expects is one way (Rosenfeld et al, 2005), and articulating key functionalities and requirements is another. Generally, there is agreement that government intervention is appropriate when the private market fails to achieve the desired goals for IT services and products. The lack of agreement on data specifications and strategies for interoperability could be considered market failure.

In many countries, integrated information systems are a long way from a reality, although the usage rates for HIT in physicians' offices is quite high: Henderson and colleagues (2006) reported 89 per cent usage in 2003–05 in Australia. Electronic prescribing and ordering tests were the most common uses of this technology. Only about one-fifth of physicians used all the clinical functions available.

It is noteworthy that examples of providers and provider/payers who have developed model integrated information systems have several features that make investment of time and resources in robust clinical HIT systems worth their while: they own their own hospitals, employ their own physicians and their membership is stable (Kleinke, 2005). Two examples of robust health information systems from both the private and public sector are the US Veterans Health Administration and Kaiser Permanente Health Plan in California. In both examples, they meet Kleinke's criteria for investment in technology being worthwhile. Single-payer systems are more likely than others to have those critical features in place.

Integrated financing

It is clear from the literature that: (1) when there are two or more different programmes paying for overlapping services, cost shifting is expected to occur; and (2) if the right financial incentives are in place, the most appropriate services in the least restrictive settings are likely to be provided. What is less clear and subject to much debate is how much and at what level financial integration is needed to address cost shifting (Leutz et al, 1994; Wiener and Skaggs, 1995; Leutz, 1999), and whether shifting financial risk to providers through some sort of fixed payment per person (rather than per service), such as capitation, is the best way to get the most appropriate, least expensive services delivered.

How much financial integration is needed seems to depend on the community where the programmes exist and what opportunities are available. It has been suggested that divided financing (and accompanying regulations) is the single most significant factor driving service fragmentation and inhibiting integration. The pervasiveness of fragmented systems (or ‘non-systems’) of financing services for people with complex or long-term chronic care needs is, no doubt, a major impediment to developing a true continuum of care. There are examples where governments have consolidated financing of their aged care programmes. For instance, in Australia, the federal government has recently taken over the largest community care programme previously operated as a state/federal partnership. This moved the aged care system closer to having integrated financing at the payer level that could, theoretically, be joined with the federally funded Medicare acute care programme (The Myer Foundation, 2003).

To the extent that integrated financing systems are meant to address the issue of cost shifting, it seems sensible that pooling the various sources of funding is a way to reduce this. This pooling can happen at one or more of several levels: payer, provider or consumer. The ability to bring these sources together is complicated by the fact that, especially with regards to long-term and supportive services, in many countries there are often a large number of payers involved. They can be from the national, state and local levels, and from both public and private sectors.

Largely, integrated financing has been considered in the context of bringing together acute and LTC financing. The pooling of funds across these two service sectors is more difficult because that many view the acute care system as inherently medical and the LTC system as inherently social. Over time, these distinctions have lessened as now traditional LTC providers are delivering a very high level of services for very sick people. There is now considerable overlap in the sorts of services each of these systems provide, and considerable overlap in their goals.

Importantly, it is often the case that medical systems are funded differently than LTC systems, creating further barriers to integration. Each system comes with its own regulatory and reporting requirements. The success of pooled funding relies, in part, on waiving some of the coverage rules and removing the requirements that specific evidence be provided on how money is spent and on whom.

Consequently, at the provider level, integration means more than just bringing the various funding sources together. First, because there are often

separate or even contradictory regulatory and reporting requirements that create major obstacles for providers, payers must also be willing to allow flexibility in the way money is used regarding the customary coverage rules, and shift their thinking away from specifying units of care that must be delivered to instead tying reimbursement to desired outcomes.

Second, there needs to be a rethinking of programme-specific philosophical differences reflected in client contribution arrangements. It is common for public acute care systems to be free at the point of delivery for many services (especially primary care and prescription drugs), whereas there are often high cost sharing or strict financial eligibility criteria associated with social care programmes.

Stone and Katz suggest that ‘one of the questions facing payers and providers interested in developing an integrated approach is whether capitation is a necessary prerequisite for the development of a comprehensive delivery system’ (1996, p 222). There is much enthusiasm in the literature for capitated payments as a strategy for creating the right financial incentives for providers. Wiener and Stevenson (1998) include among four specific goals for integrated care shifting risk to providers through capitation. Similarly, Stone and Katz (1996) suggest cost-containment features of integrated systems include prepayment, full or partial capitation. A number of factors might affect a provider’s ability to assume financial risk, including the total negotiated capitation rate, the ability to negotiate favourable contracts for services the organisation does not offer directly, information management capability and the dedication of other resources from a sponsoring organisation (Kane et al, 1992).

Probably the most important issue in assumption of financial risk is how the budget is set for both acute and LTC services. There are many technical issues that need to be resolved in risk assessment and stratification. For example, is there a global budgetary cap (where provider risk includes enrolment), or a per capita budgetary cap? If the goal is to change inefficient provider behaviour, are there some savings built into the budget? On the LTC side, who is the appropriate comparison group – people in the community, or people in nursing homes? If the target population is meant to be frail older people, or people with multiple chronic conditions, how does the capitation rate adjust for these characteristics and others?

As suggested above, the other integrating factors, particularly information sharing and organisational integration, play a role in a provider’s ability to assume financial risk. It is likely that a provider organisation will need to

access at least some external services to be able to offer the entire continuum of care. In these circumstances, how sophisticated management is at negotiating rates and contracts, or even getting other providers to assume some risk, will bear heavily in the organisation's success in assuming risk. Additionally, a well-developed information system will be useful in tracking and benchmarking costs. Given all these issues, critics point to alternative approaches to capitation or full provider assumption of risk. For example, some integration models entail payers providing financial incentives (such as retrospective financial micro-incentives) for adhering to evidence-based guidelines and for rewarding specific clinical interventions (Rosen et al, 2011). Other models rely on different payer sources coming together in various combinations of capitation and fee-for-service, depending on the scope of their programme (Booth et al, 1997).

Recommendations for future policies

Given that greater integration of health and social care is a reform objective with several important components, the key question here is how to design policies that are both coherent and work with the strengths and priorities of the existing local systems. Some of the key considerations are outlined below.

All health care is political; all integration is local

It is often said that all health care is political, but some aspects of health care should not be. Not only do health and social care represent a large fraction of overall spending in all developed countries, but these activities also have an impact on every person in different ways – either as consumers, providers, taxpayers or some combination of all three. Moreover, there is often considerable vested (and invested) interest in maintaining the status quo. Taken together, these characteristics make any health or social care reform a highly politicised debate. The greatest obstacle to progress in integrated care, or any reform for that matter, can be politicians representing narrow special interests.

It could be argued that the most appropriate concerns of government policies are equitable access to care, the quality of that care, and its cost, and that government should use its commissioning and regulatory authorities to shape these. This then leaves the details of how care is delivered left to the local community of providers. Policy-makers ought to respect the idea that all

integration is local, and there will be differences in the content and degree of integration efforts depending on local opportunities.

This ‘let a hundred flowers bloom’ approach to delivery also reflects the fact that there does not appear to be one best way of delivering integrated care. The government should avoid prescribing what is to be done; rather, it should encourage a range of different approaches that meet local needs. There is value in allowing active experimentation with a range of new ways of integrating care and then of leveraging experience and learning from demonstrations. For example, in the UK, the Department of Health and national partners saw an ongoing need for robust, high-quality evidence to inform decisions about how to develop integrated care to suit different contexts, settings and circumstances. In 2013, the Integration Pioneers programme was launched to support a variety of different strategies to break down barriers to integrated care and support and to deliver better joined-up care. The programme allows selected organisations to take leadership roles in testing and then promoting various models of integration. Also built into the programme is a process for communicating lessons to the broader provider domain (DH, 2013).

Learning from the process, seeing what works is, indeed, critical to the next step of making demonstrations scalable. There are at least two things that governments should try to extract from experiences with different approaches. First, proper economic evaluations need to be conducted on integrated care models and demonstrations. As earlier sections of this chapter suggest, the evidence on integrated care and its component pieces is often ambivalent and sometimes discouraging. Results from well-designed economic evaluations and other research evidence should be shared more systematically.

Second, even with different national contexts, there are a number of dilemmas that are commonly shared – for example, which risk stratification techniques work best at identifying populations that would benefit most from integration or what training (and re-training) efforts of professionals across health care and social care disciplines are best at encouraging interdisciplinary coordination and mutual respect. Identifying best practices in these and other universally-relevant areas would be highly productive.

Balancing government policies with market strengths

It is worthwhile carving out the appropriate role of policy-makers within the framework of the four mechanisms helpful to integrating care – namely, organisation and structure, care management, integrated information systems and integrated financing. Although used in the context of IT, Iglehart's phrase 'the delicate dance of government and the market' (2005), captures quite elegantly the importance of getting this right in the broader integrated care discussion. It seems that the appropriate role of government could be different for each of these mechanisms. So, while aged care providers consider any range of relationships, from shared ownership to coordination or linkage, with others in the continuum of care without the involvement of government, a more active role for government might be appropriate in other areas. These include designing information systems, supporting care management processes and developing a system of finance that creates the appropriate incentives to promote changes to the balance and mix of services and behaviour change that is needed for successful integration of care. To a degree, differences in this delicate dance will depend on the local mix of providers and what proportion come from each of the public, private and voluntary sectors. Certainly, where public providers are prominent, they should lead by way of example.

Organisation and structure

There is reason to argue that in two areas – organisation and structure and, to a lesser extent, care management – the best strategy is to let local conditions and opportunities guide development. For organisation and structure in particular, the diversification of primary, secondary and long-term care providers across public, private and voluntary sectors makes integration at the level of shared ownership an enormous challenge. While it is certainly easier to control utilisation and costs when most or all services are provided within an integrated organisational structure, it seems unwise for policy-makers to be too heavy-handed in specifying how much organisational integration is needed to achieve articulated outcomes. With clear lines of accountability, united vision and leadership, and clearly defined expectations, organisations bound by contractual relationships should be able to achieve comparable results to those with shared ownership.

The challenges are magnified when integrating across acute and long-term care two very different systems with different orientations. Traditionally, the focus of acute care tended to be on 'cure', delivered by highly skilled

workers with a medical focus, and on costly technology. On the other hand, the focus of LTC tends towards ‘care’ delivered in a ‘low tech, high touch’ way by low-paid workers in a system that is often viewed as chronically underfunded. Moreover, as a rule, health and LTC services are not paid for by the same sources or organised at the same level of government. The disjuncture on so many aspects of these two systems worries traditional LTC advocates who think the acute system will dominate and LTC will either become overly medicalised, or the funding levels will worsen even more. This nervousness is also evidenced within health care. Iacobucci (2014) recently suggested that, in primary care, the term ‘integration’ is often viewed suspiciously as a euphemism for hostile takeover by large, powerful hospitals (that is, secondary care).

The diversity of local communities should be sufficient to create opportunities for many different configurations under which providers can work together, ranging from shared ownership to contractual relationships. There is no need for prescriptive government intervention with regards to organisation and structure for the likely result is that government will throw a party and nobody will come.

Care management

Enormous efforts have already been made in the areas of case management, care management and care coordination as described earlier and so, likewise, the role of policy-makers should be fairly narrow. Although some of these efforts do arise from government initiatives, many are a product of market innovation. Some excellent examples are found in the single assessment processes in the UK, multidisciplinary assessments in Italy, standardised communication protocols and formats (for example, MedCom in Denmark and Wiesbaden Geriatric Rehabilitation Networks in Germany), single access points to care (One-Window in the Netherlands, PRISMA [Preferred Reporting Items for Systematic Reviews and Meta-Analyses] in Canada and CARTS in the UK) and defined pathways of care (Hospital at Home in the UK).

There are clear lessons to be learned about the deleterious effects of rigid requirements in this broad area. Take, for example, the case of Australia’s Team Care Arrangement (TCA). In 2005, the Australian federal government introduced a series of additional financial payments for health care professionals if they created TCAs for chronically ill people who required

ongoing care from at least three health care providers. Under this scheme, health professionals were paid for performing activities related to an individual's care plan. While a comprehensive evaluation of this initiative has not been conducted, critics point out that the rigid requirements placed on health care professionals, as well as the emphasis on the process of planning rather than implementing real behaviour change, diminished the impact that this TCA stream of money has had (Young, 2013).

Within this broad area is the topic of interdisciplinary care planning and, in particular, the role of general practitioners (GPs). Although there is literature advocating for a GP to be at the centre of the team-based approach, this can be a challenge because generally GPs are not well trained in collaborating with other disciplines, nor are they trained to manage older people with complex needs that extend beyond medical care to social needs. While their specific role on the team is, of course, an issue best left to the organisation, there are at least two ways policy-makers can help remove barriers to the successful engagement of physicians. The first is through curriculum development and medical education that focuses on leadership and working across disciplines. The second is through funding mechanisms. Policy-makers can specifically make provisions for payments to cover the time of physicians in team-planning processes or create other appropriate incentives for such efforts.

Integrated information systems

Enormous public and private effort has gone into creating systems and processes for sharing information to help support both external accounting reporting and internal care-related decision-making. IT standardisation would be enormously simplifying and helpful. It is harder to standardization for internal care-related decision-making than with external reporting concerning clinical care and financial measures.

It is important not to lose the creativity associated with the considerable entrepreneurial investments that have been made. Yet preservation of what the market has produced should be balanced with a certain level of government involvement around issuing explicit instructions about what IT capabilities it expects for external reporting and articulating key functionalities and requirements. Also important is the fact that integrated information systems are expensive. So there needs to be an articulation of who will be responsible for paying for the substantial commitment of time

and resources needed to develop a good integrated information system, and this should be aligned with who will benefit from development of these systems.

Ideally, an integrated information system will include a single client record that combines (1) financial, (2) clinical, and (3) utilisation information. It can be used by multiple providers, public and private payers, and shared across multiple sites. Thinking about the three types of information involved, the answer to the question ‘What is the right public/private balance for integrated information?’ is ‘It depends’. Again, the interrelatedness of each of the integrating mechanisms is an important consideration in discussing this balance.

Take, for example, how the information requirements of government and providers might be different in the context of a capitated risk-based payment strategy that seeks to decrease demand and improve efficiency in contrast to an activity-based strategy where more work means more income. In the former, government is most concerned about serving an appropriately targeted population and the outcomes of care for that population. Consequently, measuring health and functional status and changes to such are of greatest importance. As long as the time horizon over which the provider is financially responsible for the outcomes of the individual is long enough,² the information needed for reimbursement and oversight should be mostly limited to measuring those outcomes of care in some systematic way. Ostensibly, commissioning and regulatory bodies will not require information about service utilisation and unit cost. At the very least, then, uniform, standardised assessments and how they are shared should be defined by public policy.

Generally, if a fee-for-service approach is used, the information requirements associated with payment and oversight are more substantial. There is a need for specific definitions about how utilisation and costs are measured and reported. Most certainly, to achieve efficiencies, there must be more flexibility in reporting requirements with integrated care systems, and it is harder to see how a system of flexible pooled funding is achieved with a fee-for-service payment system. On the other hand, in a fee-for-service environment, payment strategies such as reimbursement for ‘virtual’ visits can be used to influence the creation of HIT.

To the extent that the integrated financing system is pooling funds from a variety of sources, its success relies, in part, on removing the requirements that specific evidence be provided on how money is spent and on whom.

What information management capabilities are needed is certainly also influenced by what configuration of providers is used to offer the continuum of services needed, and whether they are offered under shared management or contractually arranged. When a lead provider must contract with other providers for services outside its own continuum, the ability to negotiate prices and track utilisation will have an impact on its ability to assume financial risk. The information system specifications are best set by the providers (private or public) themselves.

Finally, information systems and care management are inextricably linked. For that part of an integrated information system that is associated with the internal decision-making regarding care, providers should take the lead in defining their information needs, particularly in a risk-based financing environment. The only situation where government prescription might be appropriate is when they are commissioning for care management as a separate billable service.

Integrated financing

In the area of integrated financing, it is easiest to argue for a strong government role. Ultimately, what an integrated financing mechanism hopes to achieve is flexible pooled funding. Regardless of whether the pooling occurs at the patient, provider or payer level, policy-makers must determine what services should be covered, what eligibility criteria are used for benefits (entitlement or means tested), the expected responsibility of family and the individual, how to negotiate roles and responsibilities between various levels of government (local, state, federal), and which financing mechanisms and incentives should be used to encourage a rational, efficient and effective integrated approach.

It is important to emphasise both the pooling function as well as flexibility in how funding may be used. Reiterating the integrated information systems discussion above, funders must be willing to remove the requirement to report how money is spent and on whom.

Australia recently made important progress towards creating flexible pooled funding in LTC. They have consolidated responsibility under the federal government for all aged care services from supportive through to skilled residential care. These new financial arrangements have the ability to remove the previous barriers between streams of money and to offer more flexible arrangements with providers so savings can be used to pay for

additional services, care coordination and other kinds of integration infrastructure. The Australian federal government has indicated that it wants to offer more ‘packaged care’ using monthly payments for a flexible set of services aimed at achieving certain outcomes (delaying or substituting for residential placement) rather than paying for individual services. While they have stopped short of offering a guarantee to care, this moves them closer to being able to integrate LTC with their Medicare health care entitlement programme.

Managing expectations

Generally, the theoretical arguments for integrated care have been clearly articulated in many different international contexts, as have the concepts underlying the practice of integrated care. However, since there is still no common definition of what integrated care means and how it is to be achieved, the evidence base on how well the goals of integrated care are met by these systems is mixed. Over and over again, one reads that any of the integrating mechanisms (organisational structure, care management, information systems, financing) by themselves are not enough to produce significant changes in the way care is delivered and certainly not enough to result in cost savings. Consequently, it is important to manage expectations when reform involves anything less than all the component pieces.

One of the integrated models that has incorporated all the integrated mechanisms, that is, interdisciplinary team care planning, integrated information systems, capitated risk-based payment and, to a lesser extent, shared ownership of the continuum of services, is PACE in the US. It is one of the most extensively documented integrated health and social care programmes that exists today. With considerable enthusiasm from its architects and many others, PACE has grown from a single demonstration programme located in San Francisco in 1973 to permanent provider status, with 104 programmes operational in 31 states. However, within the well-articulated principles of the model, there has always been considerable variability, making it difficult to draw uniform conclusions.

Generally speaking, PACE has been successful at improving functioning among its enrollees, reducing institutional use, and staff are more satisfied working in a PACE environment. On the other hand, there has been little evidence of cost savings. The ability to generate savings is almost entirely driven by the capitation rate each site has been able to negotiate,³ and the

ability to negotiate favourable prices for services outside its own continuum, especially hospital services.

As Leutz (1999, pp 89-91) describes in his seminal writing on the five laws of integration, ‘integration costs before it pays.’ Specially allocated funds, both public and private, are often associated with integration pilots. Some examples are the Better, Sooner, More Convenient Health Care in the Community national initiative in New Zealand, the Better Care Fund in the UK, and the Pioneer Accountable Care Organization demonstration in the US and the Robert Wood Johnson Foundation support for the PACE replications. Sustainability after these special funds are depleted is an ongoing concern.⁴

A lot of integration infrastructure – be it clinical and financial information systems, care planning processes, leadership training or contract negotiation – is expensive to purchase and develop or difficult to implement without additional resources. Hoping that early savings, especially through reduced hospitalisations, can be used to pay for integration infrastructure is naïve and overly optimistic. A recent report (Goodwin et al, 2014) on the cost-effectiveness of seven international case studies of integrated care showed that only one produced significant cost savings while the others either produced better outcomes at no additional cost or had no evaluation of cost-effectiveness at all.

Final thoughts

This is an important time for policy-makers to look beyond the immediate short-term pressures of weakened economies, and to develop a shared vision of what future locally planned services should look like. Their ambition should be to adopt an evidence-based approach to what kinds of national investments are needed to take integrated care from a series of small demonstrations to scalable national models. To do this, policy-makers should think not just about how to spend small purses of specially allocated funds, but about how entire health and social care budgets should be spent. Integrated age care will play an increasingly important part in the future delivery of health and social care. The challenge now is to act on the evidence and to do so at scale.

Notes

¹ Information sharing is so vitally important to the success of care management and the entire system, that it is discussed separately.

- ² If a client is allowed to freely move between providers in risk-based arrangements, the financial incentives to underserve will undermine the effectiveness of the system.
- ³ In the early 1990s, monthly capitation rates for the original demonstrations ranged from US\$2,147 to US\$5,973 (£1,281 to £3,564).
- ⁴ The original eight PACE replication sites received between US\$700,000 and US\$1,734,000 (£418,000 to \$1,034,000) from private foundations to develop their adult day health centres and staff, and to expand services.

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TWELVE

Multilevel governance and its effects on long-term care support

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Introduction

Since the 1980s, in many Western countries new universal oriented long-term care (LTC) policies have been established. Up to then, prevalent, often residual, LTC policies were generally administered at local or regional levels. The introduction of more universal LTC policies resulted in a greater involvement of central levels of government, which was followed by the establishment of complex territorial interrelationships of LTC policies (see, for example, Vabo, 2010a). As a consequence, the (changing) interplay of local, regional and central political levels became crucial for policy development, implementation and its effects (Strohmeier Navarro Smith, 2010; Vabo, 2010a; Burau and Vabo, 2011; Ranci and Pavolini, 2013).

States can be seen as latecomers in an arena where a wide range of social actors, such as the family or civil society, had been traditionally involved in the administration, provision and financing of LTC support (Burau et al, 2007; Vabo, 2010a, 2010b). Burau and colleagues (2007) state that the issue of LTC does not easily fit into the public nature of policies, because home care stretches across sectors: private (family) and public (the state, markets and civil society). In addition to territorial restructuring, the reorganisation of the mode of interplay between different sectors was selected as one strategy to adapt public LTC support faced with increasing needs for services and decreasing informal, family resources. For example, policy schemes – such as cash allowances – were introduced to maintain informal, family care. In addition, a trend to marketise care provision can be found, characterised by the introduction of market principles and closer forms of cooperation between the state and private not-for-profit and for-

profit providers (Burau et al, 2007; Ungerson and Yeandle, 2007; Strohmeier Navarra Smith, 2010; Theobald, 2012).

The involvement of wider social actors and the newly-defined forms of cooperation between them and the state have an impact on the logic of a policy field previously dominated by the logic of the family and civil society. Research findings have revealed an increasing influence of the logic of the market, accompanied by extended state regulation and control of service providers (Bode et al, 2011; Theobald, 2012). As a consequence, a co-existence of different logics of governance is evident (Burau et al, 2007; Dingeldey and Rothgang, 2010; Osborne, 2010).

The concept of multilevel governance was created as a tool to analyse these complex governing relationships within welfare policies. First, it enables us to map the territorial dimension of welfare policies, that is, governmental layers at local-regional-central levels and the corresponding processes of rescaling. Second, it considers the involvement of further social actors in welfare policies outside the governmental framework, for example, the market, civil society and family (Peters and Pierre, 2010). In a cross-country comparison, Kazepov (2010) adapted the concept of multilevel governance by introducing the term ‘subsidiarisation’ to examine recent welfare state reforms. This concept captures two processes of change in welfare policy design and its implementation. First, it addresses the vertical dimension of change, that is, territorial reorganisation of welfare policies, and second, the horizontal dimension, that is, the involvement of further societal actors. In their analysis of rescaling processes in different welfare areas, Kazepov (2010) found that reform processes do not occur in an institutional vacuum, but are shaped by the existing institutional setting of the welfare system in each country, and furthermore, by the institutional design of the distinct policy field.

The concept of welfare (multilevel) governance focuses on analysis of the shifts in governing arrangements and the underlying politics, but neglects the substantive consequences of the shifting arrangements (Daly, 2003; Burau et al, 2007; Dingeldey and Rothgang, 2010). Research in this policy field indicates a significant impact of the pattern of territorial or horizontal multilevel governance on the establishment of universal and integrated public support (Strohmeier, Navarro Smith, 2010; Vabo and Burau, 2011; Ranci and Pavolini, 2013). The focus of this chapter is a systematic analysis of patterns of multilevel governance in LTC policy – the

interplay of governmental layers at local, regional and central levels and the involvement of wider social actors – and the effects related to universal and integrated public LTC support. In the following section patterns of multilevel governance arrangements are first analysed in a cross-country comparison of four countries, namely, Australia, Germany, Italy and Sweden. The effects of distinct patterns on the establishment of universal and integrated public support are then shown. Finally, key future challenges are discussed.

Patterns of multilevel governance

Australia, Germany, Italy and Sweden were selected as representatives of distinct care models in order to reveal complex vertical and horizontal multilevel governance arrangements. Based on research, care models can be distinguished by institutional regulations of public support, that is, eligibility criteria, level and type of support, and by the roles assigned to the state, family, market and civil society in care provision, financing and regulation embedded in distinct cultural values (for different care models see, for example, Anttonen and Sipilä, 1996; Bettio and Plantenga, 2004; Burau et al, 2007; Simonazzi, 2009).

For the comparison country examples representing different care models are selected. Germany is selected as an example of a continental European ‘publicly supported informal care model’ characterised by an emphasis on the significance of the family and active subsidiarity by the state. Despite reductions of coverage and trends to marketisation, Sweden can still be viewed as representing a Nordic public service model emphasising the role of services and state responsibility. Italy, as a Southern European country, represents a family-oriented model of LTC support based on ideas of passive subsidiarity (see Bettio and Plantenga, 2004). Finally, Australia can be viewed as a mix of a liberal system (comparable to the UK’s orientation towards tax-based, means-tested and service-oriented support) but complemented by traditional social democratic ideas of universal public support and the strong role of welfare associations with regard to care provision prevalent in Continental European countries.

Care models are further characterised by multilevel governance arrangements, that is, a distinct interplay of territorial levels – central, regional and local – and the involvement of wider social actors. In the

following, these patterns of vertical and horizontal multilevel governance arrangements in the four countries are mapped out with regard to basic governance instruments, namely, administration, provision, financing and regulation. The analysis focuses on the predominant LTC schemes established in each country. With regard to vertical multilevel governance, we distinguish between arrangements located at distinct levels – central, regional (federal states, districts or provinces) and local. Here we also look at policies that are assigned to one level but are framed by policies at higher vertical levels that aims to standardise policies or public support structures available locally or regionally (see Kazepov, 2010). Horizontal governance arrangements are mapped out based on the form of involvement of wider social actors.

Administration and provision of long-term care support

The analysis of administration or provision instruments reveals distinct patterns of vertical and horizontal multilevel governance arrangements, mainly between countries, but also between policy schemes within countries (for an overview of multilevel governance structures on administration and provision, see Table 12.1).

In Germany, the quantitatively most significant care policy schemes – long-term care insurance (LTCI) and health care insurance – are characterised by central laws that provide a strong framework for regional-level administration. Responsibility for administration and financing is assigned at regional levels to LTCI or to health care insurance funds (cf Theobald, 2011b; Theobald et al, 2011). Based on a model of purchaser-provider split, the insurance funds negotiate contracts with non- or for-profit private providers specifying types of services, prices and quality assurance measures. With the introduction of a market-oriented care infrastructure towards consumer choice, the former domination of non-profit providers in care provision declined and the proportion of for-profit providers markedly increased. In 2011, 50 per cent of the users of home-based services were served by non- respectively for-profit private providers, within residential care 37 per cent of beds services were offered by for-profit providers, 57 per cent by non-profit providers and 6 per cent by public providers. Within the framework of LTCI, beneficiaries may choose between a cash benefit, home-based or residential services. In 2011, 47 per

cent of beneficiaries opted for a cash benefit only to support family-based care (German Federal Statistical Office, 2013). Since 2000, migrant workers are increasingly – mainly irregularly – employed in private households (Theobald, 2011a). Public support within the framework of LTCI is supplemented by means-tested benefits provided by the Assistance to Long-Term Care Scheme, which is framed by central law at a medium level and administered at local levels. In keeping with a weakly defined central law on the Old-Age Assistance System, local levels are responsible for a coordinated development of a locally adapted social infrastructure in cooperation with civil society actors and private for-profit providers. Finally, the system of tax deductions to support paid care provision within private households is administered by local tax authorities throughout the country, but based on centrally defined principles.

Table 12.1: Administration/provision: state level and wider social actors involved

Country	Area	State level	Social actors
Germany	<i>Home help/residential care</i>		
	Social/private LTCI	Regional, centrally framed (strong)	Care insurance funds, non/for-profit providers
	Assistance to LTC	Local/centrally framed (weak)	Non-/for-profit providers
	<i>Home help</i>		
	Old-Age Assistance	Local, centrally framed (weak)	Civil society, non-/for-profit providers
	<i>Cash benefits</i>		
	Social/private LTCI	Regional, centrally framed (strong)	Care insurance funds
	<i>Home nursing</i>		
	Social/private health insurances	Regional, centrally framed (strong)	Social/ private health insurance funds, non-/for-profit providers
	<i>Tax deductions</i>	Central	Private households
Sweden	<i>Home help/residential care</i>	Local, centrally framed, weak	Mainly public providers
	<i>Home nursing</i>	Local, regional, centrally framed, medium	Mainly public providers
	<i>Cash benefits</i>	Local	
	<i>Tax deductions</i>	Central	Certified private firms
Italy	<i>Home help</i>	Local	Non- and for-profit providers
	<i>Residential care</i>		
	Nursing homes	Regional	Non- and increasingly for-profit providers
	Care homes	Local	
	<i>Home nursing</i>	Local, regionally framed	Non- and for-profit providers
	<i>Cash benefits</i>		
	Companion payment	Local, centrally framed (medium)	Private households as employers: migrant carers
	Local/regional cash benefits	Local, regional	
	<i>Tax deductions</i>	Central	Private households
	<i>Home help (Home Support Programme)</i>	Central, joint federal/state delivery	Mainly non-profit, public local, for-profit providers
Australia	<i>Residential care</i>	Central	Mainly non-profit, public, some for-profit providers
	<i>Home nursing (Home Support Programme)</i>	Central	Public, non-/for-profit providers
	<i>Cash benefits</i>	Central	Central funding agency, Centrelink
	Carer allowance, payment		
	<i>Tax deductions</i>	Central	Australian Tax Office
	Private LTC expenditure		

In contrast to Germany, in *Sweden*, generally fewer social policy schemes and social actors are involved in public support, while central laws or regulations leave considerable leeway for political decisions made at local levels. The responsibility for the administration of home-based and residential care services was assigned to the municipalities by the Social Service Act of 1982 and the 1992 Ädel-reform. The latter also opened up an opportunity to transfer responsibility for home nursing to local levels, which was implemented by two-thirds of Swedish municipalities (see SOS, 2008; Szebehely and Trydegard, 2011). Against the background of a public service model, under the Local Governance Act 1991 municipalities may choose a purchaser-provider split model and contract out care service provision to private providers. The Free Choice Act 2009 aimed at encouraging municipalities to introduce a care market based on public, for-profit or non-profit providers and consumer choice models. While almost all municipalities have introduced a purchaser-provider split model, in 2012, in 60 per cent of Swedish municipalities all home care provision was still publicly run, while 65 per cent of municipalities did not use private residential care providers. In 2012, 23 per cent of service hours within home care were provided by private providers, and 21 per cent of residents lived in privately run facilities. Since 2007, tax deductions based on general taxation are available to reduce private costs with regard to care/housework-related services provided by private companies (Erlandsson et al, 2013; Meagher and Szebehely, 2013).

In *Italy*, the administration and provision of support is split between different policy schemes, governmental layers and wider social actors, and not based on any central law or regulative framework (cf Strohmeier Navarro Smith, 2010; Tediosi and Gabriele, 2010; Gori, 2012). Central government is responsible for the main universal benefit (companion benefit) while assessments are conducted at local levels and decisions on eligibility are taken at regional levels. No clearly defined eligibility criteria or country-wide assessment tools are available. Further cash payments are introduced and administered at local or regional levels, depending on the authorities concerned. LTC in Italy is increasingly outsourced, with approximately 60 per cent of home-based care delivered by private (mainly non-profit) providers, albeit with a rising proportion of for-profit providers (Gori, 2012). Within residential care services, about 35 per cent of beds available are offered by public providers, 43 per cent by non-profit providers and 22 per cent by for-profit providers (Tediosi and Gabriele, 2010). Take-up rates of different types of benefits for elderly citizens highlight the significance of

centralised, universal cash benefits (in 2011, 12.5 per cent of those aged 65+), while home care services and residential care services are more rarely used with 5.5 and 2.5 per cent respectively in 2010 (Lamura et al, 2014). Against the background of family-oriented values of care provision, the dominant use of unregulated cash benefits facilitated the emergence of a private care market, often in the form of the irregular employment of migrant carers in private households (Gori and Da Roit, 2007; Gori, 2012). The austerity policies introduced since the financial crisis in 2008 cut the financing transfers from central to regional levels, which, dependent on the region, impede the development of a care infrastructure. The cuts strengthen the family orientation of care provision supported by the still available national cash benefit, while the demand for migrant care workers remains strong (Picchi and Simonazzi, 2014). A limited annual tax benefit of €400 to €800 is available to legally employ a care worker within the family framework (Gori, 2012).

In *Australia*, prior to the 2012 reforms, home-based care was split between federal, state and local government. Home nursing and cash allowances for family carers were already administered at central levels (cf AIHW, 2011; Australian Government, 2011, 2012a, 2012b). The 2012 reforms were a move by the federal government to take over the complete administration of community care from the states. In future, the formerly separately organised programmes of home care provision at state and local levels and home nursing programmes will be organised as part of the new Home Support Programme. Under post-2012 arrangements, the federal government contracts directly with all providers, whether local government, for-profit or non-profit aged residential or community care organisations and home nursing agencies. Currently, charities and welfare associations dominate in care delivery, and recent reforms are not aimed at establishing a purely market system, although they are aimed at increasing competition between providers.

Financing of long-term care support

In general, comparable patterns of territorial interplay and involvement of wider social actors are visible with regard to administration, provision and financing. In addition, related to the instrument of financing, patterns of horizontal multilevel governance are strongly influenced by the mode of public financing – based on taxes or insurance – and the public–private

divide of LTC costs (for an overview of multilevel governance structures on financing, see Table 12.2).

Table 12.2: Financing: state levels and wider social actors involved

Country	Area	State level	Social actors involved
Germany	<i>Home help/residential care</i>		
	Social/private LTCI	Regional, centrally framed (strong)	Social/ private care insurance funds
	Assistance to Long-Term Care	Local taxes, tax transfers	
	<i>Home help</i>		
	Old-Age Assistance	Local taxes, tax transfers	Civil society
	<i>Cash benefits</i>		
	Social/private LTCI	Regional, centrally framed (strong)	Social/ private care insurance funds
	<i>Home nursing</i>		
	Social/private health insurances	Regional, centrally framed (strong)	Social/ private health insurance funds
	<i>Tax deductions</i>	General tax revenues	Private households
Sweden	<i>Home help/ residential care</i>	Local taxes (mainly)	
	<i>Home nursing</i>	Regional taxes	
	<i>Cash benefits</i>	Local taxes (mainly)	
	<i>Tax deductions</i>	General tax revenues	Private households
Italy	<i>Home help</i>	Local taxes	
	<i>Residential care</i>		
	Nursing homes	General tax revenues; regional taxes, local completion	
	Care homes	Local taxes	
	<i>Home nursing</i>	Regional taxes	
	<i>Cash benefits</i>		
	Companion payment	General tax revenues	
	Local/ regional cash benefits	Local/regional taxes	
	<i>Tax deductions</i>	General tax revenues	Private households
Australia	<i>Home nursing/home help</i>		
	Home Support Programme	General tax revenue/ co-payment	National Assessment Agency
	Health insurance	Central – tax and private pay	National Agency (Medicare)/ private health insurance funds
	<i>Residential care</i>	General tax revenue/ private pay means-tested	National Assessment Agency
	<i>Cash benefits</i>		
	Carer Allowance/ payment	Central	Central funding agency, Centrelink
	<i>Tax deductions</i>		
	Private LTC expenditure	Central	Australian Tax Office, private households

In *Germany*, two distinct modes of financing can be distinguished (cf Theobald, 2011b; Theobald et al, 2011). Long-term care insurance (LTCI) and health care insurance – mainly social insurance-based systems complemented by mandatory private insurance schemes that cover approximately 11 per cent of the population – are comparable to the tax-based Assistance to Long-Term Care Scheme and Old-Age Assistance System, and a more recent law on tax deductions. Governance of the two insurance-based schemes is based on a mix of strong central regulation and regional implementation by para-state social insurance funds. Private costs related to LTC service provision amount to 33 per cent (Rothgang et al, 2010). The Assistance to Long-Term Care Scheme and Old Age Assistance System are financed by local taxes embedded in a complex mix of locally levied taxes and regional and central transfers. After means testing, the financing of supplementary LTC support – the Assistance to Long-Term Care Scheme – is mandatory for the municipalities, while support within the Old-Age Assistance System is optional, which has led to very divergent local service structures.

In *Sweden*, long-term care services – home-based and residential – and home nursing services are tax-financed mainly at local levels (85 per cent of costs), while the central level contributes around 10 per cent of total costs based on non-dedicated grants. Private costs (co-payments) are very limited and cover about 5 per cent of all LTC costs (Szebehely and Trydegard, 2011). As an element of health care provision, home nursing services are financed by regional taxes, although payments are transferred to local levels if the authorities take over the administration and provision of home nursing services. Home nursing services are free of charge for users (Strohmeier Navarra Smith, 2010). Finally, tax deductions are financed by general tax revenues.

In *Italy*, long-term care and home nursing services are also tax-financed, but embedded in a more complex split between different levels (cf Strohmeier Navarra Smith, 2010; Tediosi and Gabriele, 2010; Gori, 2012). Wide differences exist between the regions with regard to available services. Home nursing services are covered by local health authorities' budgets that, as part of a National Health Service, are financed by general taxation and regional taxes. Home nursing services are provided based on needs and are free of charge for users. Home help services are financed by municipalities based on their own taxes and grants from the central level. Despite huge local differences, there has been a sweeping introduction of means testing and co-

payments over the last decade. In addition, financial responsibility for residential care services is divided between municipalities for care homes and regions for nursing homes. Universal, central-level cash benefits and tax deductions are funded by general taxation, while local or regional taxes are funded at local or regional levels, respectively.

The most recent reforms in *Australia* led to a stronger central-level concentration of financing responsibilities. Australia has a publically financed national health care insurance system called Medicare, which can be supplemented by private insurance to cover higher rates of reimbursement or extra services. All public programmes in Australia are tax-funded (before the recent reform at different territorial levels) and usually require some co-payments (Australian Government, 2012a, 2012b). Central government provides direct support for family carers, mainly based on the needs of care recipients (AIHW, 2011). The financing of cash benefits is located at the central level, as is the majority of funding for providers of residential care or care packages through basic federal-level government subsidies. Until the recent reforms, financing of home-based care was split between central and state (regional) levels. The former home-based care programme (Home and Community Care Programme, HACC) was co-funded by both the federal government (around 60 per cent) and local, state and territorial governments (about 40 per cent). Co-payments generally cover about 30 per cent of residential care and about 10 per cent of community care for elderly citizens (Australian Government, 2011). With regard to residential care, government subsidises actual care costs, and beneficiaries are expected to cover the accommodation component. States and territories previously funded their proportion from a general services tax. Under the 2012 reforms, the federal government rescinded this tax and tightened means-testing arrangements and co-payment provisions to put much greater emphasis on user contribution according to means (Australian Government, 2012a, 2012b).

Regulation of long-term care support

In contrast to administration, provision and financing, regulation can still be viewed as a public task in all the countries selected. Furthermore, with the exception of Italy, central levels are strongly involved in regulatory issues, mediated by different levels of central regulatory coerciveness (for an overview of multilevel governance structures on regulation, see Table 12.3).

In *Germany*, all LTC policy schemes are enshrined in central law, although they differ in the degree of coerciveness of the central regulations (cf Theobald, 2011b, Theobald et al, 2011). Regulations related to long-term care insurance (LTCI) and home nursing within social health care insurance are either centrally defined or embedded in a strong central framework. The federal law on LTCI clearly defines the level of social insurance contributions, eligibility criteria and corresponding lump sum benefits, including basic approaches related to quality assurance measures, valid for the entire country. Assessments are conducted and developed by the Medical Services of the Health Insurance Funds (MDK) at regional levels based on nationwide coordinated assessment instruments. Furthermore, the federal law on social health care insurance defines situations of available home nursing support, co-payment regulations, and a general quality assessment approach for care providers that is valid nationwide. Within the Assistance to Long-Term Care Scheme situations of public support and available benefits are defined centrally, while assessment procedures and types of benefits are decided at local levels, case by case. Finally, the Old-Age Assistance System as a goal-oriented framework is only weakly defined by central law, which leaves considerable leeway for local levels. Tax deductions are strongly regulated related to the amount of financial support available and the employment conditions of the carers, but do not take individual needs into account.

Table 12.3: Regulation: state levels and wider social actors involved

Country	Area	State level	Social actors involved
Germany	<i>Home help/residential care</i>		
	Social/private LTCI	Central, centrally framed	Medical Service Health Insurance Funds (MDK)
	Assistance to Long-Term Care	Central, centrally framed	
	<i>Home help</i>		
	Old-Age Assistance	Local	
	<i>Home nursing</i>		
	Social/private health insurances	Central, centrally framed	MDK
	<i>Cash benefits</i>		
	Social/private LTCI	Central, centrally framed	MDK
	<i>Tax deductions</i>	Central	
Sweden	<i>Home help/residential care</i>	Centrally framed	National Board on Health and Welfare (NBHW)
	<i>Home nursing</i>	Centrally framed	NBHW
	<i>Cash benefits</i>	Local	
	<i>Tax deductions</i>	Central	
Italy	<i>Home help</i>	Local	
	<i>Residential Care</i>		
	Nursing homes	Regional	
	Care homes	Local	
	<i>Home nursing</i>	Regionally framed	
	<i>Cash benefits</i>		
	Companion payment	Centrally framed	
Australia	Local/regional cash payments	Local/regional	
	<i>Tax deductions</i>	Central	
	<i>Home help</i>		
	(Home Support Programme)	Central	National Assessment Agency, Department of Social Services, Aged Care Quality Assurance Agency
	Residential care		
	<i>Home nursing</i>		
	(Home Support Programme)	Central	National Assessment Agency, Department of Social Services, Aged Care Quality Assurance Agency
	<i>Cash benefits</i>	Central	Centrelink
	<i>Tax deductions</i>	Central	Australian Tax Office

In contrast to Germany with its emphasis on central regulatory power, regulation in *Sweden* for LTC provision is characterised by strong local discretion embedded in the weakly centralised regulatory framework of the Social Service Act (Rauch, 2008; Trydegard and Thorslund, 2010). As a goal-oriented law the Social Service Act gives local authorities considerable discretion in matters such as defining eligibility criteria, corresponding public support, assessment procedures and quality assurance measures. An exception is the regulation of co-payments for the use of home-based and residential care services, where an upper limit of SEK1,780 in 2013 (€187 in February 2015) per month is defined by law. Since 2000, more formalised and equal assessment procedures have been introduced throughout the entire country together with a more restrictive care policy (Trydegard and Thorslund, 2010; Vabo and Szebehely, 2012; Erlandsson et al, 2013). Home nursing is more strictly regulated by the Health and Medical Services Act at the central level. Comparable to Germany, the Act defines distinct situations of public support for home nursing services, while physicians prescribe home nursing services in individual cases (SOS, 2008). Tax deductions are regulated at central level and can be used to purchase tax-subsidised care- or household-related services by certified companies. Tax deductions are not related to individual needs or corresponding needs assessments (Meagher and Szebehely, 2013).

In *Italy*, LTC service provision and home nursing is generally characterised by high levels of discretion at regional or local levels and a lack of central regulations or central frameworks (see Strohmeier Navarra Smith, 2010; Tedosi and Gabriele, 2010; Gori, 2011). Eligibility criteria are set at either the regional level for home nursing or the local level for home help services, while for the latter, municipalities decide on means testing or the level of co-payments. Assessments are conducted by professionals at local levels for both home nursing and home help services. Eligibility criteria for the universal cash benefit are weakly defined on a central level, and assessment procedures are decided and conducted at local levels. Additional local or regional cash payments are designed on local or regional levels. Employing central level guidelines on a minimum level of quality assurance, it is up to the regions to define their own quality control and quality assurance measures. Comparable to other countries in our study, regulations on tax deductions with regard to care- or household-related services within private households are defined by central government.

Australia's 2012 reforms strengthened central-level regulatory powers. Even before the reform, cash benefits, residential care services, a large part of home-based services, particularly in relation to higher levels of care dependencies, were already regulated at central levels (AIHW, 2011; Australian Government, 2011). Ante-reform, assessment for residential or home and community care services was conducted by a national infrastructure of regionally based multidisciplinary Aged Care Assessment Teams (ACATS), which made formal recommendations for residential and/or community care. Post-reform, ACAT functions are to be absorbed into the national online Senior's Gateway Assessment Service. It is not yet clear whether there will be any regional access points to carry out face-to-face assessments. Part of the new Seniors' Gateway will be the developing of indicators and the setting up of a rating system for aged care services that will be published on the My Aged Care website (see www.myagedcare.gov.au/). A new body – the Australian Aged Care Quality Agency – was established at a central level under the reforms, to accredit and monitor Australia's residential and home care providers from July 2014 (Australian Government, 2012a, 2012b). Eligibility criteria and needs, as well as financial assessments (and thus corresponding private costs), will be defined at central levels, thus providing a further instrument to circumscribe eligibility and financial means assessment.

Effects of multilevel governance

Examination of multilevel governance arrangements in the four countries compared reveal distinct patterns. With regard to vertical multilevel governance, in Australia, following its recent reforms, a centrally administered, financed and regulated type of LTC support has emerged. In Germany, the most significant policy schemes can be described as strongly framed at a central level but oriented towards implementation at regional levels. In contrast, LTC support in Sweden is more weakly framed at a central level with the local levels enjoying high levels of discretion. Finally, the Italian support system reveals only sparse central regulations and high levels of regional and local discretion. From the perspective of horizontal multilevel governance the countries differ mainly with regard to administration and provision and a public–private split with regard to financing. Characteristic of Sweden is the still strong integration of administering, provision and financing of services within governmental networks and a strong emphasis on

the public financing of LTC services. Australia follows Sweden with a dominance of public administration, although in the former welfare associations are also assigned a strong role in care provision. Furthermore, in contrast to the stronger territorial integration, recent reforms put more emphasis on individual financing responsibility. From a horizontal perspective, Germany and Italy can be described as family- and market-oriented systems, albeit in very different ways. In Italy, a mainly irregular private care market has emerged within the family framework, while formal care provision is less significant (see, for example, Gori, 2012; Costa, 2013). In Germany, on the other hand, a market-oriented formal care infrastructure was established. Despite the family orientation, the often irregular employment of migrant carers within the family framework is modest compared to Italy (Theobald, 2011a). With regard to financing, considerable levels of private financing can be found in both countries embedded in different allocation patterns in both countries, that is, universal but basic support in Germany, and a stronger means-testing element in Italy.

The impact of country-specific vertical and horizontal governance patterns on universal and integrated care provision is examined here against this background. The analysis is based on the assumption that different patterns of vertical and horizontal multilevel governance and their interrelationships strongly influence the development of universal and integrated public LTC support. Universalism is discussed from the perspective of universal access defined by institutional regulations, but also by universal outcomes, that is, coverage with distinct types of LTC support throughout the countries. Integration is considered pertaining to institutional policy designs related to administration, provision, financing and regulation, as well as distinct measures established to strengthen integration.

Multilevel governance and territorial universalism

Patterns of universalism emerging in the countries compared – as an administrative principle and related to universal outcomes – are analysed against the background of the country-specific interaction of existence and strength of centrally (framed) regulation, the definition of the private–public mix of financing and the mode of involvement of wider social actors, for example, family or the market.

LTCI in *Germany* can be taken as an example of a strongly centrally framed policy scheme, which promotes territorial uniformity and thus

universal access throughout the country. In contrast, the mode of involvement of the market and the family and the (only basic) level of public financing counteracts the effects of central regulations on universal outcomes. Processes of marketisation are based on individual price negotiations between providers or associations and insurance funds on a regional level, followed by price competition in a care market. Lower prices for home-based services in the new federal states – due to lower wages – combined with nationwide defined lump sum benefits enhance public support for care services and lead to higher take-up rates of services in these states compared to the former Western federal states (Rothgang et al, 2009). Furthermore, the lower price levels for residential care services in the new federal states more rarely require the use of supplementary means-tested public assistance payments (German Federal Statistical Office, 2012). Finally, the emphasis on family care provision combined with high private costs related to service use promotes the development of a dual structure of care provision characterised by a dominance of informal family care provision in lower social classes, and higher take-up rates of care services for the (upper) middle classes (Blinkert and Klie, 2002; Theobald, 2011b).

In contrast to Germany, the situation in *Sweden* is characterised by lower levels of territorial uniformity but higher levels of public financing and horizontal integration of public care support. Here, the weak central framework of LTC policies and strong local discretion runs counter to a lack of territorial uniformity, that is, coverage is uneven between municipalities (see, for example, Rauch, 2008; Burau and Vabo, 2011). The introduction of more systematic, equitable (but stricter) needs assessment programmes in Sweden and an emphasis on benchmarking resulted in a harmonisation of coverage rates, albeit at lower levels during the 2000s (Trydegard and Thorslund, 2010). The dominance of publicly provided care services and the high level of public financing – only 5 per cent private costs – still result in universal use of the available care infrastructure (Burau and Vabo, 2011; Vabo and Szebehely, 2012). Recent policy trends question the universalism of service use. Targeting public support to older adults with higher levels of frailty requires increasing informal, family or privately paid care provision, which, in turn fosters the development of socioeconomic unequal patterns of (privately paid) service use and re-familialisation of care provision (Szebehely and Trydegard, 2007). And new modes of financing may also strengthen unequal service use. The possibility of topping up publicly supported care services by private means and the introduction of a tax

deduction related to these private costs, which is more often taken up by higher income groups, endangers social equity in Sweden's LTC policies (Meagher and Szebehely, 2013).

Australia can be viewed as an example of an increasing level of territorial uniformity and more integrated involvement of social actors in service provision, which is, however, weakened by an increase of private financing due to the introduction of means testing for both residential and home care provision. Before the recent reform, Australian care policies resulted in considerable inequity(ies) and fragmented support (see Australian Government, 2011, 2012a, 2012b). Variability is related to differences in assessment and delivery of home-based care programmes across states and local government. The reform establishes one home-based care scheme – including home nursing – within a centrally administered Home Support Programme and centrally defined needs and financing assessment procedures. In general, the reform aims at promoting the development of greater equity and more integrated LTC support. However, tightening of means testing in residential and home care provision risks impeding the use of services by 'at-risk' groups, and thus increases social inequality. The reform has not yet been fully implemented and it is too soon to evaluate results.

Finally, in *Italy*, due to a lack of central regulation(s), the low level of public financing and the widespread private care market within a family framework, universal access and outcomes are by no means certain. The lack of central regulations resulted in huge regional differences with respect to the number of elderly citizens receiving support, as well as the type of public support (cf Strohmeier Navarra Smith, 2010; Gori, 2012). Related to service provision Gori (2011) distinguishes between balanced regions with an above-average provision of residential and home-based services, regions with a prevalence of home care or residential care, and regions – mainly in southern Italy – with weak supply, where both types are below the average. The last-named category is related to high numbers of elderly citizens receiving universal cash benefits. A clear divide can be discerned between a monetary-based welfare system, more widespread in the poorer, southern part of Italy, and a service-based welfare system in the north's wealthier regions. Nonetheless, huge differences can be found, even within the regions. Restrictive service provision and cash-oriented universal public support facilitates the emergence of a grey market for paid care provided by migrant workers within a family framework (Da Roit, 2007; Costa, 2013). The unburdening of informal carers by the employment of migrant carers is more

often used as a strategy by middle-class families. In addition, the introduction of tax deductions to support the use of paid care within a family framework, which is more interesting for (upper) middle-class families, weakens the universal use of public support even more (Bettio et al, 2006; Da Roit, 2009).

Multilevel governance and integration of public support

In this second part of the analysis, vertical and horizontal dimensions of governance arrangements are examined in their interrelationship with the dimension of fragmentation or integration of public support and care services. The dimension is considered, pertaining to institutional policy designs related to administration, provision, financing and regulation and the mode of involvement of different social actors.

In *Germany*, strong, centrally framed governance structures of LTC support enhance integration (cf Theobald, 2011b, 2012; Theobald and Hampel, 2013). In contrast, the separate organisation of LTCI, health care insurance and tax-based assistance systems on the local levels create boundary problems between the distinct schemes. However, home-based care services are provided in an integrated way, because most service providers are simultaneously involved in care provision within the framework of LTCI and health care insurance. Problems of fragmentation emerge within care provision due to a market with a diversified care infrastructure, and also due to the fragmented support provided within the Old-Age Assistance System at the local level. With the 2008 LTCI reform, local information centres were established that provide free information – even as far as continuous case management or care management services for (potential) beneficiaries and their families – to enable informed choices and the development of integrated and individually tailored care arrangements.

Following the devolution of LTC support to local levels in *Sweden*, home-based and residential LTC services (and, in two-thirds of municipalities, also home nursing services) are provided in an integrated way based on joint administration and financing, the establishment of single access points and joint delivery (Szebehely and Trydegaard, 2011). Risks of fragmentation are related, first, to increasing levels of marketisation and freedom of choice between providers with regard to care delivery. Here, single access points are obliged to provide relevant information for users. Second, fragmentation is strengthened by the introduction of tax deductions to purchase services by private for-profit care providers, or even to use service providers outside the

registered infrastructure. While the opportunity to top up publicly granted services with for-profit providers only promotes integrated care provision at the individual level, it might foster the development of a fragmented care infrastructure for the system as a whole (Meagher and Szebehely, 2013).

In *Italy*, fragmentation concerns the different institutional designs of LTC support—different types of care services and cash payments—that is related to split territorial responsibilities. Fragmentation hinders the development of individual care arrangements and exacerbates already existing territorial inequalities. Although the establishment of joint assessment teams at local levels for home help and home nursing aims to support the integrated provision of both types of services, the fragmented structure of LTC support is not overcome on the whole (Tediosi and Gabriele, 2010). In Italy, processes of marketisation relate mainly to the establishment of a grey market within family frameworks. Despite its quantitative significance, domestic care work—often done by migrant workers—is only loosely integrated into formal, professional care support, and thus contributes to a split between different types of support. Here, with limited success, local policies have been established to integrate migrant carers into the formal care system, for example, by more regulated cash payment schemes or training offers (Da Roit, 2009).

Recent reforms in *Australia* are characterised by efforts to integrate policy schemes at a central level and to establish a nationally agreed assessment process. Against the background of a complex care infrastructure, the new Seniors' Gateway aims to support citizens' informed decision-making. This reform package was preceded by a major reform and a national restructuring of hospital and health services (Australian Government, 2012c) as well as a concurrent, separate review and reform of disability services (Australian Government, 2011). The 2012 aged care reforms are targeted at the better integration of aged, health and disability services, but each of these areas has rolled out separate reform agendas that now have to be integrated at regional and local points of delivery. The federal Labor government initiated a grants programme to examine integrated delivery models (Australian Government, 2012c). The implementation of the reforms is still at an early stage, so emerging effects cannot yet be evaluated. Australia had a change of federal government in November 2013, but this did not change the major direction of reform.

Key challenges for the future

The analysis reveals complex multilevel governance arrangements – a mix of policy schemes, governmental layers and the involvement of different social actors – and related patterns of universal and integrated care provision. Against this background three key challenges – related to universalism and the fragmentation of care support – and their embeddedness in multilevel policy development are outlined.

In Germany, Australia and Sweden, LTC policies evince a shift towards stronger territorial uniformity, and thus, increasing universalism. In Germany, since the mid-1990s, and in Australia following the 2012 reforms, territorial uniformity has been strengthened by the establishment of a strong central policy framework. In Sweden, rising territorial uniformity is based on the introduction of soft measures, such as benchmarking or central guidance for more systematic needs assessment (Trydegard and Thorslund, 2010). In these countries an increasing involvement of further actors, such as the family and the market, counteract universal care support. In Sweden, the positive trend towards territorial uniformity is called into question by processes of refamilialisation due to targeting of public support and the risk of a divided public and private care infrastructure. Both developments show a clear class-based profile. In Germany, a class-based dual structure of care provision has already emerged based on the distinction between family- or service-oriented care provision promoted by cultural values and high private costs related to service use. In Australia, the 2012 reforms aimed at facilitating more territorial uniformity as well as better integration of different care providers at local levels. However, the introduction of stricter means testing for residential care and home care services may result in socioeconomic, class-based, take-up rates, and eventually, to a dual non-universal infrastructure relating to inequity introduced by Means Testing ‘The Australian Government has prescribed annual caps on expenditure of \$25,000 for residential care, \$5,000 for home care and a lifetime cap of \$60,000’ (Australian Government 2012a). Finally, due to the inertia of institutional structures in Italy, still strong territorial inequalities combined with a dual structure of family- and service-based care provision have resulted in both regional and socioeconomic class differences. The combination of territorial uniformity, the involvement of family – and market-oriented care work and socioeconomic class-based universal outcomes – can be viewed as a key future challenge in all four countries.

Widespread multimorbidity and chronic illness among older adults requires an integrated delivery of different types of service support and

informal care provision. Major initiatives are underway in all four countries that include home nursing and home help in order to integrate care provision. The efforts range from the development of an integrated financing, administration and provision responsibility found in Sweden or Australia, to Germany's integrated service provision. Further initiatives are the establishment, as in Italy or Australia, of joint assessments, enabling the provision of comprehensive and coordinated services at the individual level. In contrast, the increasing diversification of care infrastructure and ever more complex support systems – comprising traditional types of public support, and, more recently, tax deductibility arrangements – challenge the positive effects of steadily more integrated care service provision. Here, the introduction of single access points or information services should facilitate informed choices and an integrated, individual use of diversified infrastructures. However, evaluations of local information centres in Germany established in 2008 reveal that the centres are more often used by middle-class older people or their family members (Döhner et al, 2011). The future challenge here is to combine the emerging diversification of support systems and care infrastructure with integrated and universal LTC support for all social groups in society.

Key challenges outlined related to care provision are embedded in country-specific requirements (key challenges) to develop further patterns of vertical and horizontal multilevel governance. One of the key challenges in Australia lies in the attempt to centralise and standardise LTC at the federal level, as this could mean that state, regional and local infrastructures will be undermined (Kendig, 2010). Indeed, some sectors may leave the LTC industry altogether, for example, local government, the not-for-profit charitable sector, even some state administrations, and this would leave the field wide open to the private market. In Sweden, the gradual process of strengthening the impact of the central political level by using soft measures of governance goes hand in hand with less generous and more market-oriented policies due to increasing cost considerations and outsourcing of care provision. A key challenge here is to reverse this contradictory process, which may undermine in the long run the basic pillars of LTC policy such as universalism, social equity and public responsibility. Since the introduction of LTCI in Germany, LTC policies are embedded in a well-integrated framework of vertical multilevel governance. Key challenges to be considered here are the difficulties of horizontal integration due to the market orientation of care provision and the only medium level of public financing.

Furthermore, local levels should be more involved to establish a more integrated and locally adapted care infrastructure. LTC policies in Italy are characterised by fragmentation, a lack of centralisation and an emergence of a private care market within the family context. As key challenges can be defined the development of more centrally framed, integrated policies, which include even policies related to migrant care work provided in the family context. The austerity policies in place since the economic crisis impede further efforts to meet these challenges. Due to the reduction of central financial transfers to the regions, patterns of decentralisation of care service provision are strengthened, and care provided within the family context by family members or migrants is promoted.

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THIRTEEN

Conclusion: looking ahead in long-term care policies

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The previous chapters have examined a range of strategies across OECD countries for organising, regulating and funding long-term care (LTC) public services for dependent older people in the face of the rising needs of ageing societies. These chapters have highlighted the main LTC models and reforms adopted internationally, provided a critical assessment of their successes and limitations, and drawn key recommendations for future policies. This concluding chapter reviews their findings in order to map and discuss the most important challenges and dilemmas that LTC policies will face in the years to come.

Rising demand

Future policies must take account of the expected rise in demand for LTC for older people. Chapter Two, by Wittenberg, shows that demand for LTC is expected to rise throughout the developed and developing world. The number of older people needing care is projected to rise partly because the large post-Second World War baby boom cohorts are starting to reach old age, and partly because increasing life expectancy means that a rising proportion of older people are surviving into late old age.

The growth in demand for formal LTC is a complex issue which requires careful consideration. Need for care is not determined simply by age. Much will depend on whether there is a compression or expansion of disability, that is, whether, as total life expectancy increases, the number of years with severe disability remains constant, rises or falls. The issue of the compression or expansion of disability is the subject of much continuing debate. It would not seem prudent for policy-makers to count on future reductions in the prevalence of severe disability among older people to

offset the rising demand for LTC that will result from population ageing. An expansion of severe disability, including dementia-related disability, cannot be excluded.

Demand for care services is not solely a function of the numbers needing care. It also depends on the availability of alternatives to services, the cost of care services, incomes, and expectations and preferences. The main alternative to formal care services is unpaid care by family and friends. Uncertainty about future supply of unpaid care, as discussed in the next section, could have a major upward impact on demand for formal services.

Preferences concerning types of care and quality of care may vary by age, socioeconomic circumstances, ethnicity and culture, but expectations, especially expectations about quality, seem substantially more likely to rise than fall. Future cohorts of older people are generally predicted to expect a higher quality of care than current cohorts. Their expectations may reflect the higher living standards that they have enjoyed during their working lives and their incomes in retirement. Society more widely seems likely to be unwilling to accept the shortcomings in standards of care that have occurred, especially in residential care, in several countries in recent years.

Since LTC is highly labour-intensive, its unit costs, such as the cost of an hour's home care, can be expected to rise broadly in line with earnings rather than prices. In most years, so long as productivity in the economy rises, average earnings will increase faster than prices. While there is scope to debate whether earnings in the care sector will rise more rapidly or less rapidly than economy-wide average earnings, they are likely to rise in real terms and lead to rising real unit costs of care. These factors suggest that demand for LTC services may rise more rapidly than need for care, and that expenditures will rise more rapidly than numbers needing care.

Overall, the future policy environment is likely to be marked by a rising number of people needing care, unless there is a substantial compression of disability, which is at best, very uncertain. It seems unlikely that the supply of unpaid care will keep pace with the increase in need for care. Unless it does so, there will be additional pressure on formal care services. Rising expectations for improved quality of care could also place upward pressure on demand for services. To manage this anticipated increase in demand at a time of continuing constraints on public expenditure will constitute a major challenge for governments.

The balance of responsibilities between users, families and the state

The future of LTC public systems will be shaped by reforms to the role and contributions of service users, their families and the state to the funding, provision and receipt of care. Given the ubiquity of their effects, funding reforms will be particularly important in determining the future LTC policy landscape. Funding arrangements – discussed by Fernandez and Nadash in Chapter Three – do not simply determine who bears the financial costs of care. They also affect the patterns of receipt of care by (dis)incentivising consumption, in particular through the effect of care charges at the point of need. In turn, the cost of formal care can affect the nature and degree of involvement of family and friends as carers and funders of care. The prominence of funding policies in LTC is therefore unsurprising, and so is the heterogeneity of the funding models across OECD countries. Whereas the state bears the core of care costs for individuals with the greatest needs and with the lowest financial means across all OECD countries, there is significant variability in the intensity and coverage of state support of care charges for others, reflecting important differences in cultural expectations and attitudes towards care.

Following a number of reforms resulting in greater universalisation in LTC funding, including the implementation of high-profile social security LTC systems in Germany, Japan and France, recent reforms have placed more modest requirements on the level of state financial contributions to care. This relative slowdown in the universalisation of LTC state funding has been linked, to a large extent, to the impact of the international financial crisis on all areas of public expenditure. In the LTC area, increasing fiscal constraints have led to a shift in reform objectives towards incentivising efficiency and the development of funding ‘partnerships’ between individuals and the state. Through these partnership arrangements, individuals have been incentivised to contribute to a share of increasing care expenditures.

A number of countries have sought to concentrate additional state funding on those faced with the greatest exposure to financial risk, targeting specifically those at risk of ‘catastrophic’ care costs. Caps on lifetime care costs have thus been legislated for in England and Australia, where the state

will become responsible for care costs once individuals contribute a stipulated maximum amount.

In addition, as the authors note, the need for greater efficiency in the use of public resources has led to renewed policy interest in the role of the private insurance industry, with a view in a number of countries that preparing for the costs of dependency developed in old age should be, to a large extent, the responsibility of private individuals. Overall, the success of public measures aimed at expanding the take-up of individual LTC private insurance has been, at best, mixed. The greatest advances have been observed in countries with a tradition of insurance models in other related areas (and particularly in the health care area) and in which the state has played a direct role in the specification of the insurance products offered, often specifically designed to act as top-ups to the state-funded support package. Hence, whereas countries such as the UK and the US have seen in recent years a significant reduction in the sales of private LTC insurance policies, the number of private LTC insurance policies has grown significantly in Germany and France.

Looking into the future, we might speculate that a return to economic growth will be accompanied by calls for a greater role for the state in the funding of LTC. The increasing voice of older people across OECD countries, coupled with their greater propensity to vote, is likely to increase the attention paid by legislators to the area overall. Regardless, it is almost certain that the state will continue to finance a relatively limited share of the demand for care, and will continue to rely in particular on the very significant contributions made by families and friends to the care of dependent older people.

In setting the balance of responsibilities between the state, users and families a key variable consists in the role assigned to the informal care provided by the latter, along with neighbours and friends. Over the recent decades, policies to support informal care – analysed by Schneider, Johannson, Sundström, and Tortosa in Chapter Ten – have become increasingly visible on LTC policy agendas across OECD countries.

These policies can be guided by two alternative logics, according to the different mix of tradition, legal responsibilities, health and social policy, and the economic context in each country. One logic looks at ‘the carer as a co-producer’, emphasising the role of informal care in providing adequate support for dependent older people. In this approach policies aim to

encourage potential informal carers to take on caregiving responsibilities, to stabilise existing informal care arrangements in order to avoid excessive care burdens, and to support informal carers in delivering adequate support and prevent neglect and abuse. The alternative logic considers ‘the carer as a co-client’, fostering policies to support informal care as part of the carer’s own rights, that is, to promote the carer’s well-being. Following this approach, policies have to assess the risk profile of informal carers, design appropriate interventions which mitigate these risks and encourage informal caregivers to take up care relief services. Although the evidence on the (cost-)effectiveness of measures to support informal care is quite scarce, Schneider et al note that the co-producer approach can be backed by the research on the hidden cost of informal care, concerning subjective care burden, carers’ physical and mental health, carers’ quality of life and, increasingly, poverty risks too.

In the past 15 years, a trend of convergence has occurred internationally in policies to support informal care. In fact, countries that first prioritised ‘co-producer’ approaches – such as those in continental Europe – have taken some steps towards the ‘co-client’ logic, whereas in other countries, such as in Scandinavia, the opposite route has been followed. As a result, several countries now apply dual approaches.

Since the beginning of the century most countries have declared care in the community a policy priority, see the next section along with a stated aim to support informal and family carers. Nevertheless, efforts to contain spending on institutional care are not being compensated for by an expansion of supportive services in the community, increasing – in several contexts – the burden on informal carers. In the future, the authors predict a tension between the pressure by organised patient and carer organisations towards the ‘co-client’ logic and the push in the opposite direction by the constraints of public financing.

Looking forward, the future supply of unpaid care is a key issue everywhere. If this supply does not rise in line with demand for LTC there will be either a rise in unmet needs with an adverse impact on quality of life of older people or an increase in formal care services with implications for future public expenditure. Intensive unpaid care of older people is provided mainly by spouses/partners and (adult) children and children-in-law. It is important to distinguish these sources of care. As the gender difference in life expectancy diminishes, the potential supply of care by spouses seems at

least as likely to increase as decrease. The proportion of women in late old age who are widows is expected to fall, with a higher proportion having a surviving husband who could provide care. However, the potential supply of care by adult children is more likely to fall. Fertility rates among the baby boom cohorts have been relatively low, such that a rising proportion of people reaching late old age will be childless. For those who are not childless, their children may not live near enough to provide care or may have competing demands on their time from paid employment especially as retirement ages rise.

Targeting public support

Chapters Four, by Campbell et al, and Five, by Gori et al, examine how publicly-funded LTC services and benefits are distributed among older people under different circumstances in a selected group of OECD countries. The authors note that, internationally, resource allocation is a neglected subject. Of all the topics discussed in this book, this has been the least studied in comparative work. Nevertheless, resource allocation lies at the core of LTC policy-making. It will increase in importance in the context of rising demand and uncertain availability of resources. There is a gap here in the evidence.

Since the early 2000s the balance between community-based care and institutional care has shifted more towards the former in all countries considered. OECD countries generally experience a common scenario: most users receive care in the community, but most public spending is devoted to institutional care.

Some of the countries examined have a national cash benefits programme (England, Germany and Italy) while others do not (Japan, the US and Sweden). Where cash benefits are available, the numbers receiving them have increased faster than the numbers receiving services in-kind, and cash benefits are the single care input which coverage is highest. Thus, where cash benefits are offered, they become a main pillar of the LTC system. Their spread is due to eligibility criteria, which in several countries are quite broad, and to the preferences of users and their families for cash over services in-kind (even though differences exist according to national cultures).

The dilemma over the balance between how much care to provide to each user and how many people to reach, that is, between intensity¹ and coverage,² constitutes a critical issue in resource allocation. As public resources are always limited, one of the two dimensions is inevitably privileged over the other: this is the main policy driver.

In institutions, in the country sample, coverage increased everywhere up to the early 2000s, after which it stopped growing in most countries, that is, in those reaching a minimum threshold. In the majority of those countries, coverage actually started to fall. Intensity, on the other hand, has increased in all the countries examined since the beginning of the century. Therefore, since then, intensity has been the main policy driver in institutional care in most countries, all those with coverage above a certain threshold.

In contrast, care in the community (services in kind and, where available, cash benefits) has taken a different path. Since the early 2000s, coverage has increased in each country in the sample, and intensity has followed a mixed trend, rising in some places but not in others. However, even where the rate of intensity has increased, it has been to a smaller degree than coverage. The latter, therefore, has been the main policy driver since the beginning of the century.

Since the early 2000s, expanding coverage of public care provided in the community, as an alternative to institutionalisation, has been a policy priority shared by all governments across the OECD. This aim reflects the desire to receive care in community settings by the majority of older people and their families. It is also consistent with the economic incentives underlying public budgets as the costs per user are, in most cases, lower in the community.

In contrast, to provide more adequate packages of care – increasing intensity – has not been a stated goal (almost) anywhere, either in community care or in institutional care. In the latter, in fact, it was not an explicit policy goal, and intensity increased as an indirect consequence of users' profiles changing. The priority assigned to care in the community has led institutions to admit users who are older (currently, most are aged 80 and over) and need more care (with respect to physical dependency and cognitive impairments) than in the past. This modification has produced, in turn, a rise in intensity in institutional care.

Within the common trends pinpointed above, in a number of countries - as time has gone by - the same tension has come to the surface in both types

of care. In the community, difficulties in assuring adequate intensity of care to various groups of users have occurred, therefore amplifying the burden on families and other informal carers. In some cases, such a situation has also required elderly LTC users and their families to bear substantially high private economic costs. In institutions, the increased pressure on the public purse makes it difficult (even in a context of mostly decreasing/stable coverage) to match the higher intensity of intervention required by current users, with the risk of not assuring the delivery of the care that is needed and/or of doing so with huge increases in co-payments.

Overall, community and institutional care have different policy drivers but in both – internationally – the effectiveness of the emerging care packages in matching users' needs and in assuring the appropriate intensity of services is increasingly questionable.

Regulation and governance of the long-term care system

The challenges policy-makers will have to face in the future with respect to how best to regulate and organise the LTC system can be grouped into three issues: the processes and models used for commissioning support, policies for improving quality and managing the interaction between the various institutional actors involved.

Commissioning care

In Chapter Six, Marczak and Wistow explore some of the recent trends in commissioning across OECD countries. A fundamental shift in LTC systems internationally has been the move towards the separation of the commissioning responsibilities from those of provision. This split in functions has been supported on the basis of needing to concentrate the commissioners on contracting the most cost-effective services from the most efficient providers, which is more likely to occur if commissioners are free from direct managerial responsibility for provider interests. As a result, in many countries the split between commissioning and provision has led to an increase in the role played by independent, including for-profit, organisations in the provision of care and to increased competition between providers.

Commissioning approaches and cultures differ significantly across OECD. Countries such as Canada, Australia and the US have long

traditions of involving private organizations in LTC provision, a shift that has taken place relatively more recently in the UK and other countries such as France. The picture is still significantly different in Nordic countries, where the vast majority of LTC services are still provided by public organizations, in particular in the residential care sector.

Changes in the nature of the relationship between providers and commissioners and the increasing role of the private sector have required modifications to regulatory and governance arrangements. Processes for tendering and contracting services, with the drafting of sometimes complex contracts, have become an essential component of the LTC system in those countries which opt to outsource services to providers independent from the state. In turn, the nature of the contracting arrangements adopted in different contexts has had important consequences for the type of care provided and in particular on its quality and price. Setting fixed care prices during the tendering process, for instance, has often led service providers to emphasize differences in care quality when competing for contracts.

Generally speaking, Marczak and Wistow note that the limited amount of evidence available seems to suggest that greater emphasis on contracting-out mechanisms leads to decreases in care prices and thus in overall levels of expenditure, but often at the cost of reductions in the quality of the care provided. Conversely, the costs which the outsourcing process itself incurs (e.g. spending on tendering, accreditation procedures and quality assurance, etc) can be substantial but the data on such transaction costs are often missing, making it harder to evaluate the cost-effectiveness of different commissioning models.

Arguably, an extreme form of outsourcing reform has led to the implementation of user-led commissioning, whereby individuals are empowered to make the choice over what care they receive and from which provider. Several forms of user-led commissioning exist, ranging from the allocation of vouchers entitling individuals to choose amongst a predetermined set of approved providers to cash-for-care schemes, providing older people and/or their family carers with cash transfers so that they can organise their own care arrangements. The international experience shows that user-led commissioning is characterised by less predictable and fragmented patterns of demand which can undermine the financial stability of providers, bringing with it distinctive challenges for public authorities as

they plan services for the community and try to ensure the stability of the system.

Internationally, the uptake of vouchers, so far, has been limited. Cash-for-care schemes, on the other hand, have grown substantially in a number of countries, as shown in the previous section. The rationale behind these programmes – discussed by Da Roit, Le Bihan and Osterle in Chapter Seven - can be quite heterogeneous. In a market-based approach, the user is conceptualised as a consumer who is able to make choices between providers within more or less regulated markets. In the citizen perspective, in contrast, the user is a citizen empowered ‘against’ a paternalistic welfare state – providing standardised care services, through a top-down approach, to passive care recipients – but possibly also ‘against’ marketisation which is not considered a proper way to support autonomy and social participation. Quite different is the role of cash payments in the familistic approach, whereby public authorities do recognise the need and legitimacy to support older dependent people and their families, but the latter remain in charge of arranging care.

The authors note that significant diversity in the actual design and implementation of this programme occurs across countries. Generally speaking, the available evidence suggests that users opting for cash benefits are usually very satisfied with their care arrangements, and are more – or at least not less – satisfied than in-kind service users. Recent evidence shows, however, that the need for support with the implementation of these schemes varies across types of clients and that older people might require additional support with the contractual and care management arrangements associated with the use of cash payments in some countries. Furthermore, there is not enough evidence on the link between cash payments and functional and health outcomes.

Cash payments alter the nature of the relationship between the dependent person and their family, in terms of assuring a positive acknowledgment of the care provided by the latter but also in terms of setting different expectations about the support to be given to the dependent person by the family member. The connection between cash payments and (particularly women’s) paid employment is usually influenced by the features not only of the schemes but also of the institutional and cultural context. For instance, strong incentives for later retirement and attractive labour market conditions will decrease the willingness and opportunity to provide long hours of

family care, while high unemployment or low benefit levels in the case of unemployment create incentives for informal care-giving, even more so if this provides access to some financial recognition through cash benefits.

Besides being passed on to relatives and informal carers, cash benefits can be utilised to hire one's own carer. When the care work is externalised from the family, hiring professional carers through cash benefits, these schemes strengthen the role of family carers as 'care managers'. Thus, the family is less involved in directly caring but is mostly responsible for selecting workers to involve, supervising care activities, managing administrative tasks and so on. There is a risk that individuals – either older people or relatives – acting as consumers in the care market might be placed in a weaker bargaining position, and that prices and/or quality of formal services might suffer in the long term as a result. Therefore, it will be important for systems emphasising the use of cash-for-care to put in place regulatory systems to 'manage' care markets and to support individuals in their purchasing role.

Promoting quality

Across the OECD, there is a general drive to improve the quality of LTC services, with a number of policy instruments used to pursue this aim. In Chapter Eight, Malley et al group these instruments into three typologies: regulatory, economic and information-based policies. Regulatory instruments influence providers by means of formal rules and directives that mandate compliance with specified requirements. They consist of methods of setting standards, instruments for monitoring compliance with those standards and methods for enforcing compliance with them.

Economic instruments set incentives or disincentives to induce providers to raise quality. They consist of quality-related subsidies, quality-related payment schemes or price regulation, and quality-related procurement modes. The expectation is that financial rewards will lead providers to better perform in terms of quality. Information instruments, finally, aim to influence the behaviour of stakeholders through the transfer of knowledge, the communication of reasoned arguments, and persuasion. Possible options consist of education and knowledge management, quality management systems, public reporting and feedback on quality from users, staff and members of the public.

Regulatory instruments are the most commonly used. Formal standards, set through a mostly top-down approach, and proper mechanisms to assure that providers comply with them represent the main pillar of quality assurance in most countries. At the same time, Malley et al notice a growing view, internationally, that top-down regulation on its own is insufficient to achieve the desired levels of service quality and needs to be supported by other instruments. In order to deal with possible regulatory failures, therefore, countries are experimenting with different policy levers to drive improvements in quality of care.

On economic instruments, there has been significant interest internationally in pay-for-performance schemes, but with mixed results. Such schemes lead providers to focus exclusively on those aspects of quality that are measured and financially rewarded at the expense of others. Similarly, they may engage in ‘cream-skimming’, selecting people who are easier to care for to make their assessed performance better.

With respect to information-based systems, considerable attention has been paid to public reporting schemes, developed in the hope that the publication of quality-related information affects the choice of care providers by older people and their families, and in turn raises the quality of the services on offer. Key challenges for the use of information to improve quality include the ‘distress’ nature of many LTC purchases (and in particular, the difficult and rushed circumstances during which many LTC commissioning decisions are made), and the difficulty of interpreting the quality information available.

Along with the search for a proper mix of policy instruments, the authors highlight two other main challenges that need to be faced internationally. The first relates to the typologies of indicators used to measure quality. Up to now, structural indicators – such as room size, staffing ratios and staff qualifications – prevail in OECD countries. Indicators of process and outcomes are rarely used, as they are much harder to define and measure. Malley et al stress that increasing the use of these dimensions is a crucial step to moving forward in quality assurance policies. The other challenge concerns the typology of services which quality is promoted. So far, internationally, most efforts to promote quality have concentrated on formal care provided in institutions. A key task for the future is to widen the scope of quality assurance to cover community-based services and cash benefits.

To provide quality services, a well-trained and motivated workforce is essential. Chapter Nine, by Colombo and Muir, however, shows that poor working conditions, high turnover, inadequate job quality and low pay are problems shared – to varying degrees – by most OECD countries. Against this background, the demand for a LTC workforce is expected to grow in the future, both in terms of the number of staff needed and their level of skills, due particularly to the large projected increase in the number of people with dementia or other complex care needs.

Chapter Nine reviews the strategies pursued internationally to address the need for more LTC workers. A main strand consists of policies focused on recruitment, adding new inflows to the sector. One approach is to seek new recruitment pools among groups that are underrepresented in the sector or that may not consider a career in caring. Countries have explored a range of policies that target younger workers entering the labour market, older workers who may have left the labour market, unemployed people, men and minority ethnic groups. This strategy has had limited effects, and even where people are successfully recruited, many actually use LTC work as a first step towards further employment elsewhere.

Another option for recruitment consists of attracting migrants, through both regular and irregular migration – a path already followed to various degrees by several countries. In the short term, this strategy can facilitate the recruitment of many care workers. Migrants may be willing to accept posts that local workers will not, due to the demanding nature of care work, and they may accept lower wages. Nonetheless, there are questions about the sustainability of this strategy in the longer term. In the future, countries that are currently sources of LTC workers will face ageing populations of their own and growing domestic demand for LTC. Furthermore, while international care workers may accept relatively low wages today, this may change due to pressure to recruit higher numbers.

Overall, in the long run, meeting the demand for more care workers will be challenging and focusing exclusively on recruiting will not suffice. A focus on making work in the LTC sector more attractive, through improved job quality, conditions of employment or other measures, needs to be an essential component of LTC workforce policies.

Recruitment, therefore, needs to be part of a broader strategy, as Colombo and Muir explain. Higher wages are an essential part of it, but they do not suffice on their own. Another element consists of improving work-related

conditions, avoiding high workloads, providing work-related benefits and implementing measures to promote the health and safety of carers. In addition, the LTC sector needs to value the professional skills of care workers, through granting greater professional autonomy, giving them a say in the planning of care provision and fostering a vision of providing high quality care. Another important element of the strategy consists of increased education and training, as improving the skills of the workforce is necessary for developing greater capacity to deal with complex needs.

There is evidence – as Colombo and Muir show – that a multidimensional strategy to value the care profession improves the quality of services provided. This strategy, nevertheless, has an economic cost and will have a significant impact on public budgets since some 80 per cent of the costs of care services comprise labour costs. On the other hand, it is impossible to overlook that there is little scope to substitute capital for labour or for other efficiency strategies in order to save money, due to the labour-intensive nature of LTC.

The interaction between the various institutional actors

Dependent older people with complex needs often require integrated provision of health and social care services. Chapter Eleven, by Hixon, shows that the large number of studies, pilots and polices carried out so far, internationally, to pursue this goal have proved that there is no single best approach to meet integrated care needs. In fact, what is the most appropriate strategy depends on the specific traits of the different local contexts: how best to arrange services and how best to involve the different professions in order to obtain integration are, thus, choices that need to be made locally.

International experience indicates that in the first instance, integrated care needs to become a priority at system level (national or regional), because recognising its importance on the political agenda is an essential precondition to pursuing this goal. Policy-makers, however, should not prescribe how to achieve integrated care, through a top-down approach, as such an approach is likely to be ineffective: they should, instead, recognise that integration is local, and that there will be differences in how it is pursued across different areas. Their task involves creating the best conditions for the various stakeholders involved to achieve integration locally.

The conditions that need to be set up at system level, Hixon explains, concern, mostly, financing mechanisms; properly implemented, these would avoid the phenomena – quite widespread across the OECD – of financing fragmentation and inconsistency. When there are two or more programmes paying for overlapping services, cost shifting is expected to occur, and, conversely, when the appropriate financial incentives are in place, they represent a strong driver towards integration. In order to overcome fragmented financing arrangements various strategies can be implemented, ranging from pooling the different sources of funding into a single pot to keeping such resources separate but making their design consistent. Consistency should also be pursued with respect to LTC eligibility criteria and their underlying rationale. Currently, inconsistency in eligibility criteria is a key factor inhibiting integration of care: health services are generally provided free of charge at the point of use, whereas social care services are often means-tested and accompanied by co-payments.

At system level, another requirement is the development of integrated information systems, including a single client record that combines financial, clinical and utilisation information. This record should be used by multiple providers, purchasers and professionals, and be shared across multiple sites.

Another key mechanism to promote integration is case management. It is usually built into community care programmes that aim to delay or reduce placement in residential care or that care for people with particularly complex needs. A multidisciplinary team led by a case manager is required. In different contexts, the case manager could be a professional with a social work or with a nursing background. It is important to involve General Practitioners (GPs) as well, but they should not be at the centre of the team because they are generally not trained to manage dependent older people with complex needs and often do not have the time to do it.

The search for greater integration often has to fight against considerable vested interests in maintaining the status quo – at both the political and administrative levels – as, not rarely, stakeholders are not willing to share power and responsibilities. Shared aims, a united vision, effective communications and clear lines of accountability among professionals are all important for the development of effective integrated care.

Along with the relationship between social and health care services, the other key issue concerning the interactions between different institutional

actors involves the interplay between central and local levels of government, examined by Theobald and Ozanne in Chapter Twelve. The authors highlight that the introduction of more universal LTC policies over the last 30 years has resulted in greater involvement by central tiers of government, in contrast to previous policies that were generally administered at local or regional government levels. Theobald and Ozanne note that in most of the countries in their sample, and also in a number of other OECD nations, LTC policies have experienced a shift towards greater national uniformity. Central government has set up common rules that, to various degrees and in different forms, apply to the whole country, including rules on eligibility, levels of care, funding, assessment procedures and quality regulation. This process has positively increased the territorial equity of LTC systems.

The introduction of more territorial uniformity was generally part of broader policies aimed at developing and enlarging LTC systems, but over time has changed. In several countries, the authors note, a recent trend is for higher territorial uniformity to be accompanied by decreasing public support for LTC provision, through processes such as re-familisation and the increased involvement of privately paid sources to meet care needs. Unexpectedly, therefore, territorial uniformity and decreasing public support have become two sides of the same coin. A challenge for the future, therefore, will be to monitor the effects of this combination of greater national uniformity with reduced public support on LTC.

Long-term care policies in the future

Developed countries face a triple challenge over the coming years. First, demand for LTC seems almost certain to rise in view of growing numbers of people in late old age with multiple morbidities and substantial care needs and the predicted increase in expectations on quality of care. Second, resources for public services generally, including LTC, are likely to remain constrained. Third, on the supply side, challenges can be expected regarding the availability of sufficient unpaid care and an adequate formal care workforce.

The evidence and arguments presented in this book suggest that countries should give serious consideration to a number of policy measures. These include the development of services that promote independence and reduce

the risk of requiring costly intense care; enhancing support for unpaid carers, to help them continue to care without undue stress or risk to their own wellbeing; adoption of measures that increase the expertise of the paid LTC workforce and reduce turnover and vacancies; and the promotion of approaches that increase the productivity and quality of care services, for example, through maximising the use of technology, targeting care closely to needs, and arranging the most cost-effective care package for each user taking account of their preferences. Underpinning all these measures, new agreements will need to be reached about the size and form of future state financial commitments to the care system, including mechanisms for incentivising private contributions to rapidly rising care costs.

One important limitation for the design of new LTC policies, however, is the lack of robust evidence to support their design, as stressed by Campbell et al in Chapter Five and by several other authors. Very significant gaps remain in our understanding of key questions, such as the costs and outcomes of different types of support, how best to target them to individuals with different needs, and how to integrate care support arrangements. To enhance decision-making, countries should support research to obtain robust evidence on the effectiveness and cost-effectiveness of services and policy interventions, and processes should be enhanced to embody the knowledge thus developed into the policy design process. International comparisons and international collaborative studies play a valuable role in this endeavour, as they enable countries to learn from each other's successes and failures. We hope that this book makes a small but significant contribution to this learning process.

Notes

¹ By 'intensity' we mean the average amount of care per user provided.

² By 'coverage' we mean the percentage of older people receiving public care inputs.